

“I had to give up so, so much”

**A Narrative Study to Investigate the
Impact of Chronic Fatigue Syndrome
(CFS)
on the Lives of Young People.**

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A thesis submitted in partial fulfilment of the
requirements of Bournemouth University for the degree
of Doctor of Philosophy

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Abstract

Melinda Williams-Wilson

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A Narrative Study to Investigate the Impact of Chronic Fatigue Syndrome (CFS) on the Lives of Young People.

The aim of this research was to explore the experiences of Chronic Fatigue Syndrome among a small group of adolescents, through three research questions: What are the personal experiences of young people with CFS – how does the condition affect their daily lives – including educational, social and psychological perspectives. Secondly, how does CFS impact family life – how does the condition influence not only the lives of sufferers but also those closest to them? Finally, can the knowledge base be deepened to help guide practice for those caring for the needs of adolescent CFS sufferers and their families?

The study used a narrative approach in an attempt to capture *young people’s stories*, and to provide a window of insight into the personal impacts of CFS on the lives of individuals. Open-ended interviews with eight young CFS sufferers (11 to 18 year olds) were employed that explored personal experiences of CFS. In addition four email interviews were conducted with primary caregivers to explore the impacts of CFS from a carers perspective.

Five themes arose from a generic qualitative analysis of data - adolescent CFS is experienced as: (1) having to adapt to debilitating physical symptoms; (2) living with changes in family relationships and loved one’s life experiences; (3) living with isolation and a disruption to a full and satisfying teenage life; and (4) feeling misunderstood and judged. Also a fifth and universal overarching theme, that CFS in adolescents is experienced as having to put life on hold. This is a major life adjustment, not only for the individual sufferers but for their family members also, who have to adapt to a new way of life accommodating for the limitations of one member.

The implications for clinical practice and further research are discussed.

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Preface

My initial interest in writing a thesis concerning young people with CFS was sparked by my own frustrations at the lack of knowledge and understanding in the public domain regarding this widely misconstrued condition. I went through my teenage years with a younger sister who was severely affected by the condition, which was at a time – almost twenty years ago – when knowledge about the illness was even more scant than it is today, when the condition was even more stigmatised and when sufferers and their families were publicly ridiculed thanks to negative mass media coverage and insinuations of CFS being the illness of ‘malingerers’ or linked to the cruel label of ‘Yuppie Flu’. I watched my parents flounder desperately at the lack of understanding about this mystery illness that was robbing them of their 11 year old child, fight for medical verification and vindication, and try and hold a family together despite the lack of support from medical professionals and lack of understanding from friends and family. I watched a little girl dramatically change from being a bouncy, happy, intelligent pre-adolescent to become an emaciated, seriously ill individual who missed out on her entire senior school education.

In the early stages my beautiful baby sister rapidly became a shadow of her former self, she turned into a proverbial pin-cushion as she underwent every scan and test that the medical world could throw at her, I watched my parents anxiously wait for results dreading something terminal but desperate for an answer, an explanation. The sense of isolation was immense, the feelings of guilt and responsibility for us all difficult to bear as appallingly even social workers made intimations towards abuse in an effort to explain away the dramatic decline in one little girl’s health and personality. Eventually she was well enough to cope with a few minutes of home tuition a day, the patience of the tutor was a god-send as she coaxed this poorly little girl into managing to pick up a pen and try and write a few words. In time we were given a diagnosis, she had a condition called ME or Myalgic Encephalomyelitis, what has come to be known in the literature as CFS. We were then left with debilitating symptoms, a mother and child who rarely left the house and when my mum did so to quickly pop to the supermarket she herself suffered panic attacks as

she too had been incarcerated for so long in the four walls of our house which had become like a prison. All of this because of a severe bout of flu that my sister had never recovered from. The story improves; my sister, after several years, managed to start a college course and against the odds gained very respectable results, she has gone on to hold down a responsible job in the public sector, has married and had a child. However CFS is still a part of her life, albeit a less obvious one, it still lurks in the recesses, emerges when she has something as simple as a sore throat and reminds her that it has not completely disappeared. It has been a long journey for us all as a family, but especially for my sister who has shown tenacity of character, strength of spirit and remarkable resilience over the years. My respect for her will always be rooted in her ability to carry on, despite the odds being stacked against her, and for my parents who taught me the importance of compassion, determination and sticking together as a family.

Twelve years ago I suffered with Glandular Fever, as I began to recover I went for a job which required an inoculation against Hepatitis, the combination of these two things stimulated an attack on my system which six months later was diagnosed to have become CFS, that was a month before my 21st birthday. I recognised the signs, I remember sitting in the consultant's office on the day of diagnosis preparing myself for the inevitable and for what I knew to be a long road ahead. My health over the years has hit peaks and troughs, aggravated by the simplest disruption to daily life – an active holiday, a heavy cold, that can quite simply knock me for six for weeks at a time – it is a frustrating and difficult to comprehend condition that still comes under ridicule today despite the 'realness' of its incapacitating symptoms to its sufferers.

I am presenting this background now to be completely candid about my own position as an insider researcher. I bring to the table biases – I bring an anger and frustration that are fuelled by the desire to reach goals that my body simply won't allow, and a lack of general understanding and widespread misconception, but it is that sense of dissatisfaction and disappointment which has been a driving force behind seeing this project through to completion. I heard someone say near the beginning of my course that everyone who is to succeed at a PhD requires a driving force – well, this is mine. There are advantages too of being in my position, I know the 'inside track', I can empathise with young sufferers in such a way that they don't need to expend any

unnecessary energy trying to make me understand where they are coming from, I can recognise the subtle signs as exhaustion creeps over them, and, having reached the age I have and having my own young child who has suffered ill-health from birth, I can understand from a mum's perspective just how devastating watching your child suffer can be. I believe that my background and life experiences have influenced my understanding of these particular groups of individuals (the young people and their mothers), as it has made me empathetic to their needs and this in turn has made me more open to their views and experiences. My decision to implement narrative as the methodology was done in order that individuals' stories can be kept as a whole – a holistic collation of experiences which help the reader identify with what it is to be a young person with CFS. Having my own experience of CFS to fall back on has helped during the analytic process as it has aided my identification of themes which I too have been familiar with in my past. All of my history with CFS and the effects it can have on young people's lives has aided my approach to this project by allowing me a body of personal experience upon which I could call to help root my position in the data collection process. These are all benefits of being an insider researcher and having first-hand knowledge of a situation. There are of course limitations to being a person with intimate knowledge of the subject I am studying, as previously mentioned, and issues such as personal bias have always remained at the forefront of my mind in order that I could utilise the positives of doing insider research and lessen the negatives, as far as is possible.

Acknowledgements

I would firstly like to thank the young people and their parents who made this project possible, your willingness to participate, along with your honesty and openness, made my job so much easier. I hope that I have given you the 'voice' that you deserve and I admire all of you for your perseverance which goes unnoticed so much of the time. Also, thanks goes to members of the Dorset ME Support Group who have been supportive throughout, and especially to Kate Cosgrove, your encouragement and friendship was a real bonus.

I am most grateful to my supervisors – Professor Kate Galvin, Professor Peter Thomas and Doctor Selwyn Richards – for your expertise, feedback and assistance throughout the duration of my study.

Finally, but by no means least, I would like to thank my husband, family and friends, without your love, support and belief in me I would have given up long ago, and to my little girl – you have been my inspiration and motivation to see this through to the end.

Author's Declaration

No material contained in this thesis has been presented before.

Abbreviations

AfME	Action for ME
CACFS	Chronic Fatigue Syndrome in Children and Adolescents
CDC	Centre for Disease Control and Prevention, Atlanta, Georgia
CFS	Chronic Fatigue Syndrome
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders Four
Email	Electronic Mail
GP	General Practitioner
ICD-10	International Statistical Classification of Diseases and Related Health Problems No. 10
JIA	Juvenile Idiopathic Arthritis
ME	Myalgic Encephalopathy
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PVFS	Post Viral Fatigue Syndrome
RCPCH	Royal College of Paediatrics and Child Health
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
WWW	World Wide Web

Chapter 1

Introduction and General Review of the CFS Literature - What is Chronic Fatigue Syndrome?

1.1 Introduction

In this opening chapter I provide a detailed background as to what Chronic Fatigue Syndrome is generally, its history, effects, characteristics, nature and the current research activities. I then bring to the fore my research objectives of this present study.

1.2 History and Nomenclature

In 1869 George Miller Beard first used the word 'Neurasthenia' to describe a fatiguing illness with accompanying symptoms of depression, headache and anxiety, (Beard 1869), this appears to be the beginning of recorded cases of what is now known as Chronic Fatigue Syndrome or CFS. Reports of cases of neurasthenia all but disappeared in Western countries by the onset of World War II. Ware and Kleinman make the comment;

Fatigue had become invisible...no name, no known aetiology, no ongoing research activity – nothing to relate it to current medical knowledge, (Ware and Kleinman 1992).

This does not mean that cases of chronic fatigue vanished, they were instead labelled as 'exhaustion' or 'weakness', even as 'hysteria' in some severe cases in women – the psychological overtook the physical as a reasonable explanation. From the 'twenties to the 'fifties a series of names were given to what conditions very similar to CFS, including 'Icelandic Disease' (as the name suggests, this is the title used in Iceland), neuromyasthenia, atypical poliomyelitis - the name given to describe the 1934 outbreak at the Los Angeles county hospital, and Benign Myalgic Encephalomyelitis - Acheson's term for the 1955 Royal Free Clinic outbreak (Acheson 1959). However, the well-documented cluster of cases which occurred at the Royal Free Hospital, London, in 1956 - although it should be mentioned that not

all are in agreement that this wasn't simply an outbreak of hysteria - (due to the origin of the outbreak sometimes the condition is referred to as 'Royal Free Disease'), provoked a new name: '*myalgic encephalomyelitis*' or 'ME'. This name is still preferred today by some patient groups in particular as they believe it to be more descriptive than the label Chronic Fatigue Syndrome, objecting that the extent of their illness experience is more widespread and debilitating than simply fatigue and therefore CFS trivialises the extent of symptoms suffered. Despite its preference by some, ME is not a wholly accurate term, as a direct translation is: "inflammation of the brain and spinal cord with muscle pain", which is not able to be demonstrated in all patients. Some prefer the slightly altered label of '*myalgic encephalopathy*', whereby "pathy" refers to unspecified pathology; as opposed to inflammation. ME appeared to alter from collections of cases – epidemics, to more intermittent incidences. Both ME and neuromyasthenia gradually disappeared from the literature in the 1960s and 1970s, to be substituted by more individualised cases of chronic fatigue. Concern about these sporadic cases was taken up by Ramsay (Melvin Ramsay was the recognised authority in ME from 1955 until his death in 1990) and colleagues (some of which had been involved in the outbreak at the Royal Free) who formed a research symposium at the Royal Society of Medicine. There was a significant difference between the original *contagious* clusters of outbreaks, such as those at the Royal Free Hospital and later, and indeed present day, sporadic occurrences – which are not contagious, what this shows is an alteration in the character of the illness. The increase in intermittent cases of the condition occurred on both sides of the Atlantic, however there were cultural differences between the UK and the USA, including American writings concentrating on central 'cognitive' symptoms and immunological theories, whereas British texts emphasised neuromuscular pathogenesis alongside neurological symptoms, and favour viral and particularly entroviral causes, (Wessely et al. 1998). Another label associated with CFS is that of '*chronic Epstein-Barr virus*', (EBV), the introduction of this name was made in the 'eighties due to three influential papers. The first paper published in the *Lancet* and the other two in the *Annals of Internal Medicine* in the USA (Jones et al. 1985; Moss-Morris et al. 2005; Straus et al. 1985). Further investigation has shown that the role of chronic EBV was in fact over-played;

The same authors who had presented the original data themselves concluded that 'chronic mononucleosis' was a misnomer, and should be abandoned, (Wessely et al 1998, p. 133).

This finding left the medical community relatively despondent, however despite the EBV revelation CFS/ME became a highly publicised condition in the 1980s which resulted in Holmes, Kaplan et al in the late 'eighties presenting a new case definition and a new label – *Chronic Fatigue Syndrome*, (Holmes et al. 1988).

Many patients groups in America give preference to the label 'CFIDS'; an acronym of *Chronic Fatigue Immune Deficiency Syndrome*, as a back-lash to the stigma associated with the condition being of psychiatric origin, it also emphasises the immune dysfunction element of the condition. (Other cultural differences between the UK and USA regarding CFS will be discussed a little further down). *Post-viral fatigue syndrome* or PVFS is a related condition, the distinction between the two according to researcher, Dr. Melvin Ramsay;

The crucial differentiation between ME and other forms of post-viral fatigue syndrome lies in the striking variability of the symptoms not only in the course of a day but often within the hour (Ramsay 1986).

1.2.1 Definitions of CFS

The history of isolating a definitional criteria for Chronic Fatigue Syndrome with which everyone is content has not been easy, (as indicated above), and still today remains a contentious issue. The initial clinical definition suggested by the Centre for Disease Control, the *CDC Criteria*, was announced in 1988 in the paper *Chronic Fatigue Syndrome: a working case definition* (Holmes et al. 1988) and presented some difficulties for clinicians due to the stipulation that all depression or psychiatric conditions be excluded – if major depression or psychiatric features were identified in patients then no CFS diagnosis could be given. However the overlap between CFS and psychiatric disorders appeared to be extensive and therefore the decision was made to alter the diagnostic criteria to exclude this section of the guidelines. Other problems were also isolated connected to psychiatric comorbidity and following much discussion a new definition was presented by colleagues from Green College, Oxford, which became known as the *Oxford Criteria*, (Sharpe et al. 1991). (The

Oxford Criteria should not be confused with the *London Criteria* (Dowsett et al. 1994) presented within the National Task Force report). This revised criteria maintained some of the original guideline features: six month duration of fatigue; definite onset and functional impairment, but the major focus now became physical and mental fatiguability, with associated symptoms, e.g. myalgia, mood and sleep disturbance. The original (1988) CDC criteria was altered in 1991 and again three years later resulting in what came to be known as the *Fukuda Criteria*, (Fukuda et al. 1994) and originated from America. Despite there being many similarities between the British and American definitions there are also a number of differences. The most significant of which is the US version requires identification of four out of a possible eight somatic symptoms, whereas the UK criteria depends less on the presence of somatic symptoms but does require the presence of physical and mental fatigue, as well as fatiguability. Table 1 below is replicated from Wessely et al (1998, p. 143) to illustrate the major differences in definitional criteria according to author/country.

Table 1: Differences in Definitional Criteria According to Country

	CDC (Holmes et al 1988)	CDC (Fukuda et al 1994)	Australian (Lloyd et al, 1990)	UK (Sharpe et al 1991)
Min. duration (months)	6	6	6	6
Functional Impairment	50% decrease in activity	Substantial	Substantial	Disabling
Cognitive or neuropsycholog ical symptoms	May be present	May be present	Required	Mental fatigue required
Other symptoms	6 or 8	4	Not specified	Not specified
New onset?	Required	Required	Required	Required
Medical exclusions	Extensive list of known physical causes	Clinically impaired	Known physical causes	Known physical causes

	CDC (Holmes et al 1988)	CDC (Fukuda et al 1994)	Australian (Lloyd et al, 1990)	UK (Sharpe et al 1991)
Psychiatric exclusions	Psychosis, bipolar, substance abuse	Melancholic depression, psychosis, bipolar, substance abuse, eating disorder	Psychosis, bipolar, substance abuse, eating disorder	Psychosis, bipolar, eating disorder, organic brain disorder

The issue of psychiatric comorbidity is a contentious one and some authors called for a maximum as opposed to a minimum symptom criterion in the mid-nineties, however the argument to a degree appeared to come down to a battle of semantics, and however much both the Australian group (Lloyd et al. 1990), and others (Wessely et al. 1998) advocated a call for a maximum as opposed to a minimum symptom requirement there has to date (more than a decade later) been no such alteration to the criterion. An interesting issue is raised as a conclusion to their chapter on definitional criteria, by Wessely et al in *Chronic Fatigue and its Syndromes* who state:

Any specific diagnostic criterion for CFS risks imposing an arbitrary barrier where none exists in nature, and creating spurious associations, especially when the extreme end of the spectrum (CFS) is being compared with the other end of the spectrum (normal controls). Instead, it is more accurate to consider CFS as the morbid end of the dimension of fatigue, (Wessely et al. 1998, p. 144).

This seems a noteworthy point as so many studies compare CFS with healthy controls, as opposed to comparing CFS patients with other fatigue populations.

In 2003 a paper was published reflecting the outcomes of a series of annual workshops, which ran from 2000 to 2002, in which CFS investigators from around the world gathered to discuss the ambiguities in the 1994 Fukuda case definition, (Reeves et al 2003). The workshop participants were divided into focus groups according to individual area of expertise and through a series of brainstorming

sessions a number of recommendations were decided upon to aid specific areas of difficulty including definition, standardisation of classification instruments and study design issues. The paper records the recommendations in an effort to improve the precision of case ascertainment. The authors' concluding comments identify that an operational case definition of CFS needs to be based upon empirical studies concerned with the identified biological pathways that exist in CFS. The workshops which led to the publication of the Reeves et al article drew together some of the most influential CFS researchers from around the world and, as such, presented data which reflected expert consensus within this field.

A further definition of CFS which has come to be known as the *Canadian Criteria* (Carruthers et al. 2003) has also been suggested. There are some differences between the CDC and Canadian criteria, listed in Box 1 below.

Box 1: Differences Between the CDC and Canadian Criterion for CFS

- ❖ The CDC criteria, makes "fatigue" a compulsory symptom but places less emphasis on post-exertional illness, the Canadian clinical case definition specifically selects patients whose condition worsens following exercise
 - ❖ The Canadian version stipulates that the patient must become symptomatically ill following exercise, and must also have neurological, neurocognitive, neuroendocrine, dysautonomic (e.g. orthostatic intolerance), and immune manifestations. Therefore other symptoms as well as fatigue, must be present for a patient to fit the profile
-
- ❖ The Canadian definition helps to distinguish CFS patients from other patients, including those with chronic fatigue, depression, somatisation, fibromyalgia, etc, which CFS may be mistaken for, including those that improve with exercise.

Despite the alternative definitional criteria which have been published the dominant criterion in use is that of the CDC in the USA and the UK, however the others are applied and it is worth pointing out that it is this lack of coherence in criterion being

applied universally which make it difficult to obtain accurate prevalence levels, as well as ascertainment bias (that is, how many cases are missed).

There is very little epidemiological data from within the UK - which was one of the major objectives of the MRC document on CFS presented in 2003 (MRC 2003), therefore much of the information regarding epidemiology of CFS is obtained from the USA, primarily conducted by the CDC.

In Summary...

The first recorded cases of a condition that has now become known in the literature as Chronic Fatigue Syndrome was originally called Neurasthenia and identified by Beard in 1869. Between then and present day the condition has been known by many different names including Icelandic Disease, Benign Myalgic Encephalomyelitis, Royal free Disease and Myalgic Encephalopathy. Despite now being widely referred to as CFS within the medical literature there is still today controversy over the name; different countries prefer different labels, for example, in the USA it is also called CFIDS (Chronic Fatigue Immune Deficiency Disorder), and in this country various interest groups prefer varying titles, e.g. patient groups object to the term CFS as they believe this concentrates on the symptom fatigue to the detriment of the many other symptoms sufferers experience. There have been various diagnostic criterion put forward over the years, including the CDC/Fukuda, Oxford, London, Australian and Canadian, all of which vary slightly in stipulation, the dominant criteria used in this country and the USA is the CDC/Fukuda. All of these varying labels and diagnostic criterion have made attaining accurate prevalence levels a virtual impossibility, and this has resulted in confusion surrounding the condition not only within medical professionals, but also the general public and perhaps most importantly for sufferers themselves.

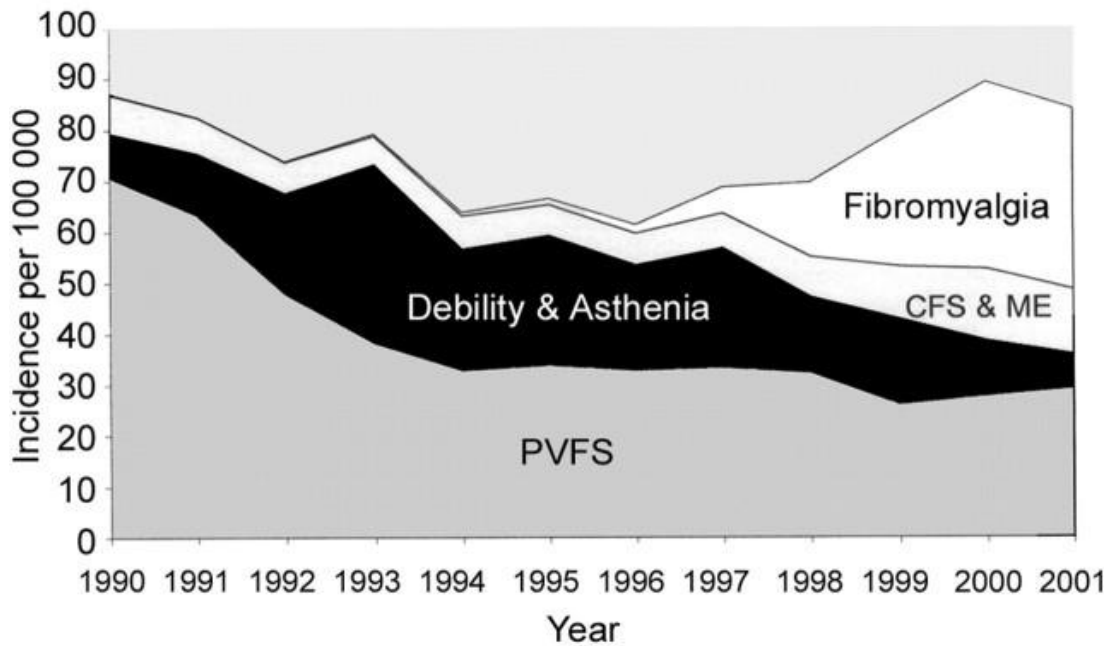
1.3 Prevalence and Incidence Rates

The revisions made to each proposed criteria seek to refine diagnostic guidelines even further, so as to give the most accurate diagnosis possible, however there remains a problem with so many different criteria being implemented depending on country which naturally impacts on ascertainment of accurate prevalence levels, as

previously mentioned. A study using the UK General Practice Research Database over an eleven year period (1990 to 2001) investigated the annual incidence of both fatigue symptoms and diagnoses recorded in UK primary care (Gallagher et al. 2004) . The figures quoted are likely to be an underestimate due to the limits of the database, but overall, evidence suggests a population prevalence of at least 0.2% – 0.4%; the commonest age of onset is early twenties to mid-forties; in children, the commonest age of onset is 13–15, but cases may occur as young as five years old; CFS is about twice as common in women as in men; it affects all social classes to a similar extent and it affects all ethnic groups.

Figure 1, replicated from Gallagher et al. (2004), *Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001*, divides the total incidence recorded into the three diagnostic groups and also shows fibromyalgia; FM, (an associated condition with CFS) diagnoses. The percentage of PVFS (Post Viral Fatigue Syndrome) diagnoses decreased from 81% of all fatigue diagnoses (excluding fibromyalgia) made in 1990 to 50% in 2001. The percentage of CFS diagnoses increased from 9% to 26% over the same period. The incidence of fibromyalgia diagnoses also increased from less than 1 per 100 000 to 35 per 100 000. CFS (a Read code) became available as a diagnosis from around 1995 when the gradual transfer from Oxmis to Read coding began. The choice between CFS and ME was examined with Read code data alone from 1995. The proportion of diagnoses of CFS out of CFS combined rose from 14% in 1995 to 71% in 2001. Two of the leading national CFS organisations; *Action for ME (AfME)* and *The ME Association* currently (2008) estimate that there are approximately 250,000 sufferers in the United Kingdom. When considering prevalence data it is important to remain mindful of the source of the information, for example the issue of self-interest which may lead to a tendency to over-estimate figures, to this ends; GPs are likely to underestimate and patient groups biased towards over-estimation.

Figure 1: Incidence of Fatigue Symptoms and Diagnoses Presenting in UK Primary Care from 1990 to 2001



1.3.1 Socio-Economic Class

As already mentioned the use of the rather glib term ‘yuppie flu’ in the press indicated a socio-economic class imbalance which is not reflected in the medical findings, however the literature does reflect the way in which there is a marked bias within specialist clinical settings and self-help groups favouring those from professional and upper social-class backgrounds. Some writers have commented on the over-representation of health-care professionals, and in particular, doctors, in ‘at-risk’ groups for CFS, (Coulter 1988), others have commented on the large numbers of teachers diagnosed with CFS, (Dowsett et al. 1990). It was observations such as these which gave credence to the labelling in the national press, and although the social class bias of chronic fatigue and CFS sufferers which so avidly caught the attention of the newspaper editors has now been shown to be inaccurate, still the label remains recognisable in the general public’s memory. The majority of researchers familiar with the growing literature base in CFS are now recognising that the over-representation of upper social classes and healthcare and teaching professionals is not an accurate reflection of sufferers but rather a picture of the *type* of sufferers who pursue specialised clinical settings and self-help organisations.

It is therefore premature, and misleading, to invoke complex aetiological theories to explain alleged social class or professional biases, before considering more plausible explanations, such as selection bias in referral,

medical recognition, and symptom attribution, (Wessely et al. 1998, p. 148).

This raises the question of how many more unidentified and untreated CFS sufferers remain in the general population who have neither received a diagnosis or accessed appropriate care and support. The primary organisation in the USA – *CFIDS America* – and the CDC (CDC 2006) estimate that over one million Americans suffer with CFS and of these less, than 20% have received a diagnosis; this is a staggering statement and gives insight into the scale of how major a problem CFS potentially is.

1.4 Presentation: Medical Perspective

The predominant feature of CFS is profound fatigue, however there are a number of words used to describe fatigue: exhaustion, tiredness, sleepiness, and so on, and different people will favour different words as an explanation of their experience. In an effort to convey the extent of fatigue sufferers with a similar condition – FM - differentiate ‘abnormal’ from ‘natural’ tiredness, as discussed later on (Soderberg et al 2002). As the definitional criteria illustrate, there are a number of other associated symptoms such as sore throat, headaches, tender lymph nodes, widespread pain, and so forth – not all of these associated symptoms need to be displayed for a diagnosis to be ascertained. The level of disability is an important consideration and, as already noted, this can be minor for some and totally incapacitating for others.

Incidences of unemployment is also high among this group of patients and the cost to the economy is great.

1.5 Economic Impact of CFS

CFS also has a huge economic impact. A survey by the national charity AfME (Action for ME), conducted in 2006, suggested that 77% of the total 240,000 people in the UK with ME had lost their jobs because of the illness, with a cost to the nation of £6.4 billion a year, (Semple 2008). A large-scale piece of research conducted in Wichita, Kansas (Reynolds et al. 2004), involved a surveillance study of CFS and estimates of productivity losses due to CFS. They report;

A 37% decline in household productivity and a 54% reduction in labour force productivity among people with CFS. The annual total value of lost productivity in the United States was \$9.1 billion, which represents about \$20,000 per person with CFS or approximately one-half of the household and labour force productivity of the average person with this syndrome, (Reynolds et al. 2004, p. 4).

Such estimates suggest staggering and widespread economic effects of CFS, with a cost not only to the individual and their family, but also to wider society. Reynolds and colleagues conclude:

Lost productivity due to CFS was substantial both on an individual basis and relative to national estimates for other major illnesses. CFS resulted in a national productivity loss comparable to such losses from diseases of the digestive, immune and nervous systems, and from skin disorders. The extent of the burden indicates that continued research to determine the cause and potential therapies for CFS could provide substantial benefit both for individual patients and for the nation, (Reynolds et al. 2004, p. 4).

1.6 Characteristics

CFS is a characteristic illness with positive features in the history such as waking profoundly unrefreshed, worse after any increase in activity, increased sensitivity to other stimuli such as noise, bright lights, alcohol and side effects of drugs. Individuals can often recognise a *boom-bust (or peaks and troughs) activity cycle*: on good days they do more than they can sustainably manage and pay for it with worse days to follow. The overlap (and coexistence) with other medically unexplained syndromes such as irritable bowel syndrome (Whitehead et al 2002) and FM (Ciccone and Natelson 2003) may also help a positive diagnosis.

1.6.1 Investigations

On seeing a patient with disabling persisting fatigue there is a core set of bloods to screen to exclude anaemia, thyroid disease, diabetes, coeliac disease etc, (Fukuda et al 1994), and then specific tests targeted at those symptoms and signs that do not fit with the diagnosis. Further investigations should be avoided if the symptoms seem characteristic of being medically unexplained. There is no universally accepted diagnostic criterion. However the most widely used currently in the UK is the US Centre for Disease control revised expert consensus, (Fukuda et al. 1994), as detailed in Box 2.

Box 2: US Centers for Disease Control and Prevention/CDC CFS Diagnostic Criteria

Six months duration of fatigue & substantial functional impairment

And four symptoms required (from list below)

Symptoms:

- substantial impairment in short-term memory or concentration
 - sore throat
 - tender lymph nodes
 - muscle pain
 - multi-joint pain without swelling or redness
 - headaches of a new type, pattern or severity
 - unrefreshing sleep
 - post-exertional malaise lasting more than 24 hours.
- Cognitive or neuropsychiatric symptoms may be present
 - New onset required (i.e. not life long)
 - *Exclusions:* Clinically important medical conditions, melancholic depression, substance abuse, bipolar disorder, psychosis, eating disorders

1.7 Possible disease mechanisms

The research literature contains several hypotheses and proposals to explain how CFS may be caused or maintained. The quality of the evidence is variable, however, and many suggested mechanisms are as yet based on associations rather than cause or linkages. CFS can best be seen as a medically unexplained syndrome. The most probable justification of potential models of explanation is central sensitisation (where the central nervous system has become sensitised to normal sensations being unpleasant, fatiguing or painful) (Nijs et al. 2005).

1.8 Understanding the Nature of CFS

The most widely applied model to understanding the nature of CFS is the Cognitive Behavioural Model of fatigue. This suggests that some individuals are more vulnerable to the development due to *predisposing* factors. The illness is then triggered by *precipitating* factors that are often multiple. This condition would tend to be self limiting if it were not for the presence of certain maintaining or *perpetuating* factors.

1.8.1 Predisposing factors

There are several recognised predisposing factors:

1. *Gender* – there is a higher incidence rate in females than males, in all age groups (Afari and Buchwald 2003).
2. *Familial* – There are studies to suggest that familial factors may play a part in susceptibility. Twin studies suggest a hereditary component but family environmental factors also may have an influence (Buchwald et al. 2001).
3. *Personality* – There is evidence both for and against the possibility that certain personality traits might predispose people to develop CFS, (Blakely et al 1991, Fiedler et al 2000). Positive findings from retrospective studies could be explained by the effect of chronic disability on personality.
4. *Other medically unexplained syndromes* – Some patients have a past or current history of other disorders, particularly fibromyalgia (FM) and irritable bowel syndrome (Kato et al. 2006; Van Middendorp et al. 2001). The association of other disorders with CFS could reflect different manifestations of a similar process or different expressions of a common predisposition. Alternatively, other disorders could in some way predispose a person to CFS.
5. *Previous mood disorder* – Most, but not all, studies have found a history of mood disorders in individuals with CFS (Fischler et al. 1997). This finding might simply reflect the fact that previous mood disorders predict future mood disorders, which often coexist with chronic illnesses, including CFS. Alternatively, this finding could reflect a common predisposition to both mood disorders and CFS.

1.8.2 Precipitating factors

A number of triggers may be readily identifiable (Hutchinson 2002)

1. *Infections* – Good-quality evidence indicates that certain infections are more

common triggers for CFS than others (Theorell et al. 1999; White et al. 1998). Infectious mononucleosis (EBV infection), viral meningitis, and viral hepatitis have been found to be followed by CFS (White et al. 1995). CFS can follow infections with herpes viruses, entero viruses, hepatitis viruses, and some other viruses, and also non-viral infections such as Q fever (Ledina et al. 2007). CFS has been reported after salmonellosis, toxoplasmosis, brucellosis and Lyme disease (Treib et al. 2000). Influenza and ‘flu-like infections can trigger CFS, but common upper respiratory tract infections do not seem to. Available evidence suggests that abnormal persistence of infectious agents does not occur in CFS, although certain chronic infections may cause similar symptoms.

2. *Immunisations* – A few reports have suggested that CFS has occurred after immunisations, though intercurrent events, including infection, might have played a part in the disease process. However, clinical trials of flu vaccine and placebo have shown no evidence to support this and data re-analysis demonstrated that the effects may have been related to the overlap of common, post-influenza immunisation symptoms and CFS constitutional symptoms (Sleigh et al. 2002).
3. *Life events* – The evidence that adverse life events can trigger CFS. Severe life events are much more likely however to provoke a mood disorder, which can be misdiagnosed as CFS. However, clinical and patient experience suggests that increased “stress” may be common around the onset of symptoms as well as a triggering event, such as infection (Theorell et al. 1999). It is unclear whether this is as a triggering, a predisposing or a maintaining factor. Stress is also recognised as a trigger for setbacks.
4. *Physical injuries* – These may be more likely to trigger the seemingly related condition of fibromyalgia than CFS, though instances of CFS after physical or operative trauma have been described (McBeth et al 2006).
5. *Environmental toxins* – Reports have suggested an association between exposure to environmental toxins, such as organo-phosphorus compounds (sheep dips), and development of disease in isolated cases (Tahmaz et al. 2003); mercury amalgam dental fillings causing CFS (Malt et al. 1997) and cases of accidental poisoning such as the incident involving twenty tonnes of aluminium sulphate being poured into the wrong tank at the Lowermoor

water works near Bodmin, which supplied water to 20,000 people in the Camelford area of Cornwall (reported in the Daily Mail newspaper in August 2001). The balance of evidence, however, indicates that this is not a common or widespread trigger (Hokama et al. 2003).

1.8.3 Perpetuating Factors

Maintaining factors are as follows:

1. *Sleep disturbance* - Will exacerbate fatigue and other symptoms. Quality sleep is not restored by the use of hypnotics, but may be helped by the use of low dose tricyclics, for example Amitriptyline and Dosulepin, (Wilson and Argyropoulos 2005).
2. *Mood disorders* - Concomitant anxiety and depression are common in CFS and predict poor outcome. They can exacerbate, modify, or contribute symptoms, and can affect adaptation and recovery (they can also be misdiagnosed in patients with CFS because of overlap of key symptoms). Antidepressants have been shown to improve mood disorders and more recently, fatigue in CFS in some studies (Thomas and Smith 2006), but not others.
3. *Inactivity* - A decrease in activity is an obvious consequence of CFS. If prolonged, this may then become a problem in its own right; and over-activity/activity beyond the level that an individual can usually tolerate will prompt a delay in the worsening of their symptoms. Observation suggests that patients who show cycles of over-activity followed by setbacks ('boom and bust') may have a more protracted course.
4. *Intercurrent stressors* - Clinical experience suggests that emotional and physical stressors, ("stress" including intercurrent infections (Hickie et al. 2006) and surgical operations) can cause setbacks in some patients.
5. *Iatrogenic illness* - These could include inappropriate advice (to exercise or rest too much), misdiagnosis and inappropriate prescribing, and failure to acknowledge the patient's illness or to provide supportive care can cause additional distress and alienation, and might encourage the patient to seek unconventional/untested remedies, some of which may cause harm, (Thompson 1990).

6. *Illness beliefs* - A fixed belief that there is some unmodifiable external cause may perpetuate ill health/disability and be a barrier to engagement in treatment, (Clements et al 1997).
7. *Lower somato-sensory threshold* – Patients with CFS display lower tolerance levels to somato-sensory stimulation, which may perpetuate inactivity and delay rehabilitation, (Bradley et al 2000).

To Summarise...

The most likely population prevalence rate is between 0.2 and 0.4%, with commonest age of onset between early twenties and mid forties in adults, women are almost twice as likely to be sufferers than men and there is no discrimination between socio-economic or ethnic group. The most dominant characteristic of CFS is profound ‘abnormal’ exhaustion with a number of other accompanying symptoms including headaches, tender lymph nodes and widespread pains. Varying levels of disability may be experienced, from little disruption to daily life for some, to total incapacitation in others. Financial impact can be great, not only affecting individuals and families, but also wider society with an estimated cost to the economy equal to that resulting from immune and nervous system disorders. CFS characteristics include unrefreshing sleep, worsening of symptoms post-activity and increased sensitivity to stimuli and chemicals. Routine investigations upon presentation of a potential CFS case include blood screening to rule out problems linked to thyroid, diabetes, etc, as well as further tests addressing specific symptoms. The lack of clear universally accepted diagnostic criteria means the diagnostic process can be a lengthy one. The CDC/Fukuda criteria is the most widely accepted in practice. CFS is best accounted for as a medically unexplained syndrome, however the most probable model of explanation is that of central somatisation. The most acknowledged model of understanding CFS is through application of the Cognitive Behavioural Model of fatigue, this includes certain predisposing, precipitating and perpetuating factors.

1.9 Other Areas of Research Exploring Cause and Treatments of CFS

Aside from the widely accepted Cognitive Behavioural explanation attributed to CFS there have been a selection of other areas of research that are more specific in nature.

1.9.1 Hyperventilation

In the early 'nineties a team of cardiologists, led by Peter Nixon, at Charing Cross Hospital in London, claimed that all of the patients previously diagnosed with CFS which were then referred to them were found to have 'effort syndrome'; that is, exhaustion and hyperventilation, (Manu et al. 1991). The team went on to make a diagnosis of chronic hyperventilation in 93 per cent of their consecutive referrals, (Hart et al. 2005). Others have agreed that the chronic hyperventilation can indeed cause similar symptoms to those displayed in CFS, (Akagi et al. 2001). It is the extent to which Nixon claims there is overlap between hyperventilation and chronic fatigue condition that is disputed by many, (including Riley et al. 1990; Saisch et al. 1994). Saisch and colleagues (Saisch et al. 1994), based at King's College London, stated:

There is only a weak association between hyperventilation and chronic fatigue syndrome. When present, hyperventilation is usually related to known causes of respiratory stimulation such as asthma or panic, (Saisch et al. 1994, p. 63).

It appears that hyperventilation may play a part in some patients with CFS, however there is little evidence to support that it is present in more than a sub-set of sufferers.

1.9.2 MRI

A study by Dr Puri and colleagues (Puri et al. 2002) has shown some abnormalities in the metabolism of fatty acids of a group of patients with CFS. Magnetic Resonance Imaging (MRI) scans were conducted in eight CFS patients and eight healthy controls matched for age and gender. Results showed the mean ratio of choline to creatine in the occipital cortex in CFS as being significantly higher than in the control group, suggesting an abnormality of phospholipid metabolism in the brain in CFS sufferers, it should be noted though that this is a relatively small sample size.

1.9.3 Tilt Table

A group of researchers at the John Hopkins University Hospital in Baltimore, USA, in 1995 claimed that vasovagal syncope or neurally mediated hypotension, is strongly linked to ongoing fatigue, (Bou-Holaigah et al. 1995), their research involving tilt table testing found that 22 of the 23 CFS patients developed neurally-mediated hypotension when tilted upright. Others too found positive associations between neurally mediated hypotension and CFS, Rowe and colleagues in 1995, studied seven consecutive non-syncopal adolescents with chronic post-exertional fatigue, four of whom satisfied strict criteria for chronic fatigue syndrome. Tilt table testing demonstrated positive results in 100 per cent of the sample, and four of the seven experienced prompt improvement in their fatigue symptoms when treated with drugs to alleviate the hypotension (Rowe et al. 1995). A 2008 study including twenty six adolescents with CFS and age and gender matched controls, reported those with CFS were more susceptible to orthostatic intolerance than controls, the cardiovascular response predominantly manifest as postural orthostatic tachycardia syndrome (POTS) without hypotension, a response only demonstrated in those with CFS (Galland et al. 2008). These findings suggest important issues for CFS researchers as not only being a possible explanation of some of the symptoms experienced by CFS patients but also as a potential new means of diagnosing and treating chronic fatigue syndrome. Despite the samples being small in these studies, they do provide encouraging findings which require further exploration.

1.9.4 Gene Expression

A study in 2005 by Doctor Jonathan Kerr and colleagues, tested whether there are reproducible abnormalities of gene expression (the pattern in which genes are switched on and off) in the blood of twenty five patients with CFS and twenty five healthy control blood donors, matched for age, sex and geographical location, (Kerr 2005). Abnormal genes showed problems in several systems of the body including the immune system, in neurological function and mitochondrial metabolism. The study discovered that CFS sufferers have a group of genes which are 4 times more active than those in healthy people, and one gene which is less active. These findings have been welcomed by sufferers and clinicians alike who hope that such evidence will eliminate the persistent belief held by some that CFS is a psychological as opposed to neurological condition.

1.9.5 Muscular

Due to the nature of chronic fatigue syndrome and sufferers being limited in terms of their physical activity, as well as the frequent complaints made by patients of muscle pain, some researchers have investigated the possibility of a disorder of the muscular structure (Connolly et al. 1993; Grau et al. 1992; Lloyd et al. 1991). An early study by Behan and colleagues in the mid 'eighties reported that abnormal biopsies were found in fifty CFS patients showing low Type I fibre prevalence (these are aerobic, slow-twitch, red muscle fibres, which are rich in mitochondria and more susceptible to disuse atrophy), and the domination of Type II fibres (the anaerobic, fast-twitch, white muscle fibres, which develop earlier fatigue and are more susceptible to muscle cramps and exertional myalgia), (Behan et al. 1985). This led the authors to conclude:

These findings confirm the organic nature of the disease. A metabolic disorder, caused by persistent virus infection and associated with defective immunoregulation, is suggested as the pathogenetic mechanism, (Behan et al. 1985, p. 211).

It is the issue of Type II disuse atrophy that is important to researchers and other studies showed supportive evidence for such findings, (Behan et al. 1991; Byrne and Trounce 1987; Byrne et al. 1985). A group led by Russell Lane published a paper in the Journal of Neurological Neurosurgery and Psychiatry in 1998, documenting a study they had conducted to investigate lactate responses in muscle fibres of patients with CFS and to what extent this was linked to muscle inactivity. Their findings showed generally less muscle changes due to inactivity than expected in the patients included in the trial, however those individuals with abnormal lactate responses to exercise had a significantly lower number of Type I muscle fibres (Lane et al. 1998). Again, such results demonstrate that muscle histometry may well play a role in some individuals with CFS, however it is not a significant finding that can be applied to all patients. One study in 1994 using magnetic resonance spectroscopy (MRS) of the muscles and brain in CFS patients found results of early intracellular acidosis in the exercising muscles and increased peaks of choline derived from the cell membrane phospholipids, and believe that cell membrane oxidative stress may offer a common explanation for the observed MRS changes in the muscles and brain of CFS patients, (Chaudhuri and Behan 2004). Some studies investigating the effectiveness of aerobic exercise training in CFS found it to be a beneficial treatment plan, (Fulcher and

White 1997), however a trial five years later (Carruthers et al. 2003) found no specific benefit for patients in primary care with persistent, unexplained physical symptoms (the bracket that many CFS patients are often placed in). There are possible reasons for this discrepancy, including varying methods of recognition and referral, however Peters et al (2002) retain the belief that exercise training is not an effective treatment plan for those individuals in primary care presenting with persistent, unexplained physical symptoms.

1.9.6 Allergy/Immune System

In 1997 an article (Rook and Zumla 1997) proposed that Gulf War Syndrome was caused by a battery of vaccines being given to veterans which promoted a shift in cytokine balance in the immune system from Th1 (for cell mediated immunity) to Th2 (antibody driven immune response). The authors indicated that resulting cases of Gulf War Syndrome were associated with three things;

- if the vaccines included pertussis;
- if vaccines were administered when soldiers were in the field, i.e. in a highly stressful situation; and
- if pesticides were used concurrently.

Research into Gulf war syndrome has been hampered due to lack of exposure records and reliance on memory recall many years after the event. However, two studies (Hotopf et al. 2000; Unwin et al. 1999) which did present supportive findings were conducted six years post-war and appear to support the original hypothesis. However, a study conducted by the Centre for Environmental Hazards Research in New Jersey, USA (Zhang et al. 1999), offered little support for the theory, providing cases of US veterans of the Gulf war who had chronic fatigue syndrome demonstrating a cytokine shift in the opposite direction to that proposed by Rook and Zumla in 1997. It seems highly suggestible that Rook and Zumla's hypothesis of allergy to vaccinations may well be associated with specific sub-groups of CFS sufferers but cannot be applied to all patients.

1.9.7 Enteroviral

The suggestion of enteroviruses as the cause of CFS has been a contentious one; some studies have provided evidence to support this theory, for example Yousef and colleagues found evidence of circulating enteroviral antigen and IgM complexes in

most patients with CFS, (Yousef et al. 1988), another study also demonstrated that CFS may be due to one or more immune disorders that have resulted from exposure to an infectious agent, (Landay et al. 1991). However, other researchers have demonstrated opposing results, (Miller et al. 1991; Swanink et al. 1994). Despite a movement away from this type of study some researchers have persisted and believe that evidence displayed in both animal models and in vitro experiments show ongoing formation of double-stranded RNA, which is paralleled in muscle biopsy samples taken from CFS patients, (Royal College of Physicians 1996). This view has been supported by other researchers, (Douche-Aourik et al. 2003; Lane et al. 2003), as well as research conducted into antiviral treatment:

Interferon α and γ act synergistically against enterovirus in vitro, and preliminary studies suggest that this combination may be an effective treatment for patients with chronic enteroviral infection. (Chia 2005, p. 1130).

The debate is ongoing, with more high quality, basic science research, to examine whether there is any validity in this hypothesis, particularly placebo RCTs needed.

1.9.8 Circadian Rhythm Alterations

Patients with CFS frequently complain of persistent changes in vital functions which are controlled by circadian rhythms, such as sleeping and waking; intellectual performance; memory; feelings of tiredness; appetite and body temperature. A dysynchronisation in the body's circadian rhythms has been linked to many of the more common symptoms of CFS - disturbed sleep, poor digestion, alterations in appetite, headaches and most prolifically fatigue. Evidence from studies of circadian rhythms in CFS patients has demonstrated evidence of the biological clock losing control of the body rhythms, (Hamilos et al. 2001; Ohashi et al. 2002; Racciatti et al. 2001; Van De Luit et al. 1998).

1.9.9 Neurological and Cognitive

Most patients with CFS experience symptoms conducive with cognitive impairment (Ray et al. 1992), such experiences are reported in both clinical observations and questionnaire studies, (Grafman et al. 1993). Others too have suggested an organic brain abnormality associated with CFS in some patients, (Buchwald et al. 2001; Cook et al. 2001). Such findings may well explain the 'brain fog' described by CFS

patients, who struggle to formulate correct words to explain their thoughts as quickly as they would like, or memory and concentration dysfunction. More research is required in this area, with carefully designed and controlled studies.

Summary of Other Areas of Research

The over-arching conclusion is that more research is required in hyperventilation, MRI, immune system, muscular, enteroviral, cognitive and circadian rhythm research. At present the findings in these areas cannot be generalised across the entire CFS population either due to small data samples used or inconclusive results and cannot presently be attributed to anything more than a sub-set of sufferers. Also there is the issue of inaccurate diagnoses, due to the complexities of making an accurate CFS diagnosis there must be a number of incorrect diagnoses made. The findings in tilt table testing and gene expression research indicate positive results, however these areas too require ongoing research.

1.10 Is CFS a Somatisation Disorder?

There is some debate whether CFS is a somatisation disorder. A somatisation or a somatoform disorder is a psychiatric diagnosis given to patients with persistent chronic physical symptoms which have no identifiable physical origin. One explanation of somatisation disorders is that the physical symptoms are a result of subconscious psychological conflicts. Patients will characteristically seek many different medical opinions in order that they receive the treatment they believe that they require. Prevalence for somatisation disorders is low, with estimates of approximately 0.2% in males and 0.2% to 2% in females (DeGruy et al. 1987; Lichstein 1986). Although currently somatoform disorder is defined in the Diagnostic and Statistical Manual for Mental Disorders (DSM IV) as a disorder in its own right, some researchers believe that '*Somatisation*' is more appropriately viewed as a dimensional construct (Wessely et al. 1999) , in which general symptoms of distress are attributed to a serious illness and some classify illnesses which are not clearly understood as fitting the definition – such as CFS. There are a number of illnesses which are considered by some to possibly be somatoform disorders, including Chronic Fatigue Syndrome, but also 'sick-building syndrome', repetition stress injury, the side effects of silicone breast implants, Gulf War syndrome, chronic

whiplash, irritable bowel syndrome, and fibromyalgia. One review (Barsky and Borus 1999) suggests that CFS may be a type of somatisation disorder, in which “benign symptoms and self-limited conditions” are falsely attributed to a serious and “new” disease, therefore exacerbating the intensity of the perceived symptoms and reinforcing patient’s beliefs that they are ill. The authors believe that certain things prolong somatoform disorders, such as specialised clinics; media publicity; litigation possibilities and sympathetic healthcare professionals. A number of studies have shown that CFS patients demonstrate higher rates of somatisation compared to other patient groups including those with depression and arthritis (Johnson et al. 1996; Katon et al. 1991), however the validity of such findings is not clear cut as assessing somatisation disorder in CFS poses some challenges (Moss-Morris and Petrie 2001). Firstly, both CFS and somatisation disorder require identification of multiple symptoms, as such, the higher the number of symptoms included in a CFS diagnosis, the more likely the individual will meet the symptom requirement of somatisation disorder. Secondly, depending upon whether the patient’s CFS symptoms are recorded as physical or psychiatric will influence whether s/he meets the diagnostic requirements for somatisation disorder (Johnson et al. 1996; Sharpe et al. 1991). Therefore, it can be argued that when considering whether CFS is a somatoform disorder one must consider the diagnostic and definitional criteria applied to both CFS and somatisation disorder.

In many ways the number of CFS patients identified as having somatisation disorder can be viewed as an artefact of the specific criteria used to define both conditions, (Moss-Morris and Petrie 2001, p. 63).

This remains an area of controversy.

1.11 Medical Management

The main things that healthcare professionals can do are:

1. Carefully assess individuals to exclude all medical and physical disorders, conducting appropriate investigations and referrals
2. Make a positive diagnosis
3. Prescribe symptomatic drug treatments, e.g. anti-depressants, low dose tricyclics, analgesics and antispasmodics

4. Offer individualised evidence based treatments, i.e. Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET)
5. Treat comorbidity
6. Offer support, acceptance and legitimisation

Most people with CFS can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged. Each individual is best managed according to a unique flexible management plan, in which specific strategies and therapies are tailored to his or her particular circumstances. All clinical interventions carry a potential risk of harm, especially if applied incorrectly; for CFS in particular, imposed, rigid programmes can be actively harmful. Treatment should be evidence based; best evidence is for Cognitive Behavioural Therapy (CBT) and graded exercise therapy (GET) (Akagi et al. 2001; Evengard and Klimas 2002; Moss-Morris et al. 2005; Powell et al. 2004; Price and Couper 2000). A recent systematic review concluded that both cognitive behavioural therapy (CBT) and graded exercise therapy (GET) showed positive results, and that three of the four RCTs evaluating CBT found a positive overall effect of the intervention, (Whiting et al. 2001).

1.11.1 Cognitive Behavioural Therapy (CBT)

This consists of planned timetables of activity and rest and a sleep routine; a gradual increase in activity and cognitive interventions with regard to negative illness beliefs. Studies examining the use of CBT in patients with CFS demonstrate positive outcomes, (Butler et al. 1991; Chalder et al. 1995; Deale et al. 2001), such studies have implemented randomised control trials to investigate the success of CBT compared to other treatment such as graded exercise or relaxation therapy. In a long term follow-up study comparing CBT to relaxation therapy (Deale et al. 2001), 68% in the CBT group and 36% in the relaxation therapy group rated themselves as either ‘much improved’ or ‘very much improved’ at the 5 year follow-up;

Significantly more patients receiving cognitive behavioural therapy, in relation to those in relaxation therapy, met criteria for complete recovery, were free of relapse, and experienced symptoms that had steadily improved or were consistently mild or absent since treatment ended, (Deale et al. 2001, p. 2039).

In studies of CFS patients being treated for depression a question arises as to whether cognitive behavioural therapy improves the CFS or the depression - a condition which is known to respond well to CBT. It is worth considering whether inactivity alone leads to ongoing CFS and what about CFS patients with CFS who are not depressed? The research findings remain inconclusive. Finally, some researchers have commented upon the inconsistencies across CBT studies, commenting that the variety of inclusion and exclusion criteria used, along with the variable amount of time and the different comparison therapies utilised make it very difficult to accurately predict the usefulness of CBT, (Carruthers et al. 2003).

1.11.2 Graded Exercise Therapy (GET)

Follows a principle of: exercise testing; creating an individually devised tolerable and sustainable exercise regime, which is then regularly revised and adjusted based on progress. In one randomised controlled trial of graded exercise therapy and flexibility treatment (in which patients were taught a stretching routine and relaxation techniques), 16 out of the 29 in the GET group compared with eight out of 30 in the flexibility treatment group rated themselves as better (Fulcher and White 1997). Other graded exercise studies (Powell et al. 2004) have also demonstrated positive results, one concluded:

Graded exercise was associated with improvements in physical work capacity, as well as in specific psychological and cognitive variables. Improvements may be associated with the abandonment of avoidance behaviours, (Wallman 2004, p. 444).

Despite these positive results, graded exercise too promotes controversy within the medical community. Some patients who have not found GET helpful or who have experienced a worsening of symptoms following graded exercise treatment also report feelings of guilt and disappointment that the treatment has not improved their condition. There is also the danger of therapists or those administering the treatment not being experienced enough to deal with a complex condition such as CFS, and pushing patients beyond that which they can manage.

A study compared CBT and GET in an adult population (ages 16 to 65), which included 144 primary care patients residing in the South East of England, with more than three months of unexplained fatigue, (Ridsdale et al. 2004). Results at follow-up confirmed that short courses of GET were not superior in results to CBT outcomes, however there was more uptake for the CBT programmes and clinicians found individuals displayed a more positive response to its initial suggestion, compared to GET. The study article concludes that brief treatment is not enough and longer programmes must be attended to encourage better more positive outcomes. Questions remain and there is much controversy surrounding CBT and GET as ‘one size fits all’ solutions to CFS and research in this area stress the importance of doctors being mindful of both patient autonomy and appropriate levels of pacing when prescribing any exercise programs, (Carruthers et al. 2003).

The conclusion appears to be that any therapy in CFS patients must be applied with caution and that great care should be taken in implementing a program to suit the individual and his/her needs, this is something which is not just important at the beginning of therapy but that is adhered to through regular and careful review throughout the process.

1.12 Prognosis

There is wide variation in the duration of condition, with some people recovering in less than a year, while others remain ill after several decades. Those who have been affected for several years are less likely to recover, full recovery after symptoms persist for more than five years is rare (Bombardier and Buchwald 1995; Vercoulen et al. 1996b; Wilson et al. 1994). Irrespective of the statistics, each individual requires the necessary assistance to maximise their chances of an early recovery and minimise the impact of the illness. (Hutchinson 2002). In the early stages of an illness characterised by prolonged fatigue, spontaneous recovery is quite common. For example, prevalence of prominent fatigue in acute illness (infectious mononucleosis/Glandular Fever) is about 41%: of these 71% had prolonged fatigue one month later; 43% at two months and only 9% at six months (White et al. 1995). However, full recovery in patients with established CFS is less common. In a longitudinal study of patients with CFS, with follow-up at 18 months, only 3% of

patients reported complete recovery and 17% reported improvement. Predictors of improvement were: subjective sense of control over symptoms, less fatigue, shorter duration of complaints, and a relative absence of physical attributions. Psychological factors were related to improvement, especially cognitive factors (Vercoulen et al. 1996b). In another study, within a tertiary care setting, recovery was found to be rare, but improvement common (Bombardier and Buchwald 1995). In one prospective study, patients with chronic fatigue syndrome were followed-up at a one year interval. Nearly two thirds reported an improvement on direct ratings of change. Poorer outcomes were linked to prolonged illness duration, subjective cognitive difficulty, and somatic symptoms: There was no influence of anxiety, depression, or general emotional distress. Results suggested that interventions that either discourage avoidance of activity or enhance perceived control could benefit the course of the illness (Ray et al. 1997).

Some studies show that younger patients have a notably better outcome. In one study 54-94% of children revealed definite improvement (with up to six years' follow up); 20-50% of adults show some improvement in the medium term and only 6% returned to premorbid levels of functioning” (Reid et al. 2003). In another study, follow-up demonstrated significant improvement in many patients during year one with continued improvement in most patients during the second and third years. Almost half (43%) of families considered their child "cured" and 52% considered their child "improved," whereas only 5% considered their child to be "the same” (Krilov et al. 1998). A third long-term follow-up study showed 80% of children and adolescents affected had a satisfactory outcome from their fatiguing illness, although the majority of these participants had mild to moderate persisting symptoms. A fifth of participants remained ill with significant symptoms and activity limitation 13 years after illness onset. CFS in children and adolescents may result in persistent somatic symptoms and disability in a minority of those affected (Bell et al. 2001).

1.12.1 Outcome Predictors

Factors associated with poorer outcomes include:

- Longer illness duration

- Subjective cognitive impairment
- Somatic symptoms
- Levels of fatigue
- Functional impairment
- A low sense of control over symptoms

Factors not associated with poorer outcomes include:

- Gender
- Life stress events
- Laboratory parameters such as viral antibody titres and immunological measures (including T-cell subset measurements)

1.13 Severely Affected CFS Sufferers

A 2002 report to the Chief Medical Officer (CMO) by the CFS Working Group (Dept of Health 2002) estimated that up to one quarter of CFS sufferers are severely or very severely affected. This set of patients may suffer such extensivity of symptoms that they are predominantly bed-bound, requiring assistance for even the most basic of personal care needs, they may also struggle with sensitivity to light, sound and smell. The severity of their symptoms means that this group of people and their carers often experience a great sense of isolation, socially and medically. The experience of severe symptoms may be a temporary one, resulting in transient periods of extreme symptoms, and as such a care package needs to be tailored carefully to meet their needs. A paper published in 1999 concerning the Chronic Fatigue Syndrome Service within the Essex Neuroscience's Centre, reported that out of 318 patients seen within the clinic (out-patient and in-patient facility), 14% (43 out of 318) were severely affected, i.e. extremely restricted mobility, and 9% (29 out of 318) very severely affected, that is classified as totally bed-bound, (Cox and Findley 1999).

Summary of Management, Prognosis and Severely Affected

Research findings within the area of management remain inconclusive, however the most widely acknowledged and utilised therapies are that of Cognitive Behavioural or CBT and Graded Exercise – GET. The note of caution which should be heeded by

physicians recommending these therapies is that doctors must resist a ‘one size fits all’ approach and instead remain sensitive to the individual needs and abilities of the patient. The issue of prognosis is also not clear-cut, with some individuals recovering within a matter of months whilst others remain ill for many, many years. The research findings suggest a promising outcome for younger sufferers. Specific outcome predictors are associated with poorer prognosis including longer illness duration, subjective cognitive impairment, somatic symptoms, levels of fatigue functional impairment and a low sense of control over symptoms. There are a small number of patients classified as severely affected, such individuals suffer extremely restricted lifestyles and suffer from extensive impairment to daily functioning due to seriously debilitating symptoms.

1.14 Comparing CFS and Other Fatiguing Illnesses

There have been some studies comparing CFS with other fatiguing illnesses. Research conducted into Multiple Sclerosis (MS) patients and CFS sufferers has found similar ratings of fatigue dimensions between the two groups, but higher somatisation scores within the CFS group, (Vercoulen et al. 1996a). When examining depression, CFS patients have been found to score more highly than MS on questions of frequent current depression, particularly following illness onset, however there was no difference in the two groups regarding major personality disorders and when comparing CFS participants with individuals diagnosed with major clinical depression the former group were recorded as having significantly less depression and fewer personality disorders, (Pepper et al. 1993). Another study comparing CFS, MS, depressive disorder and sedentary healthy controls (Johnson et al. 1996) reported significantly higher number of personality disorders and elevated neuroticism scores compared to the other three groups, and individuals in the CFS and MS groups had intermediary personality scores which were significantly higher than healthy controls. A 2002 study comparing CFS and MS sufferers on levels of functional status and fatigue, found that the CFS group had significantly lower functional status and higher fatigue levels than the comparison group, (Taillefer et al. 2002). Another category of patients suffering fatigue is that of cancer and recovering cancer patients, a study in 2002 evaluating CFS patients gender and age-matched with a group of disease-free breast cancer patients demonstrated higher levels of

fatigue, functional impairment, pain and self-efficacy in the CFS group, but similar ratings on psychological well-being, sleep patterns and concentration between the two groups, (Servaes et al. 2002). One area which CFS patients find particularly troublesome is when it is implied that such individuals must fall into a certain personality type. A paper written by Surawy and colleagues reported observations of particular personality types (“conscientiousness, perfectionism, and emotional control”) which it was proposed may lead to specific styles of coping in situations where competency and emotional control are threatened, which in turn lead to exhaustion, (Surawy et al. 1995). In conclusion to their article, however, they remark:

We acknowledge that CFS is unlikely to be a homogenous condition, and that the observations we have described may not be relevant in all cases, (Surawy et al. 1995, p. 543).

A different study conducted by Wood and Wessely four years later found no evidence of significant personality differences between patients with CFS and those with JIA, they conclude their paper:

The stereotype of CFS sufferers as perfectionists with negative attitudes toward psychiatry was not supported, (Wood and Wessely 1999, p. 385).

1.15 Specialist CFS Centres of Expertise

On May 12th 2003, Minister for Health; Jacqui Smith, announced a lump sum of £8.5 million of government funding specifically for the targeting of CFS services in England. The main focus of the financial subsidy was to set up clinical care facilities within different geographic regions of the country; launch multidisciplinary teams to support primary care services; aid clinical research and assist in the training of healthcare providers. During a speech given at a CFS Service Unit in Essex in 2002, Smith acknowledged the debilitating and widespread nature of CFS and declared the money a crucial step in benefiting CFS patients of all ages. Professor Anthony Pinching, (Associate Dean for Cornwall, Peninsula Medical School and former Deputy Chair of CFS Working Group) was pronounced chair of the group. In July 2002 different regions were invited to apply for bids for a proportion of the funding in order to initiate and facilitate a CFS service in their area, it is one of these teams

that has been implemented in the South of England for young people with CFS, that I have recruited from for this study.

In August 2007 the National Institute for Health and Clinical Excellence produced NICE guidelines for CFS/ME, as a consequence of the NHS investment in new services in England. The guidelines are consensus based, incorporating the views of the National Collaborating Centre for Primary Care, alongside a group of healthcare professionals including consultants, GPs, occupational therapists, clinical psychologists and physiotherapists, and they state assessment and treatment recommendations.

1.16 Why CFS Remains a Controversial Condition

Some of the most likely reasons are listed below:

- ❖ CFS does not fit neatly into any particular diagnostic category, as has been illustrated through exploration of some of the topics in the previous chapter, the ‘closest fit’ is within the somatoform disorder spectrum. There is major controversy about whether it is a somatoform disorder resulting in tension between patient groups and healthcare professionals. CFS incorporates an array of symptoms, not all of which are present in every sufferer, and therefore definition remains ambiguous
- ❖ Without a standard diagnostic test the condition remains open to interpretation and it comes down to individual clinicians to utilise their clinical judgement in order that diagnoses may be made
- ❖ In common with many other illnesses, there are no medications that can be prescribed for patients which will cure the condition, only medications that may or may not be helpful in treatment of some of the symptoms (e.g. insomnia or situational depression)
- ❖ Finally, when there is considerable overlap between CFS and other possible conditions of a psychiatric nature, CFS is often misdiagnosed as a depressive illness – this has been discussed at length above

A poignant parallel that Wessely and colleagues (Wessely et al. 1998) draw between neurasthenia and what is now called CFS is the depth of controversy that both conditions cause(d). In the 21st Century, just as in the late 1800s the condition causes division amongst professionals and public alike, with claims of neurasthenics not being ill, but simply showing signs of ‘nervousness’ or malingering. Anyone involved with CFS living in present day England – whether patient, advocate or researcher – will be able to relay encounters of a similar type to those negative reactions recorded in the early twentieth century. CFS is classified as a neurological disorder, under the World Health Organisation (WHO)’s International Classification of Diseases (ICD-10, 1992). Despite this *and* the Chief Medical Officer, Sir Kenneth Calman, giving CFS medical recognition in 1988 still today some refuse to acknowledge the conditions existence and in doing so fail to recognise the daily struggle that patients encounter.

Wessely et al (1998) illuminate the cause for controversy surrounding neurasthenia, which has re-emerged with CFS, which is the argument of legitimacy. Neurasthenia was considered by many cynics as an imaginary illness, just as CFS is still today considered to be ‘all in the mind’ or a case of malingering, despite Professor Sir Liam Donaldson (the then Chief Medical Officer for England and Wales) in 2002 stating the severity of disability caused by CFS saying:

CFS/ME should be classed alongside other diseases such as multiple sclerosis and motor neurone disease, (Hutchinson 2002).

There aren’t many people who would consider these two aforementioned diseases as ‘all in the mind’. CFS (and its synonyms) is classified by the World Health Organisation in the ICD-10 in Chapter VI as a disease of the nervous system, although this classification has too resulted in controversy (mainly that not all CFS patients display neurological problems) it does confirm the conditions recognition as one of physical and not psychological origin. Add to these public medical acknowledgements the recent discovery of differences in gene expression in CFS patients; namely that there is gene expression which has been isolated to only CFS sufferers, these genes are four times more active, and one gene less active, than those present in healthy controls, (Kerr et al. 2008), and it is becoming more difficult to

describe CFS as simply a state of mind. It may be argued that genetic factors could promote a certain state of mind, however expert opinion points to physical causes.

So the controversy surrounding this condition remains true today;

The Victorians never provided satisfactory answers to these dilemmas Hence when the latest fatigue syndrome, ME and CFS, made their appearance in the 1980s, it was inevitable that both doctors and patients would experience an almost identical sequence of claim and counter claim over the legitimacy or otherwise of the next syndromes, (Wessely et al. 1998, p. 120).

While the literature presents a diverse and controversial picture it is clear that CFS is relatively common and has major impact on quality of life for both adults and children/young people. It is readily recognisable and early diagnosis may improve patient outcome. Therapy should be centred around evidence based treatments of CBT and GET, and management plans should be carefully tailored to the specific needs of the individual. There is a significant number of severely affected patients who require additional support and sensitive supervision. CFS is a condition which impacts not only the patient's health experience but also effects the wider family and other important areas of life such as the ability to continue work, which naturally influences economic and financial sustainability. CFS is particularly disruptive in adolescence due to the nature of the condition interfering with academic and social life. Also the enforced reliance on parents as carers for a young CFS sufferer impacts significantly on the natural progression towards autonomy from family which should be a normal part of the development process during this period of the life-cycle.

1.16.1 The Controversy of CFS and My Own Stance

It is possible to see the major controversy there is surrounding CFS generally. There is little agreement on almost any aspect of the condition – its label, origin, the diagnostic criteria used to treat it, knowledge about prognosis, concluding findings within areas of specific research and management, and even its authenticity as a 'real' illness. It is unsurprising therefore that the condition causes so much debate amongst medical professionals, patient bodies, the media and the general public, without a clear-cut framework to begin with this condition is destined to cause issues of disagreement. This is not easy for CFS researchers and advocates who work to

promote the genuine nature of the illness, but is perhaps most damaging for sufferers themselves who are without the assurance of universal consensus.

As a sufferer for many years and now a researcher myself I too am faced with the turmoil of disagreement and must ground myself somewhere within the arena of debate. My position is one of total and unwavering confidence that this is a real and debilitating condition, and this assurance is based in my own personal experience of it, which is irrefutable. It is this personal experience which has driven my interest and focus on the specific research questions for the present study. My interest is to explore the experiences of young people and to provide a description of what it is like to live with CFS, so that greater understandings are available to professionals, families and young people themselves.

I agree that the label of 'Chronic Fatigue Syndrome' is not as encompassing as it could be and leads to confusion and disregard from those that do not (and cannot be expected to) understand the nature of the disability it can cause. The logistics of altering the name, however, are complex and will probably take many years before it is resolved, if at all. The lack of universally accepted criteria is an unfortunate one, it results in inaccurate and probably under-estimated prevalence rates and needs to be refined. Conclusions from research into cause, prognosis and management can only be confirmed or denied after further, robust studies are conducted with larger data samples and I hope that the recent genetic research breakthroughs will provide the impetus and funding to see that followed through. The large number of sufferers dealing with this misunderstood and often disregarded condition deserve conclusive answers, if nothing else to assist them in dealing with the day-to-day effects of having a chronic condition.

1.17 My Research Objectives

Through my own research I address the distinct lack of knowledge within the field concerning paediatric CFS, specifically by allowing adolescent sufferers and their families to tell their stories in an effort to aid understanding and appropriate management techniques within clinical practise. Through the growth of understanding within this domain those involved with young CFS sufferers may

become more equipped to address the day-to-day functioning issues experienced by this group of patients and those closest to them.

Chapter 2

CFS in Young People: Grounding the Focus of the Study and Reviewing the Literature within the Paediatric Domain

2.1 Introduction

Having discussed the general nature and history of fatigue, as well as CFS in general terms, I now turn attention to the focus of this present study – young people and CFS. The nature of the condition remains predominantly the same for people of all ages, however there are some important distinctions which are reserved purely for children and adolescents.

The literature concentrating on CFS in young people and children is limited compared to the adult population (Garralda and Rangel 2001), however the majority of papers which do exist have been published in the last 15 years, and there are a handful which were submitted in the five years prior to that. My review of the literature was conducted using the search terms ‘CFS’, ‘Chronic Fatigue Syndrome’, ‘ME’, ‘Myalgic Encephalopathy’, ‘CFIDS’ and ‘Neurasthenia’, in order that the broad spectrum of different labels that have been implemented over the years was covered. I also used combined terms such as ‘children AND fatigue’, ‘fatigue AND adolescents’, ‘chronic illness’ and ‘chronic fatigue’. The databases I used to search the literature included Medline, Pubmed and Google Scholar. Although I read some books and sections of books concerning the young adolescent population, I chose to mainly focus upon peer-reviewed journal papers.

2.2 Incidence and Prevalence, Demographics and Prognosis of Childhood CFS

A 2007 paper reported a child as young as two years old, and a further four children under the age of five years, who met the RCPCH criteria for CFS from a specialist CFS care centre in the South of England (Davies and Crawley 2008). As previously mentioned with reference to adult CFS, due to there being no universally accepted diagnostic criteria ascertainment of accurate prevalence figures is difficult, the same

is true (if not more so) in childhood CFS. Different prevalence studies conducted both in the UK and the USA have attempted to estimate the rate of adolescent cases of CFS with varying results. Population-based studies in the UK and USA in children up to 18 years of age have reported prevalence rates of approximately 2 per cent (Jordan et al, 2006; Bell et al, 1991; and Farmer et al, 2004). Much higher figures were reported in a 2006 study of 181 per 100,000 in an adolescent age-group, (Jordan et al. 2006). An Australian paper provided one estimate of 5.5 cases per 100,000 in under 10 year olds and 48 per 100,000 in 10 to 19 year olds (Lloyd et al. 1990). A relatively early paper by Dobbins, Randall and colleagues affiliated with the CDC (Centres for Disease Control and Prevention), conducted in 1997 reported findings from a tri-fold study looking at chronic fatiguing illness among adolescents (Dobbins et al. 1997). The investigation incorporated (1) a physician-based surveillance system of four communities over a two year period, which identified 23 adolescent cases including 7 with a CFS diagnosis; (2) a random cross-sectional community telephone survey which took place in an urban population and screened 2,249 two to 17 year olds finding five cases of chronic unexplained fatigue, one of which may have been CFS; and (3) a cross-sectional survey of school middle, junior and high-school nurses in two communities, within which 22 students were identified with unexplained chronic fatiguing illness, and of these 10 were categorised as CFS. The authors concluded that CFS was clearly present amongst adolescents, although the number of cases was lower compared to an adult population, (estimated prevalence rates of between 0.2 and 0.4% of the adult population according to Gallagher et al, 2004, see previous chapter). The difference in prevalence findings across the three studies could be attributed to the varying study designs. There was almost certainly an issue regarding the applicability of the adult case definition to this particular age group and the paper concludes by highlighting the need for further research to this end.

A similar result was found in a 2003 study in the UK (Chalder et al. 2003), which was done as part of a large survey conducted in 1999 by the Office for National Statistics looking at prevalence levels of mental illness in five to 15 year olds residing in England, Scotland and Wales. Mothers from 10,438 families were asked whether any of their children had ME or CFS and completed a general health questionnaire. Out of this sample 4,240 11 to 15 year olds were called for interview

and asked a number of questions related to fatigue and other symptoms. Findings demonstrated a prevalence rate of 0.19% according to the CDC criteria, however it has been demonstrated that this is not an appropriate diagnostic framework to use in young people and children and may well have missed many cases that a less stringent, more age-appropriate criteria could have picked up.

The following year a random digit-dialing survey of residents living in Wichita, Kansas was conducted, (Jones et al. 2004), through which a number of adolescents (aged 12 to 17) underwent a clinical evaluation to classify them as either having CFS or another fatiguing illness. Of the 8,586 adolescents assessed, 138 were identified as having fatigue for up to one month and, of those, 78% had experienced *chronic* fatigue for up to six months. After further evaluation 31 were considered to have a CFS-like illness, however out of the 11 that agreed to continue in the study none met the CDC criteria for CFS. The conclusion drawn by the authors is a prevalence rate of 338 per 100,000 for a *CFS-like* illness, however as with the other studies referenced above the application of a diagnostic criteria other than the CDC framework would have been likely to identify more actual cases of adolescent CFS. To counter-act this issue of appropriateness of the CDC criteria for use with adolescents a 2004 UK-based study applied a three-month, as opposed to six-month, duration of fatigue in a sample of 2,269 twin pairs aged eight to 17 years (with a mean age of 14 years and eight months), and concluded a prevalence rate of 2.34% for disabling fatigue lasting three months; to 1.29% for a disorder very similar to adult CFS and identifiable by the CDC definition. The result being that from age 11 years adolescents display comparable rates and types of chronic fatigue to adults, and this study demonstrates the identification of many more cases of adolescent CFS when the CDC criteria is replaced by a less stringent diagnostic stipulation, (Farmer et al 2004). Two studies conducted in the UK, the first a postal survey of 1024 GP practices looking at medically unexplained severe fatigue of more than three months duration in five to 19 year olds (Haines et al. 2005) reported 62 cases per 100,000, and the second a five year retrospective period prevalence survey of 1,098 schools in six Local Education Authorities (LEA) areas (Dowsett. and Colby 1997), identified similar prevalence rates of 62 per 100,000 and 70 per 100,000 respectively.

The RCPCH guidelines (2004) estimate a UK prevalence rate of childhood CFS as 50-100 per 100,000. The general trend is that CFS prevalence is higher in adolescence than in younger children, but the obtainment of accurate adolescence prevalence rates is largely skewed due to the application of adult criteria which results in lower numbers of cases. As yet there are no universally agreed upon criteria for use with young people, some suggest a few weeks, others believe a three month period of fatigue is more appropriate, (as mentioned previously). The lack of accurate figures regarding incidence add to the confusion and debate regarding adolescent CFS.

Children complain of somatic symptoms such as headaches and tummy aches, and this reporting increases during adolescence, as do reports of fatigue and hypersomnia, documented in a study of 14-16 year old adolescents in Finland, (Aro et al. 1987). Although the gender ratio split remains inconclusive (RCPCH 2004), the trend appears to be 3:1 – female to male; (Bell et al. 1991; Dobbins et al 1997; Dowsett and Colby 1997; Farmer et al. 2004; Haines et al. 2005; Lloyd et al. 1990; Patel et al. 2003). With regard to social class distribution the pattern reflects that in adults (discussed earlier), the differences in socio-economic class are likely to be reflective of referral patterns and not an accurate representation of the condition affecting the more affluent; the same reasoning applies to white versus other ethnic groups, (Haines et al 2005).

Those studies with extended follow-up show 60-80% partial or complete recovery with a mean length of illness of 37.5 to 49 months, (Bell et al. 2001; Rangel et al. 2000a; Rowe et al. 1999), with a small percentage – approximately 20% remaining ill, (Joyce et al. 1997). Figures from the Royal College of Paediatrics and Child Health report a statistic of 66% making a full recovery and approximately 5% remaining ill in the paediatric population, (RCPCH 2004).

CFS may affect, not only physical, but also social and emotional areas of functioning, thus impeding normal everyday life. In adolescents, this debilitation is compounded further as it restricts daily functioning at a stage when education, social activity and psychological development are of critical importance. The potential impact of any chronic disorder on education is of particular concern, as is the broader effect of the illness on parents/carers and family life. It has been claimed that CFS is

the reason for more school absence than any other condition (Dowsett and Colby 1997), mean time out of school is one academic year (Rangel et al. 2000a), and one third of cases achieve no school qualifications (Rangel et al. 2003). Thus, CFS is a very important issue in the adolescent population, impacting significantly on education.

The general conclusion appears to be that prognosis in younger patients is more favourable than in adults, when given appropriate recognition and treatment, however there do remain a small but significant number that experience prolonged disability.

2.3 Clinical Features and Symptoms

Both gradual (Bell et al. 2001; Patel et al. 2003) and sudden onset of illness (Carter et al. 1995; Krilov et al. 1998; Saidi and Haines 2006) are displayed in younger patients. Some patients report infectious illnesses preceding onset of illness, including flu; Epstein-Barr virus (EBV); and glandular fever, to name a few. For some the trigger is a major traumatic event and for others a general anaesthetic. The most common reported symptom is, unsurprisingly, disabling fatigue, which is exacerbated by activity; this may be constant or intermittent (i.e. experienced over time with some periods of remission). Other reported symptoms (Holmes et al 1988, Lloyd et al 1990, Sharpe et al 1991, Fukuda et al 1994), are listed overleaf, in Box 3.

Box 3: Additional Reported CFS Symptoms

sleep disturbance	concentration difficulties	depression
severe malaise	memory impairment	headaches
muscle pain	joint pain	sore throat
abdominal pain	tender lymph nodes	nausea

Other, less common symptoms reported, include temperature fluctuation; dizziness; photophobia; hyperacusis; weight changes; upset stomach and muscle weakness. Sleep problems have been found to include phase delay and interruptions (Stores et al. 1998), non-refreshing sleep (Bell et al. 1991; Feder et al. 1994; Smith et al. 1991), excessive sleep (Carter et al. 1995; Rangel et al. 2000b), difficulty falling asleep (Krilov et al. 1998; Walford et al. 1993), waking frequently (Krilov et al. 1998), difficulty waking in the morning (Krilov et al. 1998), also daytime drowsiness and napping (Feder et al. 1994; Walford et al. 1993). There seems to be a difference in presentation between the genders, with girls reporting more headaches and sore throats and boys struggling with school problems, memory and concentration issues and post-exertional malaise, (Crawley 2006). Many researchers have commented on the overlap between symptoms and/or diagnosis of depression and anxiety (Garralda et al. 1999); school phobia or poor attendance (Brace et al. 2000; Van Middendorp et al. 2001); and social withdrawal (Gray et al. 2001). However, such symptoms may not be true characteristics, but rather a situational reaction to the restrictions and debilitations caused by CFS.

2.4 Diagnosis and course of illness

2.4.1 Diagnostic Criteria

As mentioned earlier in this chapter the issue of diagnostic criteria in adults has been largely debated within the literature resulting in the ‘*CDC*’ (Fukuda et al. 1994), ‘*Oxford*’ (Sharpe et al. 1991), criterion, which despite slight variations are predominantly very similar in content. Studies that have applied the adult CDC criteria to children and adolescents have failed to identify adolescent cases suggesting these criteria are inappropriate to use in this population. A key paper by Jones et al identified *no* cases of adolescents with CFS using the adult criteria, (Jones et al. 2004). A major issue which arises when attempting to apply the adult diagnostic framework to children/adolescents is that a six month duration of fatigue is too long and would result in major disruption to school and social life, some have suggested eight weeks to be a more appropriate boundary (Vereker 1992), and some a three month cut-off (Royal College of Physicians 1996). In 2004 an RCPCH report *Evidence Based Guideline for the Management of CFS in Children and Young*

People was published to draw together different sections of research involving children and young people with CFS, this report includes information from a range of differing levels of evidence, (scaled from A as the highest level – high quality RCTs and meta-analyses; to D at the lowest – recommendations agreed by consensus process of panel).

The RCPCH report states;

Diagnostic delay can cause anxiety in the patient and family and delay in the initiation of an appropriate management programme. Furthermore, in practise, many children and young people will have been unwell for a significant period before being referred to a paediatrician from primary care, (RCPCH 2004, p. 27).

However, some clinicians believe that hurriedly assigning a diagnosis for an illness which is so misunderstood in young people is unwise, the argument being that many children and adolescents may suffer post-viral fatigue syndrome (PVFS) which does not evolve into CFS but rather the patient improves, in these cases some feel it is prudent to wait a certain period of time to monitor whether the patient improves as giving a CFS diagnosis may hinder rather than help.

2.4.2 CFS Diagnoses in Young People and Children

A diagnosis of CFS is recommended after routine investigations have failed to uncover another cause of illness, generalised fatigue has continued to be disruptive to the patient's life and a thorough individual and family history has ascertained no other possible condition. When making a diagnosis for childhood CFS the paediatrician needs to listen carefully to the child's description of their experiences and to other family members who may be able to paint a fuller picture by adding in details the child may have overlooked, forgotten or felt were irrelevant. Other factors including general health and past medical history, information of any recent foreign travel, diet and sleep patterns, and impact of the condition on their academic and social life are all important. The RCPCH guidelines highlight the importance of sensitivity when exploring the child's experience;

The clinician should acknowledge the distress caused to the child/young person and the parent by the symptoms being suffered, (RCPCH 2004, p. 34).

The necessity of forging a trusting relationship with the patient and their caregiver(s) is also stressed. A general physical examination, including height and weight, neurological exam, clinical signs, blood pressure and heart rate, and blood and urine screenings should be conducted, as well as other non-invasive tests such as joint mobility. In order that no undue stress is caused to the patient and family the RCPCH stress the importance of tests being conducted in as brief a length of time as possible. The RCPCH recommend that when a diagnosis has been made it should be communicated to the child/young person and family as soon as possible, and to give full explanation of what the diagnosis means and future care/management arrangements.

2.4.3 Diagnosis

A 1994 study in Massachusetts demonstrated an overlap between paediatric CFS and juvenile fibromyalgia (FM), (Bell et al. 1994). Doctor David Bell and his colleagues evaluated 27 children with a CFS diagnosis for symptoms of FM, namely the presence of widespread pain and multiple specific tender points on the body. Of the 27 patients, eight (29.6%) were positive for an FM diagnosis, results signified that there are cases of paediatric FM which may be wrongly diagnosed as CFS and that under current diagnostic criteria the distinction between the two conditions is difficult to make. In another study (Carter et al. 1996), 20 CFS patients, aged eight to 19 years, were compared to the same number of depressed and healthy matched controls and all completed a number of self-report questionnaires as well as participating in a structured diagnostic interview. Outcomes showed that certain psychological factors can help distinguish between CFS and depression, such results may aid our understanding of CFS in younger individuals and ensure accurate diagnostic decisions are made.

2.4.4 Course of Illness and Outcomes

A study looking at illness onset characteristics in paediatric CFS (Bell 1997), evaluated 23 children with unexplained fatiguing symptoms and found that ten had suffered an acute flu-like trigger, whereas the remaining 13 had experienced a gradual onset of fatigue, describing increasing bouts of infectious illness in the preceding months. The author concluded that *the majority of children and*

adolescents with unexplained chronic fatigue had a gradual onset of debilitating symptoms, I would suggest that the statistics of 13 to 10 does not demonstrate a conclusive difference between gradual and acute illness onset, however other studies have reflected larger differences between the two groups, (Bell et al. 2001). A longitudinal study was carried out in the USA reviewing the educational, social and symptomatic outcome of children and adolescents with CFS 13 years post onset of illness, (Bell et al. 2001). Questionnaire data was obtained from 35 participants – 24 female and 11 male – with the average age of illness-onset having been 12 years old. Out of the 35 subjects 13 described themselves as recovered, 15 said they were well but that the CFS was still not resolved, four believed they were chronically ill and the remaining three reported that their condition had worsened over time. The outcomes demonstrated the existence of CFS in adolescence in line with the current diagnostic definitions (presumably the CDC criteria) and that CFS may result in a persistent somatic state, with a minority remaining disabled for lengthy periods of time. A UK-based study investigating course of illness found similar results (Rangel et al. 2000b), again finding that the majority of children and young people with CFS do make a good recovery, however some suffer long-term handicaps. The figures quoted in the paper described two-thirds as recovered and the remaining participants as remaining incapacitated, upon follow-up. The article goes on to highlight the negative effects on schooling; with a mean duration of absence as being one year, and the average length of illness as 38 months, it also describes connections between illness triggers; higher socio-economic class and time of illness onset as being linked to positive recovery. A research study conducted by Krilov and colleagues in the USA set out to investigate the course and outcome of paediatric chronic fatigue, (Krilov et al. 1998). Of the 42 participants 71% were female and 94% white, the age range was split equally between two brackets; with 50% being seven to 14 years old and the other half aged between 15 and 21 years. Half of the patients had been fatigued for between one and six months, and the other for seven to 36 months. There was a high percentage of allergy sufferers; 60% and those who described sudden onset due to acute illness trigger accounted for 60% also. Commonest symptoms, reported by Krilov et al (1998), are listed, in Table 2 below;

Table 2: Commonest Symptoms of Paediatric CFS

Fatigue	100%
Headache	74%
Sore Throat	59%
Abdominal Pain	48%
Fever	36%
Memory/Concentration Issues	33%

Follow-up telephone conversations revealed 43% of families considered the child to be fully recovered, 52% believed they had improved, and 5% reported no improvement. These findings show that children and adolescents do display a similar condition to adult CFS, however there are some features which are unique to the younger population including earlier presentation and more positive outcome. A case-control study investigating demographic, medical, psychological and natural history features of paediatric chronic fatigue compared 20 participants with CFS with 20 depressed and 20 healthy controls. Those participants with a two or more month history of fatigue underwent a set of detailed physical and laboratory tests. Demographic results included a median age of fatigue patients as 14.3 years, 60% to be female and 87% from mid or upper socio-economic class backgrounds. The two features to represent most highly in the fatigue group were white and mid/upper socio-economic class status and the most commonly reported psychological features included decline in quality of life and high scores on internalising, withdrawal and social isolation behaviour. Nine out of the 20 CFS patients met criteria for depression, however the symptoms were not as marked as those reported by depressed controls. The authors conclude that there was an over-representation of white, mid/upper class patients, apart from exclusion of Epstein-Barr virus and infectious mononucleosis laboratory testing did was not advantageous in highlighting other diagnoses, chronic fatigue resulted in major alterations to quality of life and was linked to psychosocial distress. The over-representation of white, higher socio-economic class participants may well have had more to do with consulting behaviour patterns than any other explanation (Haines et al. 2005), and the less marked depressive symptom reporting may be due to those with chronic fatigue experiencing situational as opposed to clinical depression. As the authors conclude, psychosocial interventions may be beneficial in improving quality of life for those with chronic

fatigue. Another outcome study evaluated paediatric chronic fatigue patients up to the age of 21 with fatigue of more than three months, at 3.8 years after onset, (Feder et al. 1994). Almost three-quarters of participants (73%) were female, with mean age of 15 years, in 78% of cases the fatigue was preceded by acute illness. As with the previous study, laboratory testing did not prove helpful. At follow-up, the majority reported their fatigue had resolved, 29% reported some improvement and 6% stated their health was unchanged. The results, as with other studies, demonstrate optimistic prognosis for young patients. A large-scale longitudinal Dutch study in 2008 (Ter Wolbeek et al. 2008) incorporating 653 adolescent girls used questionnaires to measure fatigue severity, depression, anxiety, and CFS-related symptoms six months and 12 months after initial assessment. Just over a quarter (25.7%) of the n participants who were severely fatigued at initial assessment remained so throughout the duration of the study, these individuals had lower levels of physically activity, higher levels of depression and anxiety and shorter sleep capabilities. Results demonstrated a correlation between reduction of fatigue and less depression, anxiety and CFS-related symptoms, as well as an increase in physical activity and sleep duration. The findings showed how debilitating severe fatigue can be on adolescent lives and authors conclude that interventions should be linked to preventative and therapeutic strategies focussed on emotional well-being. Other articles concentrating on specific characteristics of child and adolescent patients include Lapp, (Lapp 2006), Davies and Crawley (Davies and Crawley 2008) and Crawley, (Crawley 2006).

2.5 Medical Management/Treatment of CFS in Children

A case study of an adolescent boy from Belgium highlights how one family suffered from accusations of Munchausen-By-Proxy as a result of poor school attendance and a decrease in his social and physical activities, (Van Hoof et al. 2006). The article describes the family's experience and the ways in which had the school staff been correctly informed the situation could have been avoided and unsubstantiated accusations of abuse prevented from adding to an already stressful situation. Obviously a case study of one individual is not necessarily transferable to an entire population, however it is possible to see one family's plight and features of this may

well be replicated across other families also. This point is true for other small-scale studies too.

Papers published on general management issues highlight the different features which must be addressed in paediatric CFS, compared to adult patient management. A paper which highlights the need for awareness by healthcare providers of the psychological, socialisation and educational needs of adolescent CFS sufferers lays out a review of the literature concerning the unique features of CACFS (Chronic Fatigue Syndrome in Children and Adolescents), it recognises those difficulties exclusive to a younger population and states that greater diagnostic and treatment challenges are present with this age group compared to adult sufferers, (Oleske et al. 2006). Similarly, a Canadian paper written by Breau et al recognises the different aspects of paediatric, compared to adult CFS, as well as highlighting the lack of well-designed controlled studies of the younger population, (Breau et al. 1999). General management papers demonstrate the different features unique to childhood CFS.

A 2002 Australian paper reported on a questionnaire study of 57 adolescents who had been involved in an intensive multi-disciplinary inpatient CFS programme, (Lim and Lubitz 2002). It reported that of the 42 individuals who returned responses the majority had shown improved physical functioning and social interaction and had returned to school, with 94% attending school half-time or less prior to the programme and 78% attending school full time post-intervention. A follow-up outpatient study was conducted at Great Ormond Street Hospital's Department for Adolescent Medicine in the UK, using a multidisciplinary rehabilitative treatment (including GET/Graded Exercise Therapy, family sessions and supportive care), of the 56 nine to 17 year olds who participated in the full rehab programme 43% had complete resolution of illness compared to only 4.5% who received supportive care alone, (Viner et al. 2004). The former group displayed improvement in Wellness scores and school attendance at follow-up compared to the latter group, and authors conclude that *the programme significantly reduced the overall severity of the illness.*

When a diagnosis of CFS has been ascertained and communicated to the child and parents a management plan needs to be formulated together with the patient,

caregivers and any other relevant professionals. The plan needs to include the points listed below in Box 4, cited in the RCPCH 2004 guidelines (p. 42).

Box 4: Management Plan for Paediatric CFS

- | |
|---|
| <ul style="list-style-type: none">· Activity management advice including establishing a baseline of activity level and gradual increases as appropriate· Advice and symptomatic treatment as required· Regular review of progress <p><i>Some individuals may also require:</i></p> <ul style="list-style-type: none">· Multidisciplinary assessment for referral for a behavioural intervention |
| <ul style="list-style-type: none">· Referral to other health professionals· Liaison with educators if more than 15 days of school has been missed |

When managing activity it is crucial to first establish a baseline that the individual can attain, even on a bad day, and work from there incorporating gradual increases in activity. Activity diaries can prove useful for some individuals, and functional ability scales such as the *AYME Young Person's Ability Scale* (Moss 2005) – a copy of which is included in Appendix E - may aid the observation of progress, although it is important to closely monitor both ability scales and diaries and to detect deterioration early so as to avoid upset to the patient and family.

Symptomatic treatment may include dietary advice, although sensitivity needs to be employed when dealing with children and adolescents struggling with weight changes, nausea, and so on. The general findings in the literature are that a well-balanced healthy diet is the most beneficial course of action and that major dietary changes which involve excluding particular food groups have not provided any conclusive results (Bagnall et al. 2002; Werbach 2000). As well as dietary advice, sleep regulation is also important. Initially cognitive and behavioural interventions such as implementing a bedtime routine, having a bath, and not watching television prior to bed, etc should be tried, if these changes are ineffective the next step is introduction of pharmacological interventions may help, although medicine should be prescribed with careful consideration of drug sensitivity levels. There is a lack of research in this area. Pain management is also necessary. If simple analgesics are

ineffectual individuals may benefit from referral to specialist pain clinics for CBT to learn to manage their pain. Failure here may mean that stronger medications are required.

2.5.1 CBT and GET

As with adults CBT and GET are treatments administered in the adolescent population, there are fewer studies concerning the efficacy of these therapies for this particular population however CBT appears to be effective in reducing symptoms and improving functioning for this age-range. The general approach to paediatric CFS care in the UK is, as far as possible, to utilise *outpatient* as opposed to *inpatient* treatment programmes, in which entire families can be involved in the rehabilitation process and disruption to the child's normal, familiar environment remains as undisturbed as possible. A study investigating GET as part of a rehabilitation programme; (Viner et al. 2004) demonstrated significant improvement in illness severity. Pacing as a management strategy is sometimes suggested for use in adolescents with CFS, elements of Pacing (Wright et al. 2005) are listed below:

- a. pacing the amount of activity to the changing needs and responses of the body by exercising to the point of tolerance and avoiding over-exertion
- b. managing energy within an overall limit – this is labelled as a ‘glass ceiling’
- c. resting when necessary but avoiding total rest
- d. avoiding physical and/or emotionally stressful situations until ready
- e. tailoring return to school to the needs of the young person taking careful heed of symptoms, the individual and family

Randomised controlled studies investigating the efficacy of CBT compared to non-treatment or a ‘waiting-list condition’ in an adolescent population have found improvement in reduction of fatigue, improved physical functioning and school attendance post-therapy, (Knoop et al. 2008; Stulemeijer et al. 2005). A research paper looking at management techniques reported that family focused CBT for 11 to 18 year olds was effective in improving functioning and reducing fatigue, and that these results were maintained and reported again at follow-up six months post-treatment, (Chalder et al. 2002). Of the 18 young people that completed the programme 15 (83%) showed improvement in symptoms. Despite this being a relatively small data-set it does confirm findings in the adult literature that CBT and

Graded Exercise Therapy (GET) are the most effective courses of management and the only evidence based treatments to date.

2.5.2 Pharmacological Interventions

One case of randomised controlled trials (RCTs) of immunoglobulin treatment demonstrated initial improvement but no significant difference on follow-up, (Rowe et al. 1999). The RCPCH warn against its usage in routine treatment due to concerns over safety of blood products (RCPCH 2004). Due to inconclusive results in RCTs with adults using magnesium injections and concerns regarding toxicity, side effects and pain on administration it is not recommended for usage in children. As previously mentioned, there has been no conclusive evidence to support dietary intervention, neither have adult trials shown conclusive evidence of effectiveness for hydrocortisone steroid therapy or anti-viral drugs, (Bagnall et al. 2002). There have been no definite results for the success of complementary therapy although this may be a route some families wish to pursue, the only caution would be relating to experimenting with several different interventions at one time or trying an alternative therapy which may interfere with medical treatment.

2.5.3 Psychology and Psychiatry

If clinicians are suspicious of psychiatric or psychological complications school assessments to explore possible bullying or educational difficulties may be necessary, (Wright and Cottrell 1997). Referral to such services needs to be explained to the patient and family sensitively so as to avoid a defensive reaction. Other avenues which require delicate handling are the possibility of family issues, including abuse (Dale and Straus 1992), and also fabrication of illness (Garralda et al. 1999).

2.5.4 Physiotherapy and Occupational Therapy

These services may be beneficial to aid children and young people with mobility issues, as some studies have illustrated; (Sidebotham et al. 1994; Vereker 1992).

2.5.5 General Practice

GPs are the most likely healthcare provider in children with CFS. In one study of children in primary care (Saidi and Haines 2006) it was found that despite 82% of

young people with CFS being referred to paediatric care, 62% remained within the care of the GP and only 24% under the paediatric service.

2.5.6 Management of Severe and Very Severe Paediatric Patients Using Clinical Guidelines

A definition of severe CFS is given in the RCPCH Guidelines, as:

Any child or young person who is so affected as to be effectively housebound for a prolonged period of time (3 months or more) must be considered to be severely ill, (RCPCH 2004, p. 66).

‘Very severe’ is defined as:

Any child or young person who is so affected as to be bedridden for a prolonged period of time (three months or more) must be considered to be severely ill, (RCPCH 2004, p. 66).

Emotional support is crucial in aiding severely affected individuals and their families, it is recommended that a key individual is nominated to liaise and organise services for the patient and family. Inpatient care is still not advised in the vast majority of cases, even for the most severely affected, when patients are too ill to attend for outpatient services the individual responsible for overseeing of care should arrange visits to the family home to assess condition and progress. Referral to social services should only be contemplated in extreme circumstances, under guidance laid down within the Children Act 1989, (Sections 17 and 47 – see below), when it is in the child’s best interest to do so, (RCPCH 2004).

“

Section 17 of Children Act 1989: requires social service departments to safeguard and promote the welfare of children in need, defined as being unlikely to achieve or maintain a reasonable standard of health or development or whose health and development is likely to be significantly impaired without provision of services or who is disabled”

Section 47 of Children Act 1989: If the initial assessment triggered by a referral under Section 17 concludes that the child is at risk of possible harm or has suffered harm then this will lead to a strategic discussion to plan a

section 47 enquiry. If the risk of harm is confirmed during the section 47 enquiry then a child protection conference will be convened

” (RCPCH 2004, p. 71).

2.6 Psychosocial Issues in Relation to Adolescence

Psychological adjustment is an important consideration in any chronic health condition of childhood/adolescence, due to the impact that long-term debilitating symptoms can have on self-esteem and social interaction abilities. Garralda and Rangel conducted a review study of publications and found that the main symptom in childhood CFS is fatigue, along with presentation of a variety of other physical symptoms and prolonged functional impairment, they also concluded that mood disorders are present in at least 50% of patients in this sub-set and that treatment should be centred upon family engagement and rehabilitation programmes which can benefit even the more severely impaired, (Garralda and Rangel 2002). Treatment of depressive symptoms may be necessary in some patients, although the RCPCH guidelines advise caution in prescribing anti-depressants to children and young people. Regular paediatric review is necessary to check on individual and family coping; discuss activity progression and review management plans. Any relapses need to be dealt with sensitively, being careful not to apportion blame to individuals for pushing themselves too hard. Any patients or family members wishing to research the condition further should be guided towards the most suitable information sources, as simply typing ‘CFS’ into an internet search-engine may well produce unmonitored and inappropriate information within the public domain. Involvement in patient support groups may prove beneficial for some and help patients and carers with issues of isolation, however they won’t be helpful for everyone. Counselling or family therapy may be appropriate to help individuals and families with some of the consequences of living with a chronic illness.

In a study conducted in Holland, (Van Middendorp et al. 2001), 36 adolescent girls who had fulfilled CDC criteria for CFS, mean age 15.2 years and mean syndrome duration 19.7 months, participated in a two-part study (1) interviews questioning premorbid problems and (2) questionnaires regarding psychosocial functioning,

distress, attitude and coping skills. Results showed positive attributes such as adequate self-esteem, scholastic and social abilities, but some weaknesses included low competence in adolescent-specific tasks (athletic and recreational activities and romantic affiliations) and internalising distress. The researchers concluded that the girls in the sample demonstrated an optimistic outlook on life regardless of present situation which may benefit psychological adaptation, however this may be counter-productive in encouraging participants to exceed physical limits of the condition which in turn could prolong the illness. The lack of control group in this study may well reflect a weakness in design and have an impact on findings, without a comparison group it is more difficult to put the conclusions in context. Carter colleagues also found higher levels of internalising psychological distress in their sample of adolescent CFS patients, when compared to age and sex matched individuals with juvenile rheumatoid arthritis despite there being a similar decline in physical and social activities in the two groups, (Carter et al. 1999). This result may be attributed to CFS patients having less time to adjust to their condition than the arthritis group who may well have had the condition for many more years and had more time to accept the constraints on their lifestyle. Another study, based in the USA, compared 10 matched healthy adolescents with 10 cancer patients currently in remission and 10 CFS patients, (Pelcovitz et al. 1995), the results again showed higher internalising scores in the CFS group compared to the two comparison groups. Studies looking at personality traits have found increased personality disorder in some CFS patients, compared to healthy controls, (Rangel et al. 2000a), although this was a relatively small-scale study (25 CFS patients and 10 healthy matched controls). Other psychological issues such as anxiety, depressive traits and decreased social competence were found to be present in adolescents (mean age 15.6 years and mean time after illness onset of 45.5 months) with a history of severe CFS, in a combined interview and questionnaire study, (Garralda et al. 1999), again of relatively small sample size (25 CFS and 15 healthy controls). Despite these results there are differences in the symptomatology of depressed patients compared to those with CFS, as a 1996 research study in the USA demonstrated, (Carter et al. 1996), 20 adolescent (8 to 19 year old) chronic fatigue patients were compared with matched controls diagnosed with depression and healthy controls on including negative self-attributions, social relationship disruption and life changes. Findings showed distinctions between the three groups of subjects, illustrating that depression is a

separate entity to chronic fatigue. A UK based piece of research comparing 28 children with CFS and 27 with emotional disorders (ED) found that the first group displayed fewer pre-morbid psychological problems and less psychiatric co-morbidity than the second, demonstrating a difference in clinical presentation between CFS and ED, however there were overlaps within the two groups including measurements of self-esteem, (Garralda and Rangel 2005).

As this area of research shows, young CFS sufferers can maintain a positive outlook on life, which is reflected in efficient coping strategies and they display differing traits to depressed and ED patients. Many studies have demonstrated high levels of internalising symptoms within adolescent CFS patients, and I posit that this may be connected to the vague character of the condition – there is uncertainty regarding almost every aspect of the illness including the lack of universally agreed upon diagnostic criteria, the scepticism present in the media, public domain and even in some GP surgeries, the lack of medication other than symptomatic treatments and rehabilitation programmes, and the lack of universal prognosis. I would also suggest that in studies comparing juvenile rheumatoid arthritis with CFS it is possible that the former group have had longer to adapt to their situation, and again there is more certainty surrounding it as a medical condition.

2.7 Specialist Care and Interventions

Generally speaking outpatient care involving the general practitioner and local paediatric team, and in areas where it is possible the new specialist CFS services, are the most appropriate form of management, however in a minority of cases inpatient care may be necessary, to;

(a) facilitate a rapid medical investigation to enable a definitive diagnosis of CFS to be made; and (b) for assessment and to explain the management plan to the family in a setting where all members of the local multidisciplinary team are on site, (RCPCH 2004, p. 54).

2.8 Transition to Adult Services

Due to the chronic nature of CFS often lasting years, and because CFS in childhood has a peak prevalence point of late-adolescence, the paediatrician will at some point need to transfer the patient from children's services to adult care for those patients

who have not recovered. This transition will mark the end of what, for some, would have been a relatively long-term and trusting relationship between clinician, and patient and family. It is hoped that the development of specialised CFS services will overcome some of the issues related to transition of care, as the major difference between adult services, compared to paediatric care is the lack of cohesion.

2.9 School Issues

Research has shown that the impact of CFS on education can be significant, for example Dowsett and Colby 1997; Patel et al. 2003; and Walford et al. 1993. Studies comparing children with CFS with children suffering from other chronic conditions have demonstrated that those with CFS show more school absence than individuals with Juvenile Idiopathic Arthritis (JIA), (Brace et al. 2000), and cystic fibrosis, (Walford et al. 1993). When considering young people's academic lives it is important to make provision for not only the physical elements of the condition (fatigue, muscle pain, and so on) but also the cognitive difficulties, such as disrupted memory and concentration. Provisions to accommodate children with CFS should include allowances for sleep impairment; the tiring effects of travel to and from school; movement around school buildings; being excused from sports activities; etc. for some children, home tuition may be the only realistic method of education continuity and it is important to implement this arrangement as soon as is practicable to avoid individuals falling behind their peers. In severely affected children it is important for the healthcare team to keep communicating with the school, in the hope that a return to some form of education will be possible in the future. when sufficiently recovered a return to school may be an anxiety-fueled experience for a young person who has missed not only academic classes but also the social relationships integral to school life. The academic lives of young CFS patients can be severely disrupted and this can impact on qualification achievement and projected economic stability, as well as issues of disappointment, lowered self-esteem and social isolation. A five-year retrospective period prevalence study was conducted in six English Local Education Authority areas which incorporated confidential responses to questionnaires from 1098 schools, which included information gathered about 27,327 staff and 333,024 pupils, (Dowsett and Colby 1997). This large-scale study concluded that 42% of all medically certified long-term sickness absence was

attributed to CFS, and that this was, far in excess of any other medical cause. Another follow-up study reported that of 28 children and adolescents (seven to 17 year olds), all suffered disruption to their academic or career plans, and 15 experienced difficulty returning to school following long-term absenteeism, at three year follow-up one third still reported disabling symptoms, (Sankey et al. 2006). The article highlights the need for early recognition of symptoms and attribution of diagnosis, and the importance of ongoing paediatric support and educational support.

It is not difficult to see the enormous impact that CFS can have on the lives of young people, interfering with educational attainment and social relationships, many suffer psychologically and academically due to long term absenteeism and all require ongoing support from healthcare and academic professionals.

Conclusion

To summarise, of the limited amount of literature that exists diagnostic difficulties include the overlap between childhood CFS and other conditions, such as fibromyalgia (FM), however certain psychological factors can help physicians distinguish between CFS and depression. It is not difficult to see the way in which a lack of universally agreed upon diagnostic definition may lead to wrong diagnosis and missed cases altogether, without a definitive diagnostic criteria to work from health professionals have a very difficult task. There are generalised features concerning course of illness and outcome, including more cases being linked to a gradual, as opposed acute onset of fatigue, linked to increasing bouts of infectious illness in preceding months. The overarching symptom is fatigue, but other common symptoms include headaches, sore throat, abdominal pain, fever and cognitive difficulties. Prognosis of young sufferers is generally optimistic, with the majority (70 to 75%) showing significant improvement if not complete resolution of the illness, however there are a remaining amount of 25 to 30% who report continuation of symptoms long-term. It must be reiterated that the sample sizes of these studies are small, which impacts on the extent of generalisations that can be made. Features of childhood CFS differ to the condition shown in adults, however psychosocial interventions have shown to be beneficial. The case-study article highlights that poor management can lead to traumatic consequences for individuals and families, as demonstrated by the mis-labelling of a CFS case as Munchausen-By-Proxy and

although this is a single case it does draw attention to the difficulties that can be experienced by families, however effective treatments include family-focused CBT programmes, which have proven to lead to an improvement in functioning and a decrease in fatigue.

2.10 Other Medical Issues Covered in the Paediatric CFS Literature

Above I have concentrated on those issues in the literature most closely connected with the content of my study, below I present a brief overview of articles concerning ‘more medical’ issues within paediatric CFS.

2.10.1 Orthostatic Intolerance

Research into postural orthostatic tolerance (POTS) using tilt table testing has been a popular area of investigation within the adolescent population and results have shown a positive correlation between autonomic dysfunction and some CFS symptoms, (Karas et al. 2000; Stewart et al. 1999a; Stewart et al. 1999b).

2.10.2 Neuroendocrinology and Neurology

A study conducted in Holland compared 15 adolescent girls with 14 age and sex-matched healthy controls and found a resistance of the immune system to regulation by the neuroendocrine system in the experimental group, leading authors to suggest that CFS be viewed as a disease of deficient neuroendocrine-immune communication, (Kavelaars et al. 2000). An English neurology study has shown that some patients with CFS are deficient in folic acid, (Jacobson et al. 1993).

2.10.3 Nephrology and Immunology

A Japanese nephrology study of 9 fatigued children showed severe typical Nutcracker Phenomenon (also known as renal vein entrapment syndrome), which is a compression of the left renal vein between the abdominal aorta and superior mesenteric artery, and the authors concluded that there is an association between severe nutcracker phenomenon and autonomic dysfunction symptoms in children with CFS, (Takahashi et al. 2000).

A double-blind randomised controlled trial to assess the efficacy of intravenous gamma globulin for the management of CFS in adolescents, (Rowe 1997). Findings showed significant mean functional improvement at six-month follow-up of 70 11 to 18 year olds with a positive diagnosis of CFS according to the CDC criteria and average duration of illness of 18 months, functional scores were based on school attendance, school work, social and physical activity.

2.10.4 Sleep disorders

A UK based study by Stores et al investigated sleep issues in adolescent CFS sufferers, (Stores et al. 1998), 18 11 to 17 year old participants were evaluated using a home polysomnographer and compared to findings in gender and age matched controls. The CFS group displayed distinct sleep disturbance in the form of both brief and longer awakenings. An investigation into the cause of this poor quality of sleep was conducted in The Netherlands with a group of 13 CFS patients and 15 healthy age-matched controls, by collecting saliva samples through the night to test for melatonin levels, (Knook et al. 2000). Findings demonstrated increased melatonin levels during the first part of the night which was concluded to be the reason for poor sleep pattern and thus unrefreshing sleep in CFS patients.

2.10.5 Infectious Agents

A relatively large-scale study was undertaken in the UK by Professor Peter White and colleagues to investigate the role of viruses in CFS in 250 primary care patients presenting with glandular fever or an ordinary upper respiratory tract infection, (White et al. 1998). The prevalence of CFS six months after glandular fever onset was 9 to 22% compared to 0 to 6% following an ordinary upper respiratory tract infection, therefore glandular fever was considered to be a significant risk factor for both acute and chronic fatigue syndromes.

2.10.6 Genetics

A study of 670 twin pairs demonstrated that unexplained fatigue has a distinct family link, with both genetic and shared environment factors requiring further exploration, (Farmer et al. 1999). This need for further exploration was reiterated in a paper examining the heritability of CFS in children, (Crawley and Davey Smith 2007).

Conclusion

All of these studies concerning the more medical aspects of CFS demonstrate some explanatory links with childhood/adolescent CFS, however the majority of them are relatively small-scale and require further exploration through robust clinical trials with careful design and larger sample sizes before universal findings can be assumed. The one over-arching conclusion that can be drawn is that CFS is a debilitating condition which impacts young people heavily, affecting academic, social, psychological, family and emotional areas of functioning, and that the current research base (despite the dramatic increase in the last 15 years), is still very small. The lack of universally accepted diagnostic criteria impacts negatively on the ascertainment of accurate prevalence levels and this affects the generic knowledge about the condition in not only the medical domain but the public arena also which undoubtedly influences the personal attributions and outlooks taken by patients and those closest to them.

2.11 Comparing Paediatric CFS with other Fatiguing Illnesses

An adolescent study analysing young people with CFS contrasted with individuals with JIA and mood disorder illustrated the major impact CFS has on education with those in the CFS category recording significantly higher school absence rates than the other two groups, also this group demonstrated considerably higher scores on the ‘Somatic Complaints’ sub-scale on the *Child Behaviour Checklist*, (Gray et al. 2001). A study looking at emotional disorders (ED) compared to CFS in adolescence (Garralda and Rangel 2005) showed considerable overlap, but differences in clinical presentation between the two groups;

There were high levels of comorbid emotional disorders in children with CFS, and the two groups were comparable on self-esteem, but CFS children endorsed more fatigue and other somatic symptoms. The two groups were comparable on age at illness onset, but parents of children with CFS reported more biological illness precipitants, more pre-morbid recurrent medical problems and infections. The CFS group had fewer pre-morbid psychological problems and less psychiatric comorbidity than the ED group, (Garralda and Rangel 2005, p. 424).

Another comparative project investigating CFS and JIA (Carter et al. 1999) demonstrated elevated levels of psychological functioning;

Paediatric patients with chronic fatigue had higher levels of internalizing psychological distress than patients suffering from JIA, despite the fact that both groups had a similar pattern of decline in social and physical activities. Duration of illness did not explain the difference in psychological symptoms, (Carter et al. 1999, p. 975).

These studies show the high levels of somatisation in both adults and children with CFS compared with other fatiguing illnesses, they also show lower functional scores and higher fatigue scores in CFS compared to MS sufferers. In adolescents, there is significant clinical overlap with mood disorders, as well as higher school absence rates and psychological distress compared to juvenile arthritis. These results show the significant impact that CFS has on individual functioning, compared to patients with different fatiguing conditions.

2.12 Conclusion: What This All Means

Prevalence rates of between 0.19 and 2% have been reported in paediatric populations, with a gender split of 3:1 female to male ration, as with adult cases CFS is indiscriminate towards differing socio-economic classes or ethnicities. Childhood CFS comes at a time of critical physical, social and educational development and has been claimed to be the reason for more school absence than any other illness. Prognosis is generally considered to be more favourable compared to adult sufferers, provided there is appropriate recognition and management. Clinical features vary widely including flu, glandular fever, trauma and so on. As with adults the dominant feature is disabling fatigue, alongside various other complaints such as abdominal pain, nausea, temperature fluctuations, to name a few. The issue of diagnostic criteria is even more complex in children than in adults, and studies that have applied the CDC/Fukuda diagnostic criteria have failed to identify any cases. The major issue of contention within the childhood CFS population is time, that delay in diagnosis can be damaging as well as significant debate over the amount of days, weeks or months that should be allowed to pass prior to a diagnosis being made. Management includes establishing a baseline of activity and then gradually increasing daily functioning as appropriate; advice and symptomatic treatment as required, as well as referral to

other healthcare services as necessary and liaison with schools should prolonged absence occur. Generally speaking inpatient care and pharmacological treatments are discouraged and the majority of ongoing care is provided by GPs, although referral to physiotherapists, occupational therapists and psychologists may improve daily functioning. Interventions include the two evidence-based management techniques utilised in adults of CBT and GET. a number of papers have been written comparing paediatric CFS with other fatiguing illnesses such as MS, JIA and depression.

Despite there being considerably more research in the adult domain of CFS than the paediatric domain, controversy still remains in many areas, this is compounded within the area of children/young people due to the lack of research and knowledge within the current literature, and this issue can only be resolved through ongoing and robust research into not only the causes and course of illness and rehabilitation, but also through studies which focus on the *effects* of the condition.

Chapter 3

The Rationale for a Narrative Study

3.1 Introduction

Having presented reviews of the literature connected to CFS generally and then more specifically to CFS in young people I now review the literature linked to my study and the methodology implemented within the project.

I have organised this review into three parts; starting with a section exploring qualitative narrative research with children and adolescents suffering from varying health conditions, I will then look at literature surrounding narrative work with adults with CFS and a related condition called FM (fibromyalgia), finally I will give an overview of the only narrative work I have found which concentrates on young people with CFS. In this way I hope to give an account of the component parts of this study – (a) narrative and (b) young people with CFS, there is a stark lack of research comprising studies with a combination of these two components.

3.2 Narrative Research in Children/Adolescents

3.2.1 The Far-Reaching Consequences of Illness at Sensitive Periods of Development

CFS in children is often compared to matched participants with juvenile idiopathic arthritis/JIA (Brace et al. 2000; Carter et al. 1999; Katon et al. 1991), they are both rheumatological conditions which are chronic in nature. A Scottish study used an ethnographic approach with open-ended interviews and participant observation to investigate the daily functioning of children with JIA, in which four families were recruited in the UK and a further three in Germany, and the children involved were aged between seven and 16 years old, (Guell 2007). Three major themes with a number of sub-themes were identified; (1) facing and taking control over uncertainties, (2) pursuing normal childhoods and (3) living between overprotection and decision-making autonomy. These predominant findings are similar to those in

my study and are relevant to children with chronic illnesses, however as the author points out only a limited amount of usefulness can be obtained from studies of differing conditions due to illness-specific characteristics. Due to the relatively small sample size alongside the lack of long-term follow-up (a key element of ethnographic research), the generalisability of the findings may be considered is restricted. However this kind of study illuminates experiences that can be useful in offering transferable insights to the wider population in question. A qualitative study implementing in-depth interviews of young people with cancer examined the effects of serious illness during the fragile stage of adolescence (Grinyer 2007), findings showed the damaging, far-reaching and long-term effects on education, careers, life-plans, friendships and so on which a 'disrupted biography' during such a sensitive period can have. Although CFS is markedly different to cancer due to the fact that it is not life-threatening, a parallel can be drawn with the impacts of having an illness which challenges many areas of functioning at a time of such developmental change.

A study used semi-structured interviews to explore the interactions that five paediatric chronic pain patients had with healthcare professionals, (Dell'api et al. 2007), found that such interactions have a profound impact on children's healthcare experiences, the importance of giving children the opportunity to communicate openly their unique experiences is discussed. An Australian study centring on interview data obtained from 27 first-year university students sampled from four demographically different campuses in New South Wales, (Weber et al. 2007), looked at the way in which personal narratives are influential in organising experiences and making sense of them. Through the students' reiterating their experiences of personal loss the researchers recognised their own role as the audience, through which they became collaborators in the individuals' stories. Finally, a Canadian case-study of a 17 year old girl's hospitalisation, (Pinto 2004), discusses the tension between patient autonomy (the individual right to self-determine treatment) and confidentiality (the private relationship between patient and physician) in adolescent healthcare. Findings showed the importance of understanding autonomy as self in relationship and confidentiality as mutual confidence, the implications of best practice are discussed with reference to the psychological risk or resilience that can be fostered during the doctor-patient communication.

Narrative research has an important role to play in gaining access into lived experience, experience that is real and personal and individual, yet it is through these individual accounts that themes can be drawn to allow insight into the worlds of certain groups of people. Illness narratives can influence healthcare practise by gaining entry into private worlds which can, in turn, inform physicians and professionals the best way of interacting with patient groups, so even a case-study with only one participant can allow the growth of knowledge.

3.3 Narrative Research about Adults with CFS and FM

3.3.1 The 'Realness' of CFS

A relatively large qualitative study in America of 50 chronically fatigued individuals from a Boston hospital, 80% of whom met either the CDC (Holmes et al. 1988), British (Sharpe et al. 1991) or Australian (Lloyd et al. 1990) operational case definitions for CFS, and involved conducting interviews over an 18 month period concerning a systematic series of open-ended questions about the participants' daily lives, (Ware 1992). The sample comprised of 80% female participants, 92% were white, the ages ranged from 23 to 66, with a mean age of 39 years, and mean length of illness was 5.7 years. The main findings are based on the delegitimising experiences of CFS sufferers as having a condition which is not 'real', where they are seen as either being 'malingerers' (exaggerating common health complaints) or 'crazy' (imagining ailments). The author suggests that these beliefs by outsiders are linked to the controversy surrounding the condition and that they contribute to the psychic suffering of the patient. Patients feel the need to either convince others of the realness of the condition or try to prove that they are not psychologically impaired, all of which adds pressure to already struggling individuals. A UK-based case-study paper written about the experience of a married couple in which the wife suffered from CFS, (Horton-Salway 2001), also recognises the ambiguities surrounding CFS as a condition and how this impacts on patients' personal self-constructs through the use of a discursive psychology approach. The woman interviewed described a pre-CFS lifestyle in which she was particularly busy which the author suggests is possibly a means by which she is trying to convince her audience of the realness of her condition and that she is not psychologically impaired, this is compared to other

papers (Ware 1992), in which the researcher has taken words at face value and surmised that by describing a pre-CFS lifestyle as frenetic and a current CFS status as reactionary to the fatigue induced, it allows participants to convey their condition as an 'opting-out' of a busy society. Horton-Salway comments on the paradox of this situation, in light of the language chosen and underlying meanings presented by participants. Continuing this issue of misunderstanding from outsiders, a study into experiences of CFS and FM was conducted in Sweden through interviewing 25 women with the two conditions, (Asbring, P. and Narvanen 2002). Findings showed that the women did encounter stigmatisation, particularly prior to diagnosis and this was conveyed through questioning of the veracity (which the women described as 'deeply violating'), morality (the discrepancy between how they viewed themselves and how they were viewed by others, for example being viewed as 'work-shy' or having their credibility questioned) and accuracy of their symptom descriptions (possibly due to the lack of visibility of the conditions), as well as the 'psychologising' of their symptoms – particularly by doctors, for example suggesting the need for psychological treatments. The participants described opposing coping technique as both withdrawal and approach strategies with regard to fellow patients, some preferring to disassociate themselves with group activity in which other patients reminded them of their illness, the alternative view was that associating with fellow sufferers gave some women a sense of acceptance and solidarity. The battle to achieve relief and understanding was also evident as one of three major themes to emerge from the stories relayed by 14 women in a different Swedish FM research project, (Soderberg 1999). Also depicted by the women were feelings of loss of freedom and a threat to integrity, Soderberg et al describe the needs of female FM sufferers to feel empowered to utilise their own resources in managing the condition on a daily basis.

The uncertainty surrounding CFS as a condition is influential in affecting sufferers' outlook and perspectives on their condition, in a narrative study in Australia, (Gray and Fossey 2003), five male and female adult CFS sufferers aged between 16 and 44 with an illness experience of between two and ten years, participated in semi-structured interviews and the Occupational Performance History Interview-II (OPHI-II). Researchers connected the uncertain aetiology and treatment of CFS to the ongoing quest for individuals to understand the meaning of their illness experience,

which was complicated by their own or others' views of scepticism and the invisibility of the illness. Participants described different types of fatigue, as well as the impact it had on their occupational abilities, relationships, and own sense of identity. The need for further research within the realm of benefits of occupational therapy for CFS sufferers is discussed. Despite the small sample size the study highlights the profound impacts of CFS on peoples' lives. The study may have benefitted from multiple interviews over time may produce deeper meanings within the narratives.

3.3.2 Different Narrative Typologies

A paper written based on the Frank's (Frank 1995) narrative typologies (Quest, Chaos and Restitution) that he proposes exist in all story-telling, used in-depth interviews to examine stories told by 17 CFS patients aged between 13 and 63 years, (Whitehead 2006). Analysis of transcripts revealed that for the majority of participants all three of Frank's typologies existed in the narratives, for two only chaos and restitution elements existed. The author notes the similarities and differences which can be recognised in narratives of CFS sufferers and those living with other chronic illnesses, but recognised the lack of a comparison group as a weakness of the research and suggests this as a potential expansion of this original study, she also realises that the local presence of a specialised CFS Clinic makes the population from which she sampled somewhat biased in nature. A 2004 study researching shared illness experiences in adult CFS patients (aged between 30 and 60 years) at a Swedish clinic, (Bulow 2004), isolated three main types of narrative: (1) self-contained personal stories, (2) orchestrated personal stories and (3) co-narrated collectivised stories. The first refers to that which was relayed between participant and lecturer or nurse, where the rest of the group of patients acted as an audience, more often than not this type of narrative was used to contextualise an example or personal illustration, other participants did not get involved in such stories aside from murmurs of affirmation. The second type of story-telling was relatively rare within the study, involving all participants participating in the presentation of their own narratives, as such this can be a lengthy process in a group situation. The third, most common type of narrative displayed within the study involves collaboratively told stories between two or more participants, which when offered together allow a collectivising of experiences. The use of narratives within groups can benefit some

patients, especially in conditions which are controversial or contested, such as CFS, the setting allows individuals to feel less isolated in their experiences and can affirm a sense of self and legitimacy.

Twenty-five women with fibromyalgia, recruited from a rheumatology clinic and a rehabilitation centre, and 25 healthy age-matched controls took part in narrative interviews concerning the meaning of lived experiences of living with fatigue, (Soderberg et al. 2002), the transcripts were interpreted using a phenomenological-hermeneutic method. The two groups relayed differing accounts of fatigue, within the FM group four themes were identified: the body as a burden, an absent presence, an interfering obstacle and being in hope of alleviation, the control group displayed one major theme – the need for recovery. The main finding was the difference between the healthy women’s perception of ‘natural’ tiredness, that which could be recovered from if they were to rest, for the FM group the body became an ‘it’, something apart from themselves with which they had to manage daily life.

The adult literature on CFS and FM reviewed above is related to my study as it explores narrative within the chronically fatigued population, the obvious lack of paediatric studies within this domain is evidence of the need for more studies like mine. One of the main findings from these papers concerning the adult population is the need that sufferers feel to legitimise their condition as ‘real’ and not a figment of their imagination or a consequence of their desire to ‘opt-out’ of society, this is transferable to the younger population of sufferers and was evident through the narrative interviews I conducted. This issue can prove burdensome for patients, perhaps more so for adolescents and children than for adults, as younger patients lack the self confidence and wisdom of experience that their elder counterparts possess. The different narrative typologies explored in the reviews of papers above demonstrate the similar themes across stories and the familiar processes that story-tellers go through in their relaying of experiences.

3.4 Existing Narrative Study of CFS in Adolescents

I have spent many, many months searching the literature and compiling papers which relate to my study, this has not been that fruitful due to the lack of qualitative work

conducted within the paediatric population of CFS sufferers, however I have come across one study which the author compiled into a book *Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Journeys With The Dragon*, (Brotherston 2001), which focuses on the CFS experiences of four young girls. The participants are young women who were diagnosed with CFS in their teen years and are, at the point of research, all in their early twenties. The approach used by the researcher is that of grounded theory which focuses on theory development with a view to contribute to clinical application. The study conducted by Brotherston involved the girls participating in self-reports within an initial in-depth narrative interview, further follow-up was made by telephone conversations. A snowball sampling technique was used whereby two of the participants were known to the investigator and they asked associates of theirs if they too would be interested in participation. The book details the way in which CFS has impacted the young women's lives socially, academically and emotionally, and depicts how a stigmatising chronic illness has affected them each as individuals. It is meant as a guide for adolescents and their families, and as an insight to aid professionals in clinical practise. Many of the themes and experiences explored within the book are reflective of issues raised within my study and in this way it is reassuring that the experiences relayed by my participants offer transferable insights to the wider adolescent CFS population.

A book, *Young Hearts*, compiled by the Tymes Trust (The Young ME Sufferers Trust), offers a selection of poetry written by young people with CFS. The poems cover all aspects of what CFS is like as a young person and provide insight into the lives of individuals struggling with many aspects of the condition. I have included a selection of these poems in the Findings and Discussion chapter to illuminate some of the aspects raised by my participants, and demonstrate that many of the day to day difficulties associated with having CFS as an adolescent are replicated amongst other sufferers also.

3.5 Conclusion

In this review of narrative literature related to my study I have attempted to give an overview of three main areas: narrative studies with children and adolescents of

general health problems; narrative studies within the adult population but linked to CFS, and finally a review of the limited amount of literature available which focuses upon CFS experiences in young people using a rich descriptive approach. In this way I have aimed to cover the different elements of my research, working within the confines of there being very little work done specifically using narrative methods within a paediatric sample.

Revisiting the original rationales for the research;

- (1) Allowing young people and their primary care-givers to speak openly (possibly for the first time) about their CFS experiences
- (2) Attempting to address some of the controversy and unbelief surrounding CFS
- (3) Contributing to the literature base concerning adolescents and CFS, which is minimal at present
- (4) Using the capturing of adolescents stories to suggest ways in which academic and medical professionals may assist and support young sufferers and their families

Chapter 4

Adolescence

4.1 Introduction

In a study focussing on the specific population group of adolescents it is important to identify and define what adolescence is, and to examine the physical, cultural, psychological and social characteristics which influence and differentiate it.

The English word ‘adolescence’ is derived from the Latin ‘*adolescere*’, which means ‘to grow’ or ‘to come to maturity’, the Oxford English dictionary defines adolescence as the ‘process of developing from a child to an adult’.

The teen years, 13 to 19, are often seen as the period of adolescence, however this is closely linked to the English counting system and is not true of all languages. As far back as ancient Greece philosophers alluded to different time spans within the life-cycle, Aristotle described a cycle of three seven-year periods – infancy, boyhood and young manhood – individuals must go through prior to achieving mature adulthood, (Lerner and Steinberg 2004). However, it is only since the 20th century that adolescence has been recognised as a distinct part of the lifecycle and subsequently been subject to scientific study.

The progression from adolescence to adulthood varies according to function, culture, country and even differs within the same country. Certain behaviours and activities in Western society are reserved for adults; including smoking, consumption of alcohol, sexual maturity, political voting, joining the armed forces, entering into binding legal contracts, driving a motor vehicle and the independent decision to marry. The legal age of consent to do all of these things is often seen as the maturation beyond adolescence and attainment of adult status. The age of majority in Scotland is 16, in England and Wales it was changed from age 21 to 18 on 1st January 1970. The age of criminal responsibility varies quite dramatically throughout the world, (as Table 4 shows), from as young as seven years old in Ireland and

Switzerland to 18 in Belgium. There is some room for flexibility for the court to decide whether an individual should take some level of responsibility when the initial age cut-off has been met and minors may be tried in a juvenile court. There was much controversy caused by the trial of the two boys found guilty of murdering toddler James Bulger in 1993 as they were just over the age of criminal responsibility (10) and so were punished in an adult court to the full extent of the law, which some believed was wrong, (Tunstall 2000).

The legal working age, that is, the age at which an individual is legally permitted to work, varies between countries and linked to the type of work to be undertaken, working hours, working conditions, whether part or full-time, the interference with school hours, and so on. In the UK young people are permitted to work a minimal number of hours at age 13, full-time employment is only legal upon attainment of a National Insurance number at the age of 16.

The United Nations (UN) Convention on the Rights of the Child (CRC) is a worldwide convention detailing social, cultural, economic, political and civil rights of children, (documented in Himes 1995). Those countries that have declared their endorsement of the CRC are obligated by international law to ensure it is adhered to and are under scrutiny by the UN to guarantee all responsibilities are met. All the members of the UN have endorsed the CRC with the exception of the United States and Somalia, and it became legally binding in 1989. The CRC has an overarching definition of anyone under the age of 18 as being a child, so this includes adolescents. The Convention maintains basic child rights, listed in Box 5.

As with minimum legal age to work, the official school leaving age differs according to country around the world, from as young as 10 and 11 years old in Bangladesh and United Arab Emirates respectively, to 18 in Poland, Italy and some states within the USA. Figure 2 illustrates the international distinctions, (taken from Right to Education website).

Box 5: Convention on the Rights of the Child (CRC) Basic Rights

- The right to life
- The right to an individual name and identity
- To be right to be raised by his/her own parents and to continue a relationship even after parental separation
- Obligations of parents to exercise their parental duties
- The right to an individual opinion which may be voiced and acted upon when appropriate
- The right to live a life free from abuse or exploitation
- The right to privacy
- The right to voice their own perspective and receive objective legal counsel during care disputes
- The prohibition of capital punishment in children

Figure 2: Map to Illustrate Minimum School Leaving Age According to Country



The legal age of heterosexual consent varies widely around the world from as young as 12 and 13 in the Philippines and South Korea respectively, to 18 in Iraq and Vietnam for example, or even 21 in some situations in various states of the USA. The age of consent for homosexual intercourse also varies widely, from as young as 13 in Spain and parts of West Africa to being totally illegal at any age in Saudi Arabia and Iran. Some countries have laws against heterosexual consent unless

married and all homosexual activity is illegal, for example, Iran and Sudan. This issue of legal consent is intricately entwined in religion and, as can be seen from some of the examples given here, many Muslim countries have much stricter laws.

The literature in these domains is vast and therefore I just wish to point to how relevant they are in connection with this study as opposed to give a comprehensive overview of the area.

4.2 Puberty.

Puberty is essentially a set of changes which culminate in a young person achieving fertility, it is the period in which there are the most sexual changes, secondary to conception. During this time a child's body develops the characteristics of an adult; including a deeper voice and larger adam's apple for boys and the development of breasts, start of menstruation and a more curved figure in girls. A key characteristic of puberty is the marked increase in physical growth in both genders, often referred to as a 'growth-spurt'. During this major growth phase the body's composition of water, muscle, fat and bone alter to result in the characteristics we know as adult male and female bodies. The significant increase in hormones triggered by the pituitary gland releases the necessary levels of oestrogen and testosterone into the blood stream, which influences development of the secondary sex characteristics. Generally the start of puberty is earlier for girls than boys, (12 to 14 years).

Although in the past puberty has generally signified the onset of adolescence in modern society, this view has been challenged by puberty increasingly occurring earlier, resulting in 'preadolescents' and extending later than the teen years, thus making strict definition more complicated. The World Health Organisation (WHO) characterises adolescence as between 10 and 19 years of age and similarly the age group I chose to study was 11 to 18 years, reflecting the general age group of senior schooling through to the end of A' Level stage education.

4.3 Adolescence and Sexuality.

Although issues of sexuality and culture are not directly linked to my study they do provide insight into the types of pressures that young people are contending with in

modern day society and that is the reason I have chosen to include background information on these topics.

Alongside the onset of puberty is the emergence of sexuality/sexual desire, which brings with it a new and complex turmoil of thoughts and feelings. Many factors influence the individual's attitudes towards sexual expectations, including culture, religion, family values, peer pressure and social mores. What is sexually acceptable in 2008 is very different to that of 100 years ago, or even 50 years ago. Also, sexually acceptable practises in Western society are very different to that which is acceptable in a tribal community for example. This is, of course, true of people of any age, however sexual activity in adolescents has become increasingly accepted in modern society. The consequence of sexual activity at an earlier and earlier age has increased the number of risks adolescents are open to, including a boom in teenage pregnancies (Kane and Wellings 1999), the rise in sexually transmitted diseases in this age-group (Nicoll et al 1999), and emotional turmoil resulting from mental immaturity and fear of abuse.

Research conducted into sexual activity of adolescents and their parental relationships have shown that the nature of adolescent-parental relationships impacts the view that the young person takes when considering sexual relationships. One study in the USA surveyed 751 black youths and found that those young men with good maternal relationships, as well as those boys who were aware of their mother's disapproval of premarital sex were more likely to abstain from sex or have less frequent sexual relations, and those who were sexually active were more consistent in their use of contraceptives. Those adolescent boys who were dissatisfied with their maternal relationship were more than twice as likely as their counterparts to be having sexual relationships, (Jaccard et al. 1996). There are of course cultural elements to this result which should be considered, as black American teenage boys may well conduct themselves differently to other racially and culturally variable populations. An interesting part of American culture which has gained increased media attention in recent years is that of virginity pledges, a study of 870 12 to 16 year olds in California revealed that those who made personal as opposed to public oaths of abstinence were less likely to renounce their decisions, (Bersamin et al. 2005).

Anthropologist, Margaret Mead (1901 – 1978), in the 1920s claimed that the emotional turmoil experienced by Western adolescents was linked to cultural causes, and believed that in those cultures where sexual activity was permissible and not seen as a taboo subject the adolescents experienced much less anxiety. Mead's work was met with outrage in America when it was published and has provoked controversy for over 80 years, however the issue of sexual practises in distinctly different cultures and the taboo aspect of underage sex is a topic that still today sparks greatly emotive responses from different spheres in society. It cannot be ignored though that the emotional, psychological, physical and financial costs of underage sex are issues that feature highly on all government parties' agendas, highlighting that it is an issue of concern throughout society, regardless of political affiliation. Lerner and Steinberg (2004) consider the Western culture's overarching view that adolescent sex should be delayed until individuals have reached maturity so as to avoid pregnancy, sexually-transmitted diseases, abortion and so on and point out that researchers have continued to shy away from reporting on adolescent sexual experiences as ethical governing bodies do not favour such study. In fact, Katchadourian (1990) upon review of the literature in this area;

Concluded that insufficient attention had been devoted to sexual behaviour as part of the normal process of becoming an adult physically and psychosocially...sex must take its rightful place among other bodily functions and human experiences, (Lerner and Steinberg 2004).

Custom and tradition influence patterns of sexual behaviour, for example the practise of male adults having sexual intercourse with young female virgins in parts of Africa, as they believe that this is a cure for AIDS.

4.4 Adolescence and Culture

There is a wealth of literature concerning this topic and so for the purposes of this study I had to be selective in what I chose to include in this thesis, I have chosen those aspects of the area which I feel are of the most relevant to the study.

Culture and adolescence has been touched on above however there are traditional culturally-specific 'coming of age' ceremonies celebrated in different countries of the world. To name a few; in China and Japan, at the age of majority; 20, (before

which it is illegal to smoke, drink or vote), young people participate in a traditional ceremony. The Chinese tradition has seen a recent resurgence in the '*Guan Li*' for men and the '*Ji Li*' for women, during which individuals are given a 'style name' (also called 'courtesy name'), which is a mark of adulthood and respect and intended to replace their original name. The traditional Japanese coming of age ceremony is called the *seijin shiki*, and is held on the second Monday in January. The ceremony involves participants listening to speakers in a government building, the ceremony is concluded by the young people receiving money from the government. In Latino countries there is a tradition called the *Quinceañera*, celebrated on young females' fifteenth birthdays, it marks the age of adulthood and involves a celebration in which candles are lit. In Papua New Guinea boys are initiated into adulthood by a ceremony involving them dressing in a conical hat with long strands of leaves hanging from the edges as far as their waists. In Western societies such as the United Kingdom, Australia and New Zealand, the eighteenth birthday is often celebrated as this is the legal age to drink and vote and often marks the transition into adulthood. In the United States a 'sweet sixteen' party is sometimes celebrated, (more commonly for girls), as this marks the legal age to drive and so represents a move towards adult responsibility.

Cultural coming of age ceremonies or traditions linked to religion are also celebrated. In the Catholic and Anglican Churches confirmation services are held when young people become independent members of the church, it signifies a mark of maturity. In the Jewish faith a boy at the age of 13 and a girl at 12 years old become known as *Bar Mitzvah* and *Bat Mitzvah* respectively. Although the ceremony is not a formal coming of age ceremony it has become known as a rite of passage reserved for those reaching a level of maturity from which point they must fulfil Jewish laws. The tradition involves a religious ceremony during which acts of liturgy are performed by the young person, and often in modern times the ceremony is followed by a family celebration. Within traditional Hindu families reaching maturity demonstrates that the young person has reached a point where they are aware of their family and societal responsibilities. Traditionally girls are dressed in saris for the celebrations.

In modern Western culture adolescents are seen as a major commercial market and are bombarded by the media via television and magazines with products including pop music, mobile phones, clothes, make-up and video games. The 'latest trend' or most fashionable items are heavily promoted and the recognised pressure of advertising combined often with peer pressure means the marketing aimed at this age-group is highly successful.

4.5 Adolescence and Psychological Theories

As with the previous section, this is a huge domain and I could have included a lot more information than I have, but for the purposes of this study have only selected that which I felt was beneficial to providing an adequate background to my study.

In amongst the barrage of physical changes experienced during adolescence there are many emotional and cognitive changes also, resulting in mood swings and shifts in attitude. Pioneering American Psychologist G. Stanley Hall (1844 – 1924) in 1904 described this period as being '*of storm and stress*', alluding to the emotional turbulence experienced by adolescence (and indeed those closest to them!) However this historical view is in modern-day Psychology not accepted as a universal concept, instead it has been adapted to incorporate a more balanced view in which the biological, social and psychological changes are seen as being processes of '*reorganisation*' of the individual in order that s/he adapts to the cultural expectations of adulthood, (Lerner and Steinberg 2004). Adolescence is not only a time of experimentation but also a period in which beliefs and convictions, and therefore personalities, are shaped.

There are several key psychological theories surrounding adolescence including Piaget's Theory of Cognitive Development; Freud's psychosexual stage model; Erikson's stages of psychosocial development and Kohlberg's stage theory of moral development.

Jean Piaget (1896 – 1980), was a Swiss Philosopher, natural scientist and Child Psychologist, he formulated a theory of cognitive development which involves four stages, (adapted from Slee 2002), in Box 6;

Box 6: Piaget's Stages of Cognitive Development

- | |
|--|
| <ol style="list-style-type: none"> 1. The <i>Sensorimotor stage</i>: (birth to age 2 years), during which children experience the world through movement and senses, a major feature of this stage is the learning of object permanence 2. The <i>Pre-operational stage</i>: (2 to 7 years), which involves the acquisition of motor skills 3. The <i>Concrete operational stage</i>: (ages 7 to 11), in which children begin to think formulate logical understanding of concrete events |
| <ol style="list-style-type: none"> 4. The <i>Formal operational stage</i>: (11 upwards), sees the development of abstract reasoning |

Cognitive development in adolescence involves two major features: (a) movement from concrete to abstract thinking and (b) decrease in egocentric thought (by about 16 years old). Between the ages of approximately 11 and 14 years old adolescents experience predominantly egocentric thought which Piaget believed explains certain behaviours in this age-group, including self-consciousness; feeling under constant scrutiny (Piaget refers to this as ‘the imaginary audience’); feeling unique and isolated in their own experiences and thoughts (this has been named ‘the personal fable’); and the belief that they are indestructible, which cognitive theorists says accounts for participation in risk-taking behaviours. It is considered to be through the affiliation with friends and peers and the sharing of thoughts and feelings that adolescents feel less isolated and alone. Before this stage, according to Piaget, a child’s thinking is concrete it is the acquisition of formal reasoning that allows individuals of about 15 years old to think in a more three-dimensional way, exploring and anticipating a number of possible outcomes that do not yet exist.

American Psychologist, **Lawrence Kohlberg** (1927 - 1987), worked as a professor at the University of Chicago as well as Harvard University, he developed a stage model of moral development, which built upon the theoretical framework laid down by Jean Piaget. Table 3 shows the stages of Kohlberg’s theory, (adapted from Goswami 2004);

Table 3: Kohlberg’s Stage Theory

<i>STAGE</i>	<i>ISSUES OF MORAL CONCERN</i>
<i>Pre-conventional Reasoning - Selfish Obedience</i>	
1	Rules followed to avoid punishment; obedience and concern for physical consequences.
2	Doing things for others because it will result in others doing things in return; concern for reward, equal sharing and benefit to self.
<i>Conventional Reasoning - Conforming to Traditions</i>	
3	Whatever pleases the majority is considered morally right; other viewpoints can be seen, conformity is prized, desire to do things for others.
4	Group authority, law, duty and rules of society prized; concern for maintaining social order for its own sake; social disapproval avoided; emphasis on the inherent 'rightness' of rules and duties.
<i>Post-Conventional Reasoning - Moral Principles Beyond Conformity</i>	
5	Internal commitment to principles of personal conscience; concern with individual rights within standards set by consensus; emphasis on fair procedures for reaching consensus and for evaluating principles and rules.
6	Concern with universal ethical principles and abstract morality affecting all beings regardless of conventional views; emphasis on universality, consistency, and logical comprehensiveness.

As in Piaget's constructivist model, it is very unusual to regress backwards down the stages, neither is it possible to skip over stages to a higher level as each stage builds upon the development made in the precursor stages. The level of moral reasoning relating to adolescence is 'Conventional' or that which is concerned with conforming to traditions, i.e. the third and fourth stages of development. Individuals at this level consider the morality of their actions compared to the expectations and views of society generally. In stage three, the individual has learnt that there is an intrinsic reward in achieving the expectations of other people to be good, and is responsive to other's approval or disapproval of them as fulfilling their societal role. Relationships At this level include virtues such as respect and gratitude and 'reasoners' view their

actions by considering how they may affect interpersonal relationships. Stage four reasoning goes a step further, not just considering how individual actions impact personal relationships and people's positive perception of them, but instead looking at the potential outcome of actions in relation to the good of society as a whole. In stage four reasoning personal responsibility for the moral upstanding of society in its entirety becomes paramount.

One of the most influential and renowned contributors to modern psychology, and often referred to as 'the father of psychoanalysis', is **Sigmund Freud** (1856 – 1939). The Austrian neurologist and psychiatrist founded the psychoanalytic school of psychology and has played a major role in shaping psychological theory despite some of his ideas being less than conventional. Freud concentrated on sexual desire as the backbone to his theoretical development and defined his concepts in terms of instinctual drives which result in personality formation, which resulted in his theory of psychosexual stages. Another of Freud's theories; the structural model of the psyche composed of three parts: the id, ego and super-ego. The first refers to the selfish and impetuous part of the psyche which ignores any potential consequences of behaviour, it is often regarded as the 'child-like' dimension of the mind. The super-ego is seen as the moral dimension of the psyche, obeying what is right and wrong regardless of any mitigating circumstances. Thirdly, the ego is the balance of the first two parts, deliberating the instinctive impulsive dimension as well as the moral code of conduct and finding a happy medium. Freud's psychosexual stage model comprises of: oral (0 – 18 months), anal (18 – 36 months), phallic (3 – 6 years), latency (6 years to puberty) and genital (puberty and beyond) stages. The label for each stage describes the physical erogenous zones in question at that particular stage of childhood, and according to Freud fixation at any particular stage results in detriment to healthy personality formation. Freud regarded the latency period of development (6 years up to the age of puberty) as a time when the ego and the id become balanced and harmonious, but then during the genital stage i.e. puberty, due to the huge increase in hormonal changes the child is faced with a barrage of instinctual desires which subsequently throw the balance of the psyche out of harmony once again. It is this major imbalance which Freud attributes to the turmoil experienced during the adolescent period.

Developmental Psychologist, Psychoanalyst and 'Neo-Freudian' **Erik Erikson** (1902 – 1994) also regarded adolescence as a tumultuous time. Erikson life-stage virtues, (adapted from Stevens, 1983), are listed in Box 7.

Box 7: Erikson's Life-Stage Theory

1. Hope - Basic Trust vs. Mistrust - Infant stage. Does the child believe its caregivers to be reliable?
2. Will - Autonomy vs. Shame and Doubt - Toddler stage. Child needs to learn to explore the world. Bad if the parent is too smothering or completely neglectful.
3. Purpose - Initiative vs. Guilt - Kindergarten - Can the child plan or do things on his own, such as dress himself. If "guilty" about making his own choices, the child will not function well. Erikson has a positive outlook on this stage, saying that most guilt is quickly compensated by a sense of accomplishment.
4. Competence - Industry vs. Inferiority - Around age 6 to puberty. Child comparing self worth to others (such as in a classroom environment). Child can recognise major disparities in personal abilities relative to other children. Erikson places some emphasis on the teacher, who should ensure that children do not feel inferior.
5. Fidelity - Identity vs. Role Confusion - Teenager. Questioning of self. Who am I, how do I fit in? Where am I going in life? Erikson believes that if the parents allow the child to explore, they will conclude their own identity. However, if the parents continually push him/her to conform to their views, the teen will face identity confusion.
6. Love (in intimate relationships, work and family) - Intimacy vs. Isolation - Young adult. Who do I want to be with or date, what am I going to do with my life? Will I settle down. This stage has begun to last longer as young adults choose to stay in school and not settle.
7. Caring - Generativity vs. Stagnation - the Mid-life crisis. Measure accomplishments/failures. Am I satisfied or not? The need to assist the

younger generation. Stagnation is the feeling of not having done anything to help the next generation.

8. Wisdom - Ego Integrity vs. Despair - old age. Some handle death well. Some can be bitter, unhappy, dissatisfied with what they accomplished or failed to accomplish within their life time. They reflect on the past, and either conclude at satisfaction or despair.

Erikson ascribed the stress to 'identity crisis' (a phrase he invented), as opposed to the battle between the id and ego, and regarded this period as an important time of identity formation. His stages of psychosocial development spanned the entire lifespan, each of which inherently contains causes of conflict for which resolutions – favourable outcomes (sometimes known as 'virtues') - must be found. Perhaps paradoxically Erikson's theory intimates that individuals must be able to concurrently hold both extremes of life-stage challenges; not disregarding either, in order that s/he may secure the optimal virtue for that particular stage. During the adolescent period (12 – 18 years of age), the major concern in psychosocial development is 'Identity vs. role confusion', which is characterised by the pre-occupation of how s/he is perceived by others, this is similar to Piaget's 'imaginary audience'.

4.5.1 Adolescence and Psychological Ill-Health

The adolescent years can see the onset of some mental problems, for example research indicates that approximately 1 per cent of the female adolescent population has anorexia or bulimia nervosa, with the majority of new cases being diagnosed in mid to late-adolescence, this equates to up to 20 girls in a typical secondary school of 1,500 to 2,000 pupils, (Ransley 1999). This problem is not restricted to girls, national research indicates that one out of every ten adolescents diagnosed with anorexia or bulimia is male, (Royal College of Psychiatrists 2000). A Scottish study investigating adolescent-onset psychosis demonstrated 5.9 per 100,000 of the population suffering from psychosis, with 55% of participants experiencing '*serious to pervasive impairment of functioning*', (Boeing et al. 2007). In one study conducted in 41 schools in England with a large number of participants (6,020), 398 participants admitted to acting upon a deliberate attempt to self harm in the

preceding twelve months, the ratio of males to females was not balanced (11.2% F to 3.2% M), and the reasons given for the attempts differed according to gender, (Hawton et al. 2002). Finally, the 1999 British Mental Health Survey which assessed 10,483 children aged 5 – 15 years, found 25 children with obsessive-compulsive disorder (OCD), that's a weighted overall prevalence of 0.25%, (Heyman et al. 2003).

4.6 Adolescence and Family Relationships

Historically adolescence has been seen as a time of turmoil and conflict especially where parental relationships is concerned, as demonstrated by Hall's description of 'storm and stress' among others. The more modern view of parent-adolescent relationships are that of positive psychology and a swing towards fostering 'connectedness' as opposed to conflict. The impact of the home and family, and especially the relationship between teen and parent is undoubtedly of major significance during adolescence, as in primary socialisation in infancy, and there are a multitude of papers written on this research topic.

4.6.1 Adolescence and Mental Health

The question of parental-relationship influence on adolescent mental health has also been widely studied. Parenting style and family influence impact relationships outside the home as a study consisting of 508 Dutch families with 12 – 16 year old adolescent members which looked at the impact of positive adolescent-parent relationships on good peer interactions found, they concluded that;

A positive self-concept and warm, supportive parenting each contribute unique variance to satisfactory peer relations, (Dekovic and Meeus 1997).

An Israeli study of 847 high school students, (Canetti et al. 1997), found that those participants who expressed high care and low control parenting style (i.e. optimal bonding requirement) reported less distress, better social support and general well-being than others in the research pool, these findings are in concordance with Bowlby's Theory of Attachment (1969), located in Box 8, adapted from Hetherington and Parke (1993).

The sometimes devastating impact of negative adolescent-parent relationships has been demonstrated by a number of studies including a large-scale (4,746 students) investigation into parent-connectedness and behavioural and emotional health in adolescents conducted in the United States, (Ackard et al. 2006), which found that the vast majority of teenagers of both sexes valued their parents' opinion when making significant decisions. However, one-quarter of respondents felt unable to talk to their mother, and over half of girls and one-third of boys felt unable to speak to their fathers about problems. Those participants who reported feeling that their mothers cared very little or not at all for them reported particularly high prevalence rates of unhealthy weight-control behaviour (63.49% females, 25.45% males); suicide attempts (33.51% F, 21.28% M); low self-esteem (47.15% F, 24.56% M); and depression (63.52% F, 33.35% M). Another study in the USA found that adolescents who reported depressed mood were found to have less connectedness with their parents, felt less social support and had lower self-esteem levels than their peers, (Lasko et al. 1996), also those who perceived either of their parents as being unhappy reported the same effects.

Box 8: Bowlby's Theory of Attachment

Ethologist **John Bowlby** (1907 - 1990), founded his theoretical framework on the work of Konrad Lorenz (1903 – 1989) regarding imprinting in baby geese (1952). Bowlby (1969) believed that human babies, as with babies of other species, has an integral set of behaviours (e.g. crying, smiling, sucking, clinging, etc) that promote an instinctual response in parents. These behaviours are necessary for parental care and subsequently survival of the species through child-parent bonding. According to Bowlby the infant's initial innate signals that provoked the parent to come to its side, would with time and consistent responsive maternal affection, be replaced by a mutual attachment to each other which leads to a long-lasting loving bond between the two. It is this healthy attachment bond which allows the child to feel safe and secure irrespective of distance from parent and will in time become the basis of expectation of other attachment figures for all future significant relationships throughout the life span.

A study by Steinberg in 1988 discussed the effect of puberty on distancing adolescents from their parents and demonstrated that it may not be a one-way direction of reaction, rather that greater emotional distance between parents and teens may speed up the maturation process, especially in girls. Hetherington and Parke report;

Girls' maturation appeared to be accelerated by parent-child distance, particularly in the mother-daughter dyad...girls who report more intense conflict, fewer calm discussions, and more behavioural freedom matured biologically faster than their peers, (Hetherington and Parke 1993, p. 195).

Similar findings were made in another study of 111 intact families with first-born seventh grade (12 years old) girls;

It is suggested that because of the nature of the interpersonal and intrapsychic processes occurring in the family around menarche, conflict may facilitate familial adaptation to pubertal change and make moderate levels of conflict normative in healthy families, (Holmbeck and Hill 1991, p. 1030).

4.6.2 Adolescence and Loss of Parent Relationships

Following on from the discussion about adolescent-parent relationships it is important to touch briefly on loss of parent relationships during adolescence and how that impacts individuals. In 1984 Black conducted comparative studies into effects of parental loss through either death or divorce, results estimated that 1.6 per cent of children in the UK had experienced death of at least one parent, as documented in Haggerty and colleagues, (Haggerty et al. 1996). Black also documented that those children who tried to maintain some sort of psychological connection with an absent parent, for example, fantasy reunions, were more commonly those who had experienced loss through divorce as opposed to death, it was surmised that this was due to children finding it easier to come to terms with death as being *final*, that the parent no longer exists, as opposed to simply living elsewhere, (Haggerty et al. 1996). A South African piece of research investigating the relationship between **parental death** and the need for mental health care, found that of 61 young people with a mean age of 11 years old, almost 60 per cent had experienced parental death or absence, (Pillay and Descoins 2006). Another study demonstrated that higher levels of warmth and discipline and lower levels of caregiver mental health problems were the two most significant variables in 'resilience' (that is, free of clinically

significant mental health issues), present in a sample of 179 8 to 16 year old parentally-bereaved children, (Lin et al. 2004). Studies looking at gender development in those affected by parental bereavement have illustrated that adolescent girls from widowed families struggled to relate well to males, feeling uncomfortable in their presence and expressing anxiety about sexuality, (Hetherington and Parke 1993). There is a relative paucity of research related to adolescents experiencing bereavement of a parent due to a number of reasons. It is due in part to the painfulness of the subject matter and the emotional difficulties integral to a study of this type, but it is also linked to the relatively low numbers of adolescents who experience such a bereavement and therefore the statistical difficulties related to finding enough participants to conduct a clinical trial, (Haggerty et al. 1996).

4.6.3 Adolescence and Divorce

An Office for National Statistics (ONS) report in 2008, (ONS 2008), detailed the number of divorces involving children in 2005 as being at its lowest for a decade, however this still amounted to 75,340, 49,892 of these involved adolescents (11 to 15 year olds). Hetherington and Parke document the type of family friction involved following a divorce;

Custodial mothers may become self-involved, erratic, uncommunicative, non-supportive, and inconsistently punitive in dealing with their children... they also show a lack of effective control and monitoring of their children's behaviour...children reciprocate in the immediate aftermath of divorce by being demanding, noncompliant and aggressive but also whining and dependant, (Hetherington and Parke 1993, p. 449).

Stress levels experienced by all members of the family is very high and relationships feel the strain. Hetherington and Parke go on to describe the way in which the mother-daughter dyads repair to the point of reaching '*exceptionally close congenial relationships*', the only threat to this being the conflict met when mothers attempt to control their teenage daughter's difficult behaviour during adolescence. Research has shown that adolescent girls in single family homes with only mother present have displayed a delayed effect when it comes to gender typing and that those from divorced homes were found to be sexually precocious when relating to males, (Hetherington and Parke 1993). Another study incorporating data collected from

1,409 adolescents (558 males and 851 females) aged 11 to 18 years who were surveyed using self-esteem measures, found that increased sexual activity occurred by adolescents in homes without fathers. Although a statistical significance was noted in the relationship between father absence and lower self-esteem, the magnitude of the difference was not large. The researchers concluded that the absence of fathers in the home has a potentially detrimental effect on choices made by adolescent children, (Hendricks et al. 2005). In father-custody families post-divorce one study by Buchanan, Maccoby and Dornbusch, (Buchanan et al 1996), demonstrated higher instances of deviant acts in their adolescent offspring, researchers suggested that this was possibly due to fathers having less knowledge of their children's activities and friendship groups, (Hetherington and Parke 1993). It is not revolutionary to say that it is the *quality* of parenting provided by fathers, whether present or absent from the home, that impacts their children's behaviour and security, this is true of children of all ages.

The timing of remarriages in single-parent families can influence how well children from previous relationship breakdowns adapt to the new step-parent's introduction into the family unit, this can often prove a difficult new situation for everyone to adapt to and especially the children who have become accustomed to living with only one parent. Studies by Hetherington (1991) and Hetherington and Clingempeel (1992), have shown that the most difficult time for successful adjustment to a new step-parent situation is during early adolescence, (Hetherington and Parke 1993). Research comparing children from divorced backgrounds and those from divorce and remarried families, with those who have remained in an unchanging family unit has shown adolescent deviant behaviour, including substance abuse and sexual promiscuity, can increase, for example, Hetherington 1991 and Hetherington and Clingempeel 1992. However the overall outlook is positive with most children adjusting to the new family unit, and the most productive form of parenting is that of an authoritative style.

4.6.4 Adolescence and Influence of Extended Families

Studies into extended family effects on adolescents have shown complicated outcomes. For example, one Canadian study demonstrated that the presence of grandparents in the household is congruent with less deviant behaviour across all

racial groups, and less likelihood of depression in Blacks. However the presence of other relatives (e.g. aunts, uncles and cousins) is associated with higher levels of depression overall, but fewer cases of deviant behaviour among those with a large number of siblings (Hamilton 2005). Along the same lines, research conducted in Spain into family rituals (for example, sharing family meals, celebrating special events and participating in joint activities) showed that those adolescents who share such family practices were less likely to present with mental health issues and demonstrated higher levels of perceived family function, (Compan et al. 2002). The study of religious moral beliefs (which are more often than not associated with established family practice), and adolescent mental health, has shown that those with religious beliefs demonstrate better mental health through;

Better control of impulses, providing better mental health stability...it enables neurotic conflicts typical for adolescence to be more easily overcome...causes healthier reaction to external stimuli...provides a healthier and more efficient mechanism of anger control which support the growth and development of personality, (Pajevic et al. 2007, p. 173).

It is clear that the family and particularly adolescent-parental relationships are of significance during this stage.

4.7 Social/Sociological Aspects of Adolescence

Adolescence is a form of secondary socialisation, although not as dramatic as primary socialisation it is still a critical part of the learning experience. During primary socialisation young children learn the ‘rules’, norms and mores of living in a specific culture, mainly within the family context, as the individual matures s/he enters new situations which also demand learning of specific modes of behaviour but these dictate the ‘correct’ way to inhabit a smaller social group within society, teenagers go through this secondary socialisation process.

Previously mentioned Anthropologist **Margaret Mead**, regarded individuals as a product of culture, each culture moulding the individual into specific manners, behaviours and customs. These cultural ways are deciphered and reinforced throughout life’s journey and its different stages of development, a cycle of ‘learning to be human’. Mead’s most well publicised writings ‘Coming of Age in Samoa’ was

met with outrage by many Americans, however she used cultural comparisons and differences to explain and evaluate American life. Her claim that the emotional turbulence experienced by adolescents in the United States was not seen in their counterparts in Samoan society due to the society's general lack of stress and was therefore down to culture and not biology was, in 1983 after Mead's death, fiercely criticised by Derek Freeman. Freeman's claim that Mead's life's work had been founded upon an anthropological myth heralded a dramatic split in opinion amongst anthropologists.

Youth can be described as a 'counter-culture', which is defined as;

Lifestyles, sets of beliefs and values that develop in opposition to the main culture, challenging its beliefs, ideals and institutions...(they) often develop amongst groups who feel isolated, threatened or who have a common interest to defend against outsiders, (Slattery 1985, p. 112).

The youth uprisings of the fifties and sixties, such as Woodstock and flower power illustrated a rebellion against conventional views and attitudes, as well as demonstrating against widely accepted political and societal decisions such as the war in Vietnam. Anthony Giddens (sociologist) describes a 'sub-culture' as

Values and norms distinct from those of the majority, held by a group within a wider society, (Giddens 1989, p. 750).

There are a myriad of youth sub-cultures which exist in modern society, characterised by a shared common interest in anything from music genres to fashion trends. One of the most well documented youth trends in the sociological literature was that of the mods and the rockers in the 1950s, each group united in their appreciation of either scooters (mods) or motorcycles (rockers). Until the 1950s there was no such thing as youth subculture. Children were seen as 'mini-adults' and catapulted into the adult world as quickly as possible. However, in the last sixty years or so, the media primarily, has made adolescence a dominant culture in its own right. There are even claims that a significant number of individuals attempt to retain adolescent attitudes of non-compliance, refusal to accept personal responsibility and self-indulgence into adulthood, resulting in a rebellious and harmful approach towards society as a whole (West 2007).

Many adolescents today go through stages of being affiliated with certain groups including for example 'indies', 'goths', 'ravers', 'skin-heads' and punks, to name a few. Identification with a particular group may mean using particular slang, sharing a common mode of dress or participating in certain behaviours and activities. Some youth sub-cultures participate in behaviours which are not regarded as socially acceptable to wider society, however in most instances the period of experimentation is short-lived and therefore relatively unobtrusive on the rest of the community.

'Teenager' is a label created and sustained by Western societies, it is not something so readily found in traditional cultures. Neither do young people in traditional societies struggle with the angst and turmoil found in adolescents from Western cultures. Some sociologists believe this to be linked to the specific rites of passage at certain ages that those from traditional cultures experience, along with their community demanding the need for them to work alongside adults from an early age. It is thought that the combination of these factors within a society where the rate of change is slower than in modern cultures makes the process of psycho-sexual development much less troublesome and indeed free of the emotional turbulence found in youth from modern societies. Some believe that the adolescent status in modern cultures is fraught with confusion due to the tension between trying to act as an adult but being treated as a child;

Teenagers are 'in between' childhood and adulthood, growing up in a society subject to continuous change, (Giddens 1989, p. 84).

Functionalists such as Einsesstadt ('From Generation to Generation', 1956) refer to a prolonged adolescent period distinct in modern cultures (linked to extended education and leisure) as leaving young people in an uncertain and vulnerable position, for which they require some sort of constancy;

The emergence of a separate 'youth' culture provides temporary stability and an alternative value-system during this period of transition...young people turn to each other for security and so there also develops an apparent 'generation gap' (Slattery 1985, p. 113).

There are a few major sociological theories regarding youth as a subculture including functionalist approaches such as that taken by one of the most well known American sociologists, **Talcott Parsons** (1902 – 1979). Building upon the functionalist work of Émile Durkheim (1858 – 1917) and Max Weber (1864 – 1920), two of the founding fathers of sociology, Parsons developed this early sociological theory and founded structural functionalism. Parsons believed that individuals progress from one area of life, e.g. family and its inherent values and norms, to another area, e.g. school or work and all of their intrinsic patterns of behaviours we experience an ‘anomie situation’, (‘anomie’ is defined as ‘lack of regulation’ or ‘breakdown of norms’). It is in this way that functionalists describe society as a socially harmonious structure, often relating it to a living organism and the way in which each part of the body is required to conduct its own function for the good of the whole. **Marxists** reject this approach to society as a whole and subsequently reject the notion that youth subcultures can be neatly explained in this way, as they believe functionalists concentrate too heavily on the cohesion of society as a congruent composition and ignore the major influence of social class. Marxist theorists recognise that working class youth and middle-class youth are very similar to their families, but totally opposing to each other, reflecting that social class is equally as divisive in young people as in adults. In their book ‘Working Class Youth Cultures’ (1976), Mungham and Pearson illustrated their theory that the skinheads of the seventies reflected not only a confirmation of their working class cultural roots, but also as a rebellion against the middle-class youth of the 1960s flower power movement, a tactical uprising against the social class system of which they are the underclass, (Slattery 1985). **Interactionists** such as Stan Cohen (Professor of Sociology at the London School of Economics), believes that this is too simplistic and rather that youth subcultures are the creation of mass media labelling by which individuals can establish their conduct within the realms of an ideological structure. **Post-structuralists** such as Dick Hebdige, (media theorist and sociologist), expand on such theories and take them a step further stating that subordinated sections of society resist the hegemony of the ruling sections and thus form subcultures, youth can be regarded as a subordinated group resisting the domination of adults.

Despite all of this, some sociologists reject the notion of youth sub-culture altogether, believing that the media has accentuated and exaggerated youth culture

differences in an attempt to create a whole new commercial market aimed at this age-bracket focusing on clothes, music, and so on, (Slattery 1985).

4.7.1 Adolescence and Positive Peer Relationships

Before moving on from social and sociological aspects of adolescence, peer relationships, both positive and negative, should be mentioned as an important element of this group's experience. Peer relationships are an important positive part of adolescent years as amidst all of the turmoil and change a solid friend network can provide reassurance of similar experiences and an outlet in which to feel at ease to talk about things which may be awkward within parental/family relationships. A study into adolescents' sense of general self-concept (self-worth and confidence) and emotional stability (calmness, freedom from anxiety and depression) illustrated the process of 'individuation', that is the process of transferring their emotional attachments from parents to peers, occurs during this period (Hay and Ashman 2003). When considering depression in adolescents researchers have found that the factors associated with depressed mood are similar in boys and girls, however a higher incidence of depression in girls is linked partly to their negative self-perceptions, also that positive interpersonal female relationships serve to protect them from depressive episodes, (Eberhart et al. 2006).

4.7.2 Adolescence and Peer Pressure

Conversely, during this period of cognitive and emotional changes adolescents may feel the need to experiment with drugs, alcohol, sex or rebellion against their parents in order to be accepted and positively viewed by their friends, i.e. the effects of peer pressure. This can be a time of stress for the individual as it causes confusion and conflict, however it can also be seen positively; as a means of them isolating those beliefs and values which are significant to them and thus be seen as a constructive step towards individuality and maturity. Adolescence is a time of growth beyond child-like understanding and behaviours, it signifies a critical period of movement towards independence from parents and towards total autonomy. During this period young people align more with the influence of their peers and often distance themselves from their families. They may experiment with new behaviours, beliefs and activities in an effort to carve out their own individuality. Ironically it is within this process of developing individual uniqueness apart from their parents that

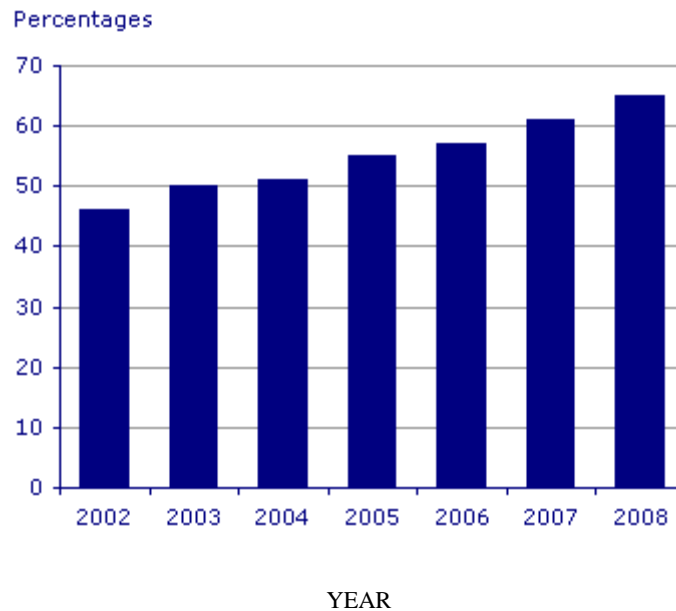
adolescents imitate and become more like each other, thus creating a paradox of what is 'unique individuality'.

4.8 Adolescence and Media and Technological Influences

The post-modern age in which we live with technological advances being made faster than most of us can comprehend demands that most, if not all, of us own a mobile phone, surf the internet, watch movies at the cinema or in our own home and check our emails at least daily. We have the ability to pause and rewind live television, talk via live webcam to our friends anywhere in the world, and know that *Google* will know the answer to almost any question we can think of! We cannot imagine life without the World Wide Web and use it for education, work and entertainment, even banking. We never have to go shopping in the rain as we can buy whatever we desire from anywhere in the world and have it delivered directly to our front door, anything from clothes, books and washing machines to our weekly groceries. The increase in more and more sophisticated computer games resulting in the XBox, Wii and PlayStation are commonplace on Christmas Wish-Lists for both children and adults alike. CDs and more recently MP3 players and IPODs are used to listen to music. We are bombarded by advertising and commercialism via the radio, television, flyers, billboards or internet from the minute we wake up in the morning and have some contact with newspapers and magazines whether we buy the daily tabloids or simply pick up a magazine in the doctor's waiting room, we are almost powerless to avoid advertising and broadcasting on some level. Adults are not the only sector of society to be inundated by these influences, children and especially adolescents are now regarded as a major consumer group and advertising is specially tailored to engulf this young and vulnerable audience. It is more unusual to see a teen *without* a mobile phone than with one, and mobile phone companies are all vying for the top spot when it comes to packages which are aimed at children and young people. All schools have computer labs which start teaching computer literacy skills to those as young as Kindergarten age and the computer is an ideal tool when it comes to resourcing information via the internet and printing it out. The number of households in Britain with internet access has seen steady growth; between 2006 and 2007 the figure went from 54 per cent to 61 per cent of UK homes having an internet

connection, that equates to 15.2 million homes, see Figure 3, (taken from National Statistics Omnibus Survey, 2008).

Figure 3: Number of Households with Internet Access in Great Britain



The switchover from analogue to digital television (which will soon be universal in Great Britain) has been successful to date, as a report published by the Office of Communication in March 2008 showed, with the number of homes in the UK having digital television sets exceeding 22.2 million. The previous quarter's report highlighted the way in which the digital switchover has prompted rises in multi-channel TV packages in British homes to reach 87.6 per cent of UK households subscribing to satellite or cable companies (Ofcom 2008). Of course all of these new technological mediums are important filters for societal change and advancement as well as successfully communicating to huge audiences incredibly quickly. News reporters through the television, radio, internet and newspapers choose what to report and how to report it, in effect not simply communicating the news but essentially creating what is considered newsworthy. Editors and television producers choose what the audience will hear and see and by what means they will receive it – whether it appears on the front page, how big a caption it will receive, who will be interviewed, if any biases or interests will be conveyed, whether any political stance will be taken in the way in which it is expressed, and so on. The audience members

are relatively passive recipients at the mercy of decisions made by senior managers and editors in positions of power and influence.

Some commentators believe the media can have a negative effect on all age-groups within society by, among other issues, concentrating on corporate propaganda; manipulating audiences for the benefit of a particular power group or political party; and being biased towards particular individuals or outcomes. When discussing news media in particular it is relatively obvious to say that the lead story in programs and papers is typically the most recent disaster, it is that which attracts audiences and the larger the story; generally speaking, the larger the audience. There is a financial motive behind exaggerating a disaster or conflict situation as it is that which sells papers and increases viewing figures and news corporations are big businesses. It is a mercenary fact that the most shocking or disturbing stories are often those that find it the front-page more readily. Large news conglomerates in Western countries of the world are under pressure to perform in order that those with a vested interest in the companies reap financial or political returns, they may well choose to 'turn a blind eye' to a story which could jeopardise their advertisers or political concerns, creating bias of accuracy. A relatively new phenomenon which has come under scrutiny in the literature over recent years is that of the so-called '*CNN Effect*' this term refers to the way war is played out in the media and the modern demands placed on 'war-fighters'; one article states:

Starting with the Vietnam War, they faced a new challenge--commanding their units before a television camera...Today, commanders at all levels can count on operating "24/7" on a global stage before a live camera that never blinks. This changed environment has a profound effect on how strategic leaders make their decisions and how warfighters direct their commands, (Belknap 2002, p. 1).

News companies in non-democratic countries must adhere to strict self-censorship in order that they remain in business and that their journalists are not fined or even imprisoned for reporting stories which challenge the political powers. Tabloid journalists and 'gutter press' publications may be verbally criticised by the man in the street but there is no arguing that this type of media generation sells newspapers and magazines. Media moguls are not the only ones who manipulate the audience, those trying to get media attention often place themselves in situations or locations

where they know that the media spotlight will fall, in turn influencing not only the reporters but the consumers too.

Sociologist Mike Males, among others, has drawn attention to the contradictory nature in which adolescents are treated in Western societies, especially America. He particularly highlights the way in which courts of law are at liberty to try adolescence as adults and yet so many policies and procedures treat them as children. Males continues in his defence of youth stating in one newspaper article that they have been vilified;

Ephibiphobia—extreme fear of youth—is a full-blown media panic. Images of “ordinary” teenagers besieging grown-up havens are everywhere. Time magazine warns of gun-toting “monsters next door.” The Times and “60 Minutes II” depict vicious young wastoids plotting terrors in pastoral sanctuaries. Teens are lost to heroin (ABC News, CNN), engage in random promiscuity in junior high school (USA Today, “Dateline NBC”), drink dangerously (Associated Press) and are just plain mean, (Males 2002).

Males goes on to dissect the American current crime statistics and draws attention to those adult crimes committed on a much larger scale which are not portrayed by the media in as dramatic a fashion as those of youth. He concludes the articles in the Los Angeles Times saying,

Today’s ephibiphobia is the latest installment of a history of bogus moral panics targeting unpopular subgroups to obscure an unsettling reality: Our worst social crisis is middle-Americans own misdirected fear, (Males 2002).

This is an interesting perspective that demonstrates the way in which those reporting the media can alter a perspective dramatically simply by the language they choose to use or omit.

Adolescents are perhaps more easily influenced by messages being received via the media than adults as they are in a phase of experimentation and questioning. Lerner and Steinberg comment upon the alarming number of hours that young people spend

subject to media influences per day, more often than not isolated in their own bedrooms, and the nature of the barrage of messages that are being depicted to them:

Either directly or incidentally, those messages describe, depict, and comment, on gods and devils, violence and altruism, love and war, friendship and enmity, politics, professions, beauty, sex, drugs, - and almost any other dimension of human concern one can imagine...an incessant consumerism frames most media messages, and they increasingly emanate from channels designed primarily – if not exclusively – for adolescent audiences, (Lerner and Steinberg 2004, p. 487).

4.8.1 Negative Impact of New Technology and the Mass Media

It is clear to see that the rise in affordable technology has made our lives easier, more comfortable and given us more choice but there is a flip-side to it all. A British Home Office report printed in 2007 detailed that the highest rise in crime in England and Wales in the previous year had been that of ‘card-not-present’ fraud, that is crime in which stolen credit and debit cards are used for non face-to-face monetary transactions, either over the internet, phone or by mail-order. The incidences of this type of crime increased by 16 per cent from 2005 to the following year, resulting in fraudulent losses of £212.6 million in 2006, (Nicholas et al. 2007). The rate of identity theft has increased dramatically thanks to ease of access to information and making purchases online, a Home Office Report published in 2008 documented a cost to the UK economy of £1.7 billion in the previous three years, (Home-Office 2006). Perhaps most alarmingly within the adolescent age-group is the increase in harassment through these technological mediums. One quarter of 11 to 19 year olds surveyed by the charity NCH (National Children’s Home) and Tesco Mobile reported having been subject to threatening behaviour via their computer or mobile phone. Out of 856 young people who participated in the survey 16 per cent had been victims of text message bullying, 7 per cent had been threatened in online chat-rooms and 4 per cent had received menacing emails. The increased popularity of camera phones has only amplified the issue with embarrassing or threatening images being circulated this way. The aforementioned report also emphasises the inability to escape this type of bullying as when individuals are subject to school bullying at least they know that when they go home from school they will be safe in their own home, this is not so with this ‘21st Century Bullying’, (McCann 2006). It is a sign of modern society that children’s protection charity such as NCH have felt the need to

employ people specifically to deal with these type of incidences, and now have a new staff member labelled a ‘technology advisor’.

4.8.2 Adolescence and the ‘Perfect Body’

An issue of concern to many commentators is that of idealised body image, more specifically recently in the press coverage is the 21st Century notion of ‘size zero’ models. One Daily Mail article, (Kay 2006), reported the story of top Uruguayan model 22 year-old Luisel Ramos, who was already very slim but had been advised by her modelling agency to lose more weight if she wanted to succeed in the fashion business. Ramos spent three months on a crash diet of salad and diet coke to reach the recently fashionable ‘size zero’, immediately following her first catwalk appearance having accomplished her goal she suffered heart failure and died. Subsequent fashion shows in Madrid and Milan called for a ban on models with a BMI (body mass index) of below 18 and it was thought that UK fashion pundits would follow this stance. However, this wasn’t the case, in fact the opposite was true with spokesmen declaring their ‘wariness of knee-jerk reactions’ and claims of ‘an over-reaction’ when asked to comment the size zero backlash. It is a fact of society today that ultra-skinny women are more often than not presented as the ‘ideal’ to the public, with so-called ‘super-skinny celebrities’ such as Nicole Ritchie, Lindsay Lohan, Calista Flockhart and Mary-Kate Olsen who have all admitted to having eating disorders and yet are publicised as beauty to be aspired to by the media. The topic of idealised body images has caused much controversy in the media as putting undue and unrealistic pressure on women, however the effect on adolescent girls is even more powerful. One Australian study (Hargreaves and Tiggemann 2004), considered the effects of idealised beauty in the media with 595 adolescent boys and girls and found a correlation between exposure to idealised media images and body dissatisfaction in girls, but not boys. Another piece of research in Ohio using meta-analysis of data from 25 studies concentrating on media images of ‘the slender ideal’, found that participants’ body image was significantly more negative and body dissatisfaction markedly higher following presentation of thin media images compared to average or plus-sized models or inanimate objects, especially in those under 19 years of age (Groesz et al. 2002).

4.8.3 Media Violence Linked to Viewer’s Reactions

Another well documented issue of concern is the link between media violence and viewers' aggression, this controversial debate stems back as far as **Albert Bandura's** 'Bobo doll experiments'. Bandura, Canadian Psychologist born in 1925, specialised in social cognitive theory and self-efficacy during his working life and is particularly famous for his social learning experiments focussing on viewing violence in children, which fuelled much future psychological discussion of media violence. Bandura's work illustrated the rise in aggressive conduct in children following their viewing violent images, (Lieberman 1993). One study of 199 11 to 14 year olds demonstrated links between the viewing of direct and indirect aggression and found that participants gave less money to, and a more negative evaluation of, a confederate than those in the no-aggression control group, (Coyne et al. 2004). Desensitisation is another important consideration when studying the effects of media-induced aggression and has been observed by reduced arousal and emotional disturbance while witnessing violence, the reduced tendency to intervene in fights and less sympathy for victims of violence, and that the relationship between violence viewing and anti-social behaviour is 'bi-directional' as young people already displaying violent behaviour tend to seek out violent viewing, (Cantor 2000). This is another factor which must be considered associated with this debate. Some researchers believe that blaming solely the media for acts of aggression or violence is too simplified and that many other social, cultural and genetic factors are also influential in the acting out of aggressive behaviours, however the role of the media in this process is widely believed to be one of the key contributors.

4.8.4 Positive Impact of New Technology and the Mass Media

It cannot be disregarded that the media does have positive impact on our lives as well as negative influences. A life without the media would mean far less knowledge about the world outside of our immediate environment; television, radio and the internet have all served to shrink the universe into a more easily accessible place, so despite the inherent biases of media portrayal at least we can simply and quickly retrieve knowledge. Another crucial role of the mass media is to educate; from news programs warning of impending violence in war-torn countries to public awareness campaigns alerting us on how to quit smoking or avoid HIV, the media can reach massive target audiences in a virtually immediate time-scale. In studies analysing the impact of media campaigns on adolescent behaviour positive results have been

obtained. For example, one American random-digit-dial telephone survey of 16,000 12 to 17 year olds found that young people in locations of higher levels of campaign exposure to an anti-smoking incentive had more negative beliefs about the tobacco industry and their practices, (Hershey et al. 2005). Similarly, results of research into the impact of anti-drug advertising in 837 middle and high-school students showed that 92% perceived an increase in their knowledge of drugs; 60% felt they gained stronger beliefs about the dangers of drugs; 52% felt they developed more negative attitudes toward drug users; and 75% reported that they had decreased, stopped, or been convinced never to initiate drug use, (Reis et al. 1994).

4.9 Adolescence and General Health Related Behaviour

There are a number of pertinent issues related to adolescents and health-related behaviour, a brief overview includes protective factors in adolescent health behaviour, health-seeking and preventing health-risk behaviour, adolescent perceptions of health-related risks and personal safety and violence, adolescent competence and self-assessed health, depression and emotional distress in young people.

A large-scale study, (1,493 participants), of high-school students conducted in an America urban school district, incorporating young people of Hispanic, White and Black ethnicity differentiated between proximal, that is health-related, and distal, i.e. conventionality-related, behaviours and the development of health-enhancing conduct, (Jessor et al 1998). Findings showed certain key proximal protective factors included value on health, perceived effects of health-compromising behaviours and parents who model health-behaviour, key distal protective factors included positive orientation to school, friends who model conventional behaviour, involvement in pro-social activities and church attendance. The authors highlight the importance of individuality and concluded that strengthening of both proximal and distal protective factors may help to promote positive health-related behaviours in adolescence. A qualitative, in-depth interview study of 22 American and Latina 13 to 19 year old girls, attending high schools in the Bronx, New York, (McKee et al 2004), investigated health-seeking behaviour concerning reproductive and non-reproductive issues. The findings showed the significance of core values such as privacy, close-relationships with mothers and a perception of sexual activity as dangerous, as

shaping the girls' attempts to meet reproductive health needs, and demonstrated that post-onset of sexual activity achieving a balance between these core values often resulted in inadequate care and support. Obviously these findings may be strongly linked to the urban area within which the study was conducted, and alternative outcomes may have been achieved from a sample of girls residing in a different city or state. A study by Dowd et al (2000) also concerned with health-seeking behaviour, this time in relation to violence and personal safety demonstrated that adolescents considered emergency departments in hospitals as frightening and confusing places, and that the role of the staff there was to treat the medical problem concerned and not to inquire or counsel about violent behaviours. It could be suggested that such outcomes demonstrate a lack of trust between young people who find themselves in danger and first-line medical staff and this undoubtedly influences health-seeking behaviours in adolescents. Studies into perception and prevention of health-related risks include areas such as violence, sexual activity, substance abuse and terminal illnesses. A longitudinal piece of research conducted in Washington, USA questioned 598 fifth-grade children and conducted follow-up at age 18, (Hawkins et al 1999). Findings showed that the group which received an intervention package throughout the elementary grades produced less health-risk behaviours related to violence, heavy drinking and sexual activity, in adolescence, compared to their counterparts. Such outcomes support the view that education during the pre-teen years can have enduring positive effects. A different study examining older adolescence (17 to 20 year olds), a sample of 189 first-year psychology students, explored the perception of future risk in five areas; AIDS, sexually-transmitted disease, serious car accidents and lung and skin cancers, (Moore and Rosenthal 1992). Findings showed that despite participants underestimating their risks to some extent, they were also capable of making discriminating judgements about their behaviour and future risk vulnerability. The characteristics of the sample involved within this research may have influenced the results to some degree, not only were they on the verge of adulthood but also they could be argued to be more educated and therefore more inclined to display sensible behaviour.

With regard to adolescent competence and self-assessed physical health in this population, a large-scale longitudinal study conducted in 19 American schools

demonstrated that specific attributes were directly linked to adolescents assessing their health to be better, these included higher levels of school achievement and more participation in sports and exercise activities over a one-year period, (Mechanic and Hansell 1987). Emotional health and depression is experienced in adolescents, with a leaning towards more girls than boys being affected, (Suris et al 1996). Longitudinal data was collected for 335 adolescents randomly selected from two school districts in the USA, (Petersen et al 1991) to explore causes of gender differences in rates of adolescent depression. The findings showed that girls were more at risk for developing depression by 12th grade, compared to their male counterparts, due to them experiencing more challenges in early adolescence, once this had been controlled for the gender differences disappeared.

Despite this being only a brief overview of the topic of adolescents and health-related issues it does give a summary synopsis of some of the issues related to young people, including health perceptions, risk-behaviours and interactions with healthcare providers.

4.10 Conclusion

As has been discussed in this chapter, adolescence is a complex period with inherent psychological, sociological, biological and legal ramifications, many of the issues raised when discussing each of these different aspects are further exacerbated in a group of young people with a chronic health condition, especially one such as Chronic Fatigue Syndrome, which is fundamentally misunderstood and still largely unspecified to the medical profession and public alike. Matters such as the increasing need for experimentation and exploration of own character and beliefs may not be altogether feasible for a young person who is home-tutored and so largely confined to home, devoid of social interaction with, and influence of, peers. Similarly, the natural increasing need for autonomy and independence is neither viable nor practicable for an adolescent who is dependant upon his or her mother who acts as their primary carer. During this study I explore and discuss such themes and identify the ways in which young people with CFS are affected by their condition and how chronic ill-health impacts upon their lives, in doing so I aim to raise awareness of the issues facing these adolescents, which will hopefully educate those who interact with

adolescents with CFS in how to improve the quality of life within this particular group.

4.11 What This Means

Adolescence is renowned for being a time of angst and turmoil as well as a period of experimentation and discovery, through the in-depth interviews I have conducted I will explore how growth in the psychological, social and biological realms are impacted further when the individual also has a chronic and largely misunderstood illness to contend with. Through a narrative approach, I wish to explore personal stories and experiences of young people with CFS, and the way in which psychological, sociological, biological and academic realms of experience have been impacted. Also the stories of primary care-givers provide a further window into the lives of families of sufferers and the ways in which they are affected. The emergent themes from these stories present an insight into how best healthcare professionals can identify with the daily struggles and desires of this particular group of patients and those closest to them.

Chapter 5

Methodology

5.1 Introduction

My overarching research aim has been to explore the personal experiences of adolescents with CFS, giving them the opportunity to speak openly and without fear of prejudice in giving an account of how the condition has affected their lives. I chose a narrative approach to achieve this aim as I was attracted to trying to hold on to the stories as a whole, in an attempt to capture a deeper understanding of the CFS experience. What follows in this chapter is an overview of narrative approaches and I describe how I conducted my research using this approach. I also outline the background to ‘Service User Research’ and give a brief overview of ‘insider research’, such as I have conducted in this project.

5.2 What is Narrative Research?

Storytelling is a fundamental form of human communication. It can serve an essential function in our lives. We often think in story form, speak in story form, and bring meaning to our lives through story. Storytelling, in its most common everyday form, is giving a narrative account of an event, an experience, or any other happening. We can tell of these happenings because we know what has happened. It is this basic knowledge of an event that allows and inspires us to tell about it, (Atkinson 1998, p. 203).

The word ‘narrative’ comes from the Latin verb *narrare*, which translated means ‘to recount’. This is narrative in its general term, the form of narrative I will be concentrating on is that which pertains to social science inquiry. On the face of it, the very nature of narratives appears simple, after all, as social beings we all engage in storytelling on a daily basis, to not only describe who and what we are, but where we’ve been and how it felt, and also as an act of interpretation and self-definition. Fairbairn and Carson write:

Much of human life is conducted through story. Many of our social institutions are comprised almost entirely of opportunities for telling and re-

telling stories, for sharing the narratives that constitute our lives, (Fairbairn and Carson 2002, p 22).

Narratives are profoundly emotional by nature, they are personal insights into a private world. The nature of storytelling may appear simplistic however, the *theory* of narrative; i.e. what the mechanisms and motivations behind storytelling are and how we interpret them in a way which remains true to the narrator but also is comprehensible to the reader is somewhat more complex.

5.2.1 The Narrative Interview Process

A major tool in narrative research is that of the open-ended interview, the main steps required for effective narrative interviewing according to Holloway and Freshwater, (Holloway and Freshwater 2007), are as follows;

1. A congenial setting where participants feel relaxed and safe to speak openly;
2. The interviewer requires good communicative and people skills in order that participants speak freely, without fear of judgement and that any emotive memories or reliving of experiences that are drawn to the surface induce as little pain as possible;
3. Finally the overall theory of gestalt, i.e. that the whole story is greater than the sum of its parts – the reason I chose the methodology I did was in order that participants' narratives would not be dissected and broken down into separate pieces, but rather kept as holistic entities in order that a true insight could be gathered.

My aim throughout the exchanges with participants (as with all narrative interviews) was to restrict my questions to a bare minimum to open up the initial story and only make comments when the participants' flow of conversation dried up, in order that they continued speaking, the flow of story from the individual remained paramount. The stories are all grounded in personal, intimate life/world experiences, however as such they all contained 'filters', those excluded elements of experiences that had either been forgotten, blocked out or that which the individual did not wish to divulge.

Narrative research refers to the recording and interpreting of participants' experiences that have been told in story format, those stories include a sequence of events and a finality or consequence. The interpretation process is a complex one;

Narratives are interpreted, both as individual units and in relation to one another, by identifying thematic and linguistic connections between the narrative segments, (Riessman 1990, p. 1195).

I identify easily with Riessman's approach, it is her work and theoretical stance which has influenced my study the most.

Narrative research and analysis has no clear-cut traditional history, rather it is made up of a number of different influences, including those from fields such as nursing, law, history, philosophy, anthropology, sociology, religious studies and government, (Charon 2001) The most common method of data collection is that of the unstructured interview, however other sources of information may also be utilised including diaries and journals, in fact any data source which provides the recounting of personal experience. It is an appropriate method only in studies with a select number of participants. Within these small, select groups of individuals narratives perform a significant role in the communicative repertoire. Narratives are used daily by human beings in their interactions with others to inform, justify, convince and so on, they also aid individuals by helping them to make sense of their own environment and experience.

What generally happens when we tell a story from our own life is that we increase our working knowledge of ourselves because we discover deeper meaning in our lives through the process of reflecting and putting the events, experiences, and feelings that we have lived into oral expression. It has always been this way. That may be why we have a need to make our lives coherent, understandable, and meaningful. Telling the story of our lives is so basic to our nature that we are largely unaware of its importance, (Atkinson 1998, p. 1).

Some investigators draw emphasis to the fact that narrative research is not simply about the content of stories (i.e. *what* is said), but also about the way that it is said by narrators (the *how*).

Narratives do not mirror the past, they refract it. Imagination and strategic interests influence how storytellers choose to connect events and make them meaningful for others, (Riessman 2005, p. 708).

This could be seen as a negative as a valid factual account is not necessarily given, however as Riessman goes on to explain this is not the issue;

Narratives are useful in research precisely because storytellers interpret the past rather than reproduce it as it was. The 'truths' of narrative accounts are not in their faithful representations of a past world but in the shifting connections they forge among past, present, and future, (Riessman 2004b, p. 7).

Those aspects that narrators either choose to draw out of their stories/past experiences or those which remain particularly memorable are the critical elements of importance in their unique social world, they are the pinnacle details which are significant to that individual.

5.2.2 Narrative as a Form of Research Has Become Increasingly Popular

Narrative research has grown in popularity over recent years and is now an established and effective form of conducting qualitative study in many disciplines including nursing, psychotherapy, social work and anthropology. Some theorists have seen this increase as a 'narrative revolution', others have commented that it is a shift away from positivist theory, there are other theories too – linked to country, culture, politics and history. The increase in narrative reports has improved its 'standing' in the social sciences, the opinion of some that autobiographical accounts are a less than rigorous method of data collection which is not worthy of being considered valid and as reliable as information obtained from more traditional statistical or physical science methods has depleted as key narrative researchers, such as Cathy Riessman and Andrew Sparkes, have provided insightful and influential studies. Riessman draws attention to this issue in her attempt to challenge the viewpoint that narrative research is in some way promoting narcissistic self-absorbed musings about the self, (Riessman 2005). Within this same debate is the contentious issue of emotional involvement of the researcher with their participants and research material, the general viewpoint within the literature has held fast for many years that emotions are in some way obstructive to the attainment of valid knowledge, such an

argument begs the question; if human beings are emotionally driven to a large extent, surely inquiry methods that are emotionally involved are not only appropriate but also crucial to increase understanding? In *Exporting ethics: a narrative about narrative research in South India*, Riessman states;

A narrative representation required that I place myself in dialogic situations and include my emotions, typically stripped from the social scientist's account. Making the backstage visible challenges the rules of much scholarly writing, including the 'monologism' that characterises some narrative accounts. Erasing the presence of the investigator, they yield a false objectivity, (Riessman 2005, p. 486).

Whatever the cause or prompt may be, the increase in narrative study since the 1980s has been significant.

The definition of a narrative is largely linked to the theoretical domain which the investigator inhabits, for example, anthropologists regard the entire story made up of interviews, observations and so on, whereas in the field of sociolinguistics the narrative is more constrained looking for plot, characters, etc. Whichever approach is implemented though, the process remains the same – that narratives must be interpreted carefully, Riessman writes:

Narratives do not speak for themselves or have unanalysed merit; they require interpretation when used as data in social research, (Riessman 2004a, p. 2).

The burden of responsibility lies firmly with the investigator to analyse the story systematically and with sensitivity.

The composition of narratives is complicated. Holloway and Freshwater describe narrative research as containing both artistic and scientific elements;

Making art is a creative act concerned with generating an effect – be it beauty or surprise. The artistic goal in narrative research adds creative, aesthetic and craft elements, but it also enhances practice. Its main strength lies in its communicative power and its immediacy. Researchers participating in it also engage their emotions, and they are not neutral or distant but empathic and close to the narrators, (Holloway and Freshwater 2007, p. 3).

There is also a more technical/scientific aspect of narratives referring to the collection, recording and interpretation of data. Whilst natural scientists may propose and test hypotheses, the narrative researcher explores constructs of reality which reflect individual experiences as opposed to generalisations, however through this process may gather similarities or themes which do extend over many individual accounts. It is in this way that narrative research is just as ‘scientific’ as empirical hypotheses-testing, as it too is rooted in gathering information which is evidence-based. Some say that narrative research is an important ‘tool’ in the process of storytellers retaining a sense of power in the field of health, that is, the individual is the one *in control* of the situation; defining their own experience in the way that *they* want it to be told.

5.2.3 Narrative Study is Different to Other Types of Qualitative Research

Narrative research differs from other types of qualitative study in a number of ways, including firstly it relies heavily on keeping the story as a whole, sequential account. Fairbairn and Carson believe this is crucial;

In our view it is regrettable that storytelling as a research method is often viewed merely as a way of gathering data to be manipulated in various ways, which probably involves cutting them up into little labelled specimens – themes and sub-themes – that can be sorted and counted and weighed. There is undoubtedly value, at times, in analysing stories at the level of the concepts or words used. However, to treat stories in this way is to fail to respect the tellers of these stories, (Fairbairn and Carson 2002, p. 7).

Secondly, the participants hold the majority of influence as they dictate the format of the participant-researcher interaction. Holloway and Freshwater;

Participants in narrative inquiry have the power to define their own bodies, identities and experiences, rather than having their reality shaped by others...people are active agents in their own experience, not passive recipients; they are able to assert themselves, ‘recover agency’ and achieve self-esteem, (Holloway and Freshwater 2007, p. 9).

Holloway and Freshwater (2007) highlight that although many researchers use the terms ‘narrative’ and ‘story’ synonymously some writers, such as steer away from the latter as they believe ‘story’ has implications of something false or made-up.

However, others believe that all narratives/stories are indeed some form of social reality – that social reality which is experienced by the narrator, and is therefore valid in its own right. The contention between that which is individually constructed as reality and that which is scientifically valid is seen as two sides of the same coin, simply two *different types* of knowledge, as opposed to one being more significant than the other, (Holloway and Freshwater 2007). Narrative research also differs from other types of qualitative inquiry due to its relational features, there is a distinct difference between narrative and other modes of investigation which require the researcher to remain unbiased and distant from the participant. In narrative inquiry the production of information is based largely upon the intimacy and depth of trust between narrator and listener and subjectivity on the part of the investigator is an important asset. Oakley (1981) comments;

The mythology of 'hygienic' research with its accompanying mystification of the researcher and researched as objective instruments of data production (must) be replaced by the recognition that personal involvement is more than a dangerous bias – it is the condition under which people come to know each other and to admit others into their lives, (Oakley 1981, p. 58).

5.2.4 Types of Narrative

Narrative research is essentially the re-telling of an individual 'story' in order to draw consensus of meaning via the overall 'plot', whilst retaining the inimitable individualities pertaining to that particular person's account. As a starting point it is crucial to understand the different elements of narratives, one author (Hanninen 2004) fleshes out three types in Box 9. These three forms of narrative simultaneously act individually and as an interactive process, it must be recognised that the told narrative – i.e. that which is told to the researcher is possibly not as 'rich' in content as the inner narrative which is intrinsic to individual identity as the former is subject to restrictions such as the narrator's ability to articulate clearly and communicate eloquently. Although I have applied a generic qualitative narrative approach for this study, using the above framework I would place my work as fitting into the third category 'lived narrative', as my focus has remained on asking individuals to describe their own life experiences of how CFS has affected their daily functioning.

Box 9: Different Types of Narrative

- | |
|---|
| <ol style="list-style-type: none"> 1. <i>'the told narrative'</i> – normally transmitted in spoken or written format; that which explains (2) the <i>'inner narrative'</i>. The purpose of the told narrative is to influence and engage the receiver and may therefore contain more self-justification and also more emotive content which the teller considers may be interesting to the listener; 2. <i>'the inner narrative'</i> – is concerned with that which the individual tells him/herself and is the process by which he/she organises his/her lived experience. The inner narrative both contains and is influenced by the individual's own moral framework, it is therefore linked to culture and context; 3. <i>'the lived narrative'</i> – centres upon that which characterises human life – it can be regarded as a sequence of narrative situations. |
|---|

Researchers in narrative study have identified various types of narrative, such as everyday, autobiographical, biographical, cultural and collective stories, (Holloway and Freshwater 2007), this study centres upon the second of these – the autobiographical story. According to Holloway and Freshwater;

The autobiographical story connects the present with the past and the future. The narrative is one of individual history and biography and helps people to come to terms with what happened to them during the course of time...individuals attempt to establish themselves as distinguishable and separate from others and to make sense of their own lives, and they justify their actions, (Holloway and Freshwater 2007, p. 16).

An autobiographical account is not simply a reiteration of life events it is inextricably linked with emotion, varying motivations and a mixture of rationales for saying or doing certain things, for example presenting a situation in a certain framework of understanding or trying to 'read' what s/he thinks the listener may want to hear and acting accordingly. It is a complex interaction.

5.2.5 Common Elements of Narratives

Despite there being different types of narratives, they all have common elements, as listed by Holloway and Freshwater (2007): firstly, they have a finite time sequence –

each story has a beginning, a middle and an end. Secondly, narrative implies narrator and audience, without either of these it ceases to be a narrative and in research the initial audience/receiver is the researcher who transmits it to a wider audience. Thirdly, it is linked to the individual – the story-teller is the creator of their own narrative, it is an account of their thoughts, feelings, perceptions, emotions and experiences. Fourthly, narratives are founded on subjective experience;

This means that the story is decided upon by the storyteller and does not necessarily describe events directly or in factual detail but depends upon their subjective experience of their experience, (Holloway and Freshwater 2007, p. 18).

It is inherently human to measure normality by our own experience, therefore the way in which we perceive events – whether positive or negative – will be measured against a ‘yardstick’ of previous experience and bound up in projected expectation. Within this we again recognise the importance of culture, context and time from which individuals cannot extricate themselves, thus despite the claimed uniqueness of each narrative it is still subject to its point in history and cultural context, and therefore shares commonalities with others. Lastly, the narrative is capable of holding the attention of an audience – receivers must be able to identify in some way with that which is being heard. Holloway and Freshwater;

Feelings experienced and knowledge acquired are transferred from the storyteller to the listener. This is only possible through subjective knowledge, knowledge which individuals share by inhabiting the same world; they understand by linking the knowledge acquired from the narrator to their own social reality, and thus researchers can become co-authors of the participants’ stories, (Holloway and Freshwater 2007, p. 19).

Bruner, (Bruner 1991), further defines narratives in terms of:

1. Diachronicity
2. Particularity
3. Intentional state entailment
4. Hermeneutic composability
5. Canonicity and breach
6. Referentiality
7. Genericness

8. Normativeness
9. Context sensitivity and negotiability
10. Narrative accrual

The first refers to the sequential time element of stories that has already been discussed, Bruner refers specifically to the time duration and names this element 'sequenced durativity'. Particularity has also been touched on previously, this relates to the way in which each story retains unique individual characteristics despite being embedded in the general sphere of the culture, context or time period to which the story belongs. There will remain within the reporting of narratives a risk of what has been expressed by the narrator not necessarily being the same as that which is interpreted by the listener, (Holloway and Freshwater, 2007).

Intentional state entailment refers to the incorporation of inanimate objects into stories which serve a function; an intentional state – however there is an unreliable relationship between intentional states and the action that follows and therefore stories are unable to supply causal explanations. Narrative accounts present...

*The basis for **interpreting** why a character acted as he or she did. Interpretation is concerned with 'reasons' for things happening, rather than strictly with their 'causes', (Bruner 1991, p. 7).*

Fifthly, the notion that narratives are related to an unusual occurrence that 'breaches' a normal/'canonical' situation. Referentiality is concerned with a story's reference to reality. Genericness is the opposite of 'Particularity', referring to the genre element of stories. Normativeness is the implication that narratives provide a particular assertion of the way in which an individual should behave, (this is linked to Canonicity and breach). Hermeneutic composability and text sensitivity relate to the way in which beliefs, background, experience, and so on, influence the researcher's interpretation of what s/he hears. Finally, narrative accrual appertains to the process of compiling similar stories or parts of stories into one accumulative whole which evolves into a culture or tradition in its own right – that new stories progress from older stories.

5.2.6 Key Elements of Narratives

Different writers describe different key elements in varying ways, according to Cobley, (Cobley 2004), the differences between ‘story’, ‘plot’ and ‘narrative’ are as follows:

1. **‘Story’** – refers to the ‘what’ aspect of the narrative - the overall entity of that which is recounted;
2. **‘Plot’** – indicates the sequence of incidences linked together that provide causation, (also referred to in the literature as ‘emplotment’);
3. **‘Narrative’** – is how the story is portrayed by the narrator – how the key players are described, and so on.

The narrative is a complex process, it is multi-dimensional in its purpose and product;

The narrative is a journey or pathway through time which is told by its author, who tells the listener what happens on the way. The narrator takes a reflective stance on events and processes on the journey. However, narrators do not merely communicate a simple story to the listener; they also clarify and reflect on the past and justify their past behaviour and link the past to their present thinking and actions, (Holloway and Freshwater 2007, p. 12).

Plot/emplotment then refers to the sequential ordering of events, Holloway and Freshwater, (Holloway and Freshwater 2007), refer to three significant parts. Firstly, *temporality*, this is concerned with the sequential beginning, middle and end of the story – its evolution through time. Next, *causation*, which may retain explicit or assumed links between cause and effect. Finally, *human interest* is a crucial element of story-telling as without interest in the story there will be no listeners and therefore the narrative will cease to exist. It is a requisite of stories that the teller attracts and retains the audience’s attention, this may involve impressing the listener or creating elements of crisis or excitement.

Whether a story is recounted true to the sequential order in which it occurred or not is irrelevant, however there are important aspects of chronology in any story which aid the narrator in the way it is presented and the listener in the way it is received. Jovchelovitch and Bauer believe that a story comprises chronological and non-chronological parts; the former pertaining to details which are described in a

sequential manner and the latter which refers to researcher's building of a holistic final entity made up from many individual parts, (Jovchelovitch and Bauer 2000).

5.2.7 Identity Construction

Our sense of self is inextricably linked to our stories and therefore examining those accounts by narrative methods is the most suitable form of enquiry;

Narrative analysis allows for the systematic study of personal experience and meaning and is very useful for exploring the active, self-shaping qualities of human thought, and the power of stories to create and refashion identity....Narratives are a particularly significant genre for representing and analysing identities in its multiple guises and different contexts, (Sparkes 2005).

It should be noted that narrative is not simply confined to the individual and identity formation, but also on a much broader level to larger constructs such as cultures and nations, and supporters of narrative inquiry believe it is equally applicable to both. Martin Cortazzi in his book *Narrative Analysis* states that:

Narrative analysis can be seen as opening a window on the mind, or, if we are analysing narratives of a specific group of tellers, as opening a window on their culture, (Cortazzi 1993, p. 2).

Touching on aspects of group narratives and also linking back into the notion of culture is the issue of different periods in the life cycle, and specifically for this study, adolescence. Throughout the lifespan we shift in and out of different identities connected to age, maturity, aspects of personal responsibility, and so on. This may be particularly evident during adolescence, as individuals progress from dependence to autonomy, and towards maturation, sorting their identity needs.

This perspective on identity formation may shed further light on some of the aspects drawn upon in the chapter on *Adolescence*, explaining the tumultuous experience that adolescence often is and the conflict which frequently arises. Archakis and Tzanne conducted a narrative study of adolescents in Greece, studying the construction of conflicting identities in interaction, they make the observation that linguistic choices are the means by which individuals position themselves within the situation, (Archakis and Tzanne 2005).

This issue of the evolving self is related to our response to different circumstances over time, these responses reflect our thoughts, feelings and expectations within the particular setting we find ourselves in. These responses also reflect that which we wish to be portrayed to others around us. The telling of stories not only recounts experiences about individuals but also contributes to how individuals create their own sense of self, and this is a complex process. Identity is linked to knowledge, selfhood, agency and power (Holloway and Freshwater 2007), and all of these issues influence our sense of uniqueness and individuality, as well as our personality and character. There is an ongoing debate within the literature as to whether individuals compose their social framework or whether their social framework creates them. Whichever view is taken the notion of identity remains a complex one relying upon and interacting with many different facets of social life.

Human beings inhabit a social world made up of an innumerable number of influences, both positive and negative. We all fall into roles of who we are which in some way define us, for example; wife, mother, daughter, sister, student, employee, friend, consumer, and so on. Within these roles we have certain duties and obligations as well as the freedom to explore and exhibit particular parts of our character. These roles also contain practical tangible elements as well as assumed, possibly unseen, components. The way that people interpret the social world is an active process, it involves the filtering of meaning via background, own experiences, perspective, culture and so on, such filters shape perception – this culminates in ‘social constructionism’. Within this process of social constructionism is the continual change and development of our perception of ourselves. The self is not static, it is constantly evolving and changing, it is in perpetual motion, (Holloway and Freshwater, 2007).

The narrative is an imperative part of this cycle of construction and reconstruction of self due to the way in which stories help us to make sense of our world and thus define who we are. We not only tell stories to other people which, as has already been mentioned, contain varying motives and influences, but we also tell stories to ourselves, to help order and organise our experience. The stories that we tell to others are impacted upon by the type of audience/listener that we are speaking to, for example, the same story will be recounted in a very different way if we are chatting

to our best friend, compared to speaking to our superior at work. Through her work on socialisation processes Peggy Miller argues that selves...

Are not so much preserved in stories as they are created, reworked and revised through participation in everyday narrative practices that are imbedded in and responsive to shifting interpersonal conditions, (Miller 1994, p. 175).

This concept of an ever-changing sense of self, an identity which adapts and evolves dependant upon situation may in part be linked to the point in time we inhabit. This is an arguable point, however it is also an interesting concept to consider – is our current perception of what is self and its ability to change, adapt, evolve, advance and so on related to the age in which we live or is it something that has always been the same? Some say that the very nature of post-modern society enables construction and deconstruction of self, like never before, the constant evolution is something that is not only possible but positively encouraged.

There are different schools of thought within the area of identity construction for example the social constructivist approach, and although I am aware of its existence this is not the theory that I subscribe to. My emphasis throughout this project has been on the participant's story being a tangible lived subjective experience.

5.2.8 Performance in Narratives

Associated with the concept of identity formation in narratives is the notion of performance in narratives, and my inclusion of this theoretical stance here is to give an overview of the background material and the way in which different notions are interlinked, performance in narrative has not been the focus of my standing. Within our storytelling we all engage in some sort of dramatisation of the account we are giving, to incorporate the listener into the story and justify the events and our role in them. Riessman in 'A Thrice-Told Tale...', highlights and legitimises narratives' inherent facets of presentation to spectators, saying:

To emphasise the performative element is not to suggest that identities are inauthentic...but rather that identities are situated and accomplished with the audience in mind. To put it simply, one cannot be a 'self' entirely by oneself, identities must be performed in 'shows' that persuade. Expressive acts, they attempt to convince an audience – they are 'performances -for-others', (Riessman 2004b, p. 312).

This concept of narratives incorporating performative details includes the way in which we wish to be perceived by others and this is influenced by the social situation we find ourselves in at any given time. In Riessman's study involving 'Tessa', a thirty-three year old white American divorcee who had experienced a violent marriage she writes;

Tessa had multiple 'selves' that she constitutes in the dramas she presents. She negotiates how she wants to be known in them, collaboratively with her audience. She does not 'reveal' an essential self (the survivor) or 'replay' the past as much as she performs her preferred and variable 'selves', selected from the multiplicity of personae that individuals switch between as they go about their lives, (Riessman 2002b, p. 204).

The individual as story-teller influences that which is communicated, this is done by the types of words and phrases that are used and the 'slant' that the narrator gives to experiences. For example, there is an inherent need in human beings in Western culture to be regarded well by those around them and as such the way that storytellers depict their tales may well present an account which enhances the way that the audience regards them. Riessman's study of 'Burt' a working-class man living with advanced multiple sclerosis and the experiences of marital breakdown demonstrates this point, (Riessman, 1990).

This demonstrates the way in which narrators are fluid in their composition of angles on the stories they tell, how they are interacting with the audience in their decision of what to say and how to say it in order that certain facets of self are described. Alongside this is the mode of communication that we use – language. Riessman comments;

Beyond making meaning, examining the story told and the story listened to can illuminate the performance aspects of language – how we create our realities and ourselves through the strategic choices we make in social interaction, (Riessman 1990, p. 1199).

Sparkes comments on the ownership of stories;

While each of the stories told is clearly framed by a powerful narrative form, this does not determine how the story is composed and the teller is capable of fashioning diverse themes pertinent to their life story and biographical particulars. As part of this creative and artful construction the teller gains a degree of narrative ownership, (Sparkes 2005, p. 204).

The multifaceted interaction that occurs during a story being recounted is undoubtedly intricate in its composition.

5.2.9 Context and Culture

The influences of context and culture are crucial ones on narratives or stories, as has been mentioned previously.

The way in which storytellers say their story, the language that is used; the terms which are utilised and the perspectives that are taken all impact on the story itself and are all inextricably linked to culture. The way that the story is recounted is dependant upon language used which is related to cultural positioning. Language is of great significance to qualitative researchers, as it not only presents a formal ‘code’ of communicative ability, but also aids us to make sense of our world and the world that we wish to convey to others through our conversationed stories, (Smith, 2008).

It is obvious that individual accounts cannot provide widespread and all encompassing generalisations across different populations through-out different eras, however individual accounts can act as a ‘window’ into one person’s life which may well have a wealth of similarities with other people in comparable situations, therefore some general themes may be extricated, but to see a little further beyond this point, the function of research employing narratives as data sources is not just to look at the *what* questions, but also the *why* and the *how* questions;

While the objectivity and generalizability of narrative data are always questionable, narrative has a higher level of explanatory power, and can be triangulated through the stories of multiple subjects to help reveal not just what happened, but why, (Gazan 2005, p. 359).

Individual stories are vital insights into private worlds which should be treated with courteous regard. One author writes on the generalizability of these distinctive personal stories;

Personal narratives contribute to the understanding of individual experience as part of general social relations and cultural values, making them useful as cultural data in general, (Steffen 1997, p. 99).

Understanding the intended meaning of narrative content is also deeply linked to culture and there can be occasions when cultural differences between narrator and listener can cause a breakdown in communication. Riessman encountered this difficulty documented in *When Gender is Not Enough: Women Interviewing Women*;

Narrating personal experience can be done in many ways, but the listener may not 'hear' what is important to the narrator, (Riessman 1987, p. 172).

Riessman goes on to describe differences in a researcher's understanding of two female interviewees – ease in comprehending meaning from a woman of the same ethnic background as herself; Anglo, white, middle-classed, compared to difficulties in understanding a Puerto Rican woman. Riessman states that despite both women being equally effective narrators there was a lack of comprehensibility between the investigator and the Hispanic woman;

The lack of shared norms about how a narrative should be organised, coupled with unfamiliar cultural themes in the content of the narrative itself created barriers to understanding between the Anglo interviewer and Puerto Rican narrator, (Riessman 1987, p. 173).

Whatever the cultural basis, be it religious, ethnic, age-related, and so on, there is a danger of a loss of true connotation between the meaning being spoken by the narrator and being received in the vein it was intended by the listener. This could be true of a reader of a narrative report, however the onus is on the investigator who's task it is to interpret the words spoken and relay them accurately.

5.2.10 Illness Narratives

Rita Charon draws attention to a simple fact;

Medicine has never been without narrative concerns, because, as an enterprise in which one human being extends help to another, it has always been grounded in life's intersubjective domain, (Charon 2001, p. 1898).

The illness narratives allows an individual to not only explain their situation but also to 'contextualise' the changes to their lives, social world and relationships with others, (Riessman 2005). Similarly, the provision of illness narratives from individuals provides an insight into their social world, a glimpse at the way in which their experience of disease or ill-health has affected them and the perspective they take on it. Illness narratives serve both patients and healthcare professionals – the former by aiding them in the process of making sense of their situation; asserting control; modifying identity; and enabling decision making and the latter by increasing their understanding and empathy and thus improving their role as carers. Arthur Kleinman in his discussion of illness narratives agrees with this method of investigation, he stresses the way in which health-care professionals can discover the true crux of patient's experiences by establishing a rapport with them. He believes that it is through this relationship that individuals not only contextualise their condition, but also that the relationships with professionals become part of their story, (Kleinman 1988). Progressing with the idea of truly understanding patient experiences, some researchers believe that during times of disruption to 'normal' life, individuals reevaluate their positioning and subsequently recreate their stories to sustain a sense of stability. On this issue, Bury believes that it is as a reaction to adverse situations that individuals 're-examine and re-fashion' their stories in order that they retain a sense of identity, (Bury 2001).

Similarly, Seale writes;

Telling narratives is a major way that individuals makes sense of disruptive events in their lives, (Seale 2004, p. 375).

This clarifies the importance of acknowledging and exploring the depth of patient experience as opposed to merely focusing upon, and medicating for, symptoms.

Imbedded in the relationship between story-teller and listener it must be recognised that there will be instances of misconstruing information simply due to the receiver's own intrinsic 'filters' – for instance, personality, background, assumptions, experiences, and so on. also, the act of story-telling involves narrators and receivers, it is a process in which the story develops over time. The initial narrative is told to the researcher, who receives and defines it in their own way (no matter how true to

the original story s/he remains), this is then transferred to another audience (the report-reader) who in turn defines and interprets it in his/her own way. The story is therefore told and re-told as the process continues. This is simply a bi-product of human nature – we receive information and attempt to make sense of it in an effort to organise and process it. It is the job of the researcher to try, as far as possible, to uphold a sense of neutrality and remain unbiased and open-minded whilst still remaining in touch with the information s/he is hearing.

With regard to patient's stories of ill health and in a plight to endorse the notion of narrative medicine Charon describes the interaction between a patient and a doctor;

“...As the patient meets physician, a conversation ensues. A story – a state of affairs or a set of events – is recounted by the patient in his or her acts of narrating, resulting in a complicated narrative of illness told in words, gestures, physical findings, and silences, and burdened not only with the objective information about the illness but also with the fears, hopes, and implications associated with it. As in psychoanalysis, in all of medical practice the narrating of the patient's story is a therapeutically central act, because to find words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness...As the physician listens to the patient, he or she follows the narrative thread of the story, imagines the situation of the teller (the biological, familial, cultural, and existential situation), recognises the multiple and often contradictory meanings of the words used and the events described, and in some way enters into and is moved by the narrative world of the patient. Not unlike acts of reading literature, acts of diagnostic listening enlist the listener's interior resources – memories, associations, curiosities, creativity, interpretive powers, allusions to other stories told by this teller and others – to identify meaning. Only then can the physician hear – and then attempt to face, if not to answer fully – the patient's narrative questions: ‘What is wrong with me?’ ‘Why did this happen to me?’ and ‘What will become of me?’, (Charon 2001, p. 1898).

This synopsis of a patient-doctor meeting shows the undercurrent of social discourse at work and the way in which both contributors are involved in a narrative interaction – its creation and its interpretation.

5.2.11 Illness Narratives and Culture

Illness narratives are wrapped up in culture, as although the individual's story maybe unique to their own experience it is embedded in the culture which s/he inhabits, and

it is this culture which influences the way in which the story is told. Frank (1995) takes this notion a step further, stating:

*The ill body's articulation in stories is a personal task, but the stories told by the ill are also social...The shape of the telling is moulded by all the rhetorical expectations that the storyteller has been internalising ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to "tell the doctor what hurts" and had to figure out **what** counted as the story the doctor wanted to hear, (Frank 1995, p. 3).*

Not only is the individual's story shaped by their cultural make-up and past experiences, some conscious and some sub-conscious, but progressing on *this* story will then become grounded in the cultural tapestry that will go on to shape the stories of others.

Charon concisely demonstrates the way in which narratives are grounded in both context and culture as well as the journey on which the narrator and researcher jointly embark in order that a collaboration of meaning is discovered and uncovered. She writes;

The narratively competent reader or listener realises that the meaning of any narrative – a novel, a textbook, a joke – must be judged in the light of its narrative situation: Who tells it? Who hears it? Why and how it is told? The narratively skilled reader further understands that the meaning of a text arises from the ground between the writer and the reader, and that 'the reader', as Henry James writes is an essay on George Eliot, 'does quite half the labour'. With narrative competence, multiple sources of local – and possibly contradicting – authority replace master authorities; instead of being monolithic and hierarchically given, meaning is apprehended collaboratively, by the reader and the writer, the observer and the observed, the physician and the patient, (Charon 2001, p. 1898).

5.2.12 Analysis of Narratives - Subjectivity as a Positive

There is a general, often silent, assumption in research that the investigator should at all times remain neutral, passive and extricated from the investigation, particularly during interactions with participants. In narrative study this traditional position is challenged throughout the process of the investigation from the early stages of intimate and trusting relationship-building with the participant, through to the

analysis stage; the researcher's own perspective and subjective breakdown of the situation is integral to good narrative studies. The emotional involvement of researchers is validated by many feminist authors in this area, who believe that it is a constructive and beneficial addition to the research. Contemporary insightful narrative inquiry has explored the author's own perspective in relation to their background and personal perspective throughout the course of their study, in order that the investigator him/herself may be positioned intuitively in the work.

The researcher, as both interviewer and interpreter of the text, is required to be submerged in the interactive process as s/he seeks to build trusting relational bridges between his/herself and the interviewee. The collaborative process of relationship-building is necessary to relax the participant, to make them feel secure, comfortable and understood, without such a bond being ascertained further exploration after the initial interview stage will not be possible, no revisits between interviewer and interviewee will be forthcoming unless some rapport has been established. (Riessman 1987). Cathy Riessman concludes this point succinctly saying;

I am arguing for a space between extremes (at one end, subjectivity is not there or is a problem to be controlled; at the other extreme, extensive representation of the researcher voice so that her subjectivity becomes the centre of the work). Because there is an inescapable relation between our life stories and our interpretative readings of the life stories of others (which are themselves interpretative), I want to bring the investigator/ interpreter out from behind the shadows and explicitly position her in the interpretive encounter – the storytelling/analysing situation. The observer's shifting subjectivity affects what she 'sees' in the Other, whether an individual or a culture, (Riessman 2002b, p. 208).

The investigator must therefore retain a certain amount of distance so that his/her subjective perspective does not become the focus of the analysis, if this should occur it would essentially mean the reporting of the *investigator's* narrative and not the participant's. Conversely, s/he must explore the research in accordance with her own subjective experience in order that s/he can fully interpret what has been said. This may be a difficult balance to strike, however it is essential to aspire to it. Related to this is the issue of investigators being 'insiders' or 'outsiders' of social situations that s/he seeks to explore, there are of course benefits and drawbacks of both positions which will be examined in more detail further on in this thesis.

I have earlier explored the relationship between context and narratives, this is of significant importance during the analysis or interpretative stage, (Riessman, 2002b). Without taking into account the context of narratives and our own contextual settings we cannot fully appreciate what is involved in a narrative, nor know how to analyse it well.

Riessman, in 'A Thrice-Told Tale...' (Riessman 2004b), highlights some of the questions that should be considered during analysis, such as:

- Why was the tale told that way, and in that order?
- In what kinds of stories does the narrator place himself?
- When are stories inserted into an account of illness and what purposes do they serve?
- How does the narrator strategically make identity claims through a narrative performance, beyond the spoken word?
- What was the response of the audience/listener, how did she influence the development of the narrative, and interpretation of it?

With these questions in mind the investigator must now embark upon the task of interpretation. There are a number of approaches that can be used to assess narrative data and these methods can be combined to create the most effective means of analysis. As has been previously mentioned, investigators require sensitivity throughout all stages of the research including the analysis phases. Holloway and Freshwater highlight another necessary skill of the investigator;

Narrative researchers take an empathic stance towards the data, and as such, researchers and participants can employ both a subjective and an objective overview when engaging with the data...rather like the concept of empathy, the researcher is involved with the data and the participant, but also keeps one foot on the outside of the interview in order to be able to observe themselves and the participant from a reflexive standpoint, (Holloway and Freshwater, 2007, p. 80).

This reflexivity is important in order that the investigator can view the data from all angles and extract as much information as possible from it, whilst still retaining and

building a trusting relationship with the participant. When beginning the task of interpretation of the study outcomes researchers should remain mindful of the fact that there is not one correct way of interpreting the text, this has been labelled as Reader Response theory;

There is no one reading of a text. Those who read narratives are themselves positioned, they enter the narratives imaginatively and participate in constructing their meanings. Interpretation is inevitably rooted in intersubjective realm, (Riessman, 2002b, p. 205).

There is no escape from our subjective self, it is part of what makes us the people we are and it is not possible to ‘switch this off’ when it comes to data analysis. Subjectivity should not be regarded as a disadvantage however, and this will be further explored a little later.

5.2.13 Remaining True to the Story

In her 1987 study, Riessman comments on the importance of meticulous transcriptions; i.e. those that have not been ‘cleaned up’ in order that they are more readable or aesthetically pleasing, but rather detailed original transcripts of conversations, (Riessman 1987).

This underscores the significance in remaining true to the narrative, even when that may appear ‘messy’, many ‘clues’ to meaning may be contained in what possibly first appear to be insignificant details; pauses, laughter, repetitions and so on. Riessman and Quinney in *Narrative in Social Work: a Critical Review* make the link between means of communication and language, saying;

*Analysis in narrative studies interrogates language – **how** and **why** events are storied, not simply the content to which language refers, (Riessman and Quinney 2005, p. 394).*

This illustrates the true ‘power’ of communication methods and how the stories are inextricably linked to language although not totally concluded by it.

5.2.14 The Evolution of Narratives

Returning to an earlier point, it is necessary to again recognise the importance of narrative research ‘evolving’ over time. In the same way, when it comes to analysis of the data, researchers should be led by the route that the analysis takes as opposed to setting out a preconceived structure or set of ideas. As the path of the data reveals itself the investigator should follow the different tangents that it takes them off in.

Narrative analysts stress the importance of keeping the story as a whole and using large sections of participants’ stories in order that a true understanding of their meaning and experience is grasped. In this way, advocates of the narrative approach believe that by keeping participants’ words in context the individual is viewed as a holistic being and not a compartmentalised set of units. A narrative is not merely the reiteration of a story it is also an exposition of that experience, so by the time the researcher comes to interpret the data this is not the original interpretation merely *his/her* interpretation of it – the primary analysis was made by the narrator before and during the story being told. As s/he begins to explore the participant’s story the researcher’s analysis begins.

5.2.15 Analysis of the ‘*hows*’ of Narratives

When listening to a story we must not only observe the words that are said but also the way in which those words are said – that is the ‘*hows*’ of the narrative. In *Analysing Personal Narratives*, Cathy Riessman gives a series of questions useful for analysing the performative aspects of narratives (Riessman 2002a), in Box 10.

Box 10: Checklist for Analysing the Performance Aspects of Narratives

- ❖ Why was the illness narrative developed that way, and told in that order?
- ❖ In what kinds of stories does the narrator place him/herself?
- ❖ How does he/she locate him/herself in relation to the audience, and vice versa?
- ❖ How does he/she strategically make preferred identity claims?
- ❖ What other identities are performed or suggested?
- ❖ What was the response of the listener/audience, and how did it influence the development of the illness narrative, and interpretation of it?

5.2.16 Factual Accounts?

In previous sections I have made reference to the questioning of whether participants accounts can be regarded as factually true and accurate and that in narrative study that is not the main concern. Clive Baldwin's study of Munchausen syndrome leads him to write that the emphasis should remain upon 'treating narratives as facts in themselves, rather than the facts they contain', (Baldwin 2004) Therefore the focus of the researcher is on how and why the storyteller describes what s/he does in the way s/he does – the actual events of the situation being described are not the crucial element of interest in narrative interpretations. Two concepts that Holloway and Freshwater highlight as being important in relation to narrative analysis are (a) *sjuzet* and (b) *verisimilitude*, (Holloway and Freshwater 2007). The former, (a) is characterised by Russian Formalists (Vladimir Propp and Viktor Shklovsky) with narrative as the *sjuzhet* (the plot) and story as the *fabula* (the chronology of event). The former (a) is defined by Copley; as the process of rearranging a sequence of events within a narrative in order that some events are more explicitly explored than others, (Copley 2004). The latter (b) is listed in the Oxford English Dictionary as being derived from Latin *verum* meaning truth and *similis* meaning similar, it dates back to founding fathers of philosophy such as Plato and Aristotle and is largely concerned with concepts of truthfulness, believability and realism. Within the realms of social science research verisimilitude is defined by Holloway and Freshwater as

Logical and meaningful connection between described objects as opposed to a completely detailed analogue of them. In this sense textual coherence in context is more important than creating something real and related to reader's expectations of what is legitimate, believable and consonant, (Holloway and Freshwater 2007, p. 83).

In *Narrative Interviewing* Cathy Riessman distinguishes four major types of narrative analysis, I will concentrate upon only that which I will be implementing – Thematic Analysis.

1. Thematic analysis (my choice of approach)
2. Structural analysis
3. Interactional analysis
4. Performative analysis (Riessman 2004c).

5.2.17 Thematic Analysis

This form of interpretation is linked to the ‘*what*’ as opposed to the ‘*how*’ aspects of the text. (The *how* is presented in my findings through inclusion of pen portraits and a distilled version of the narrative story that is told). Riessman states;

A(n) (unacknowledged) philosophy of language underpins the approach: Language is a direct and unambiguous route to meaning, (Riessman 2004b, p. 706).

This method involves careful reading of the text (or texts) in an effort to observe and understand meaning, during which process themes will emerge which are correlated. This type of analysis is helpful when comparing a number of texts to find similarities in reports of experience. It relies upon what is said and the language used, (Riessman, 2004b). This approach (as all types of analysis) has its drawbacks, namely; if analysts are concerned with discovering and linking themes what happens to elements which are significant but different – not fitting neatly into a thematic category? This is an issue which I had to address, and decided to include those *variant* themes which emerged from the participants’ stories as well as the *universal* ones.

There were a number of reasons that I chose thematic analysis, as opposed to other alternatives, and the advantages of this method of qualitative analysis (Braun and Clarke 2006) are summed up in Box 11.

Box 11: Advantages of Thematic Analysis

- Flexibility.
- Relatively easy and quick method to learn, and do.
- Accessible to researchers with little or no experience of qualitative research.
- Results are generally accessible to educated general public.
- Can usefully summarise key features of a large body of data.
- Can highlight similarities and differences across the data set.
- Can generate unanticipated insights.
- Allows for social as well as psychological interpretations of data.
- Can be useful for informing policy development.

As a relatively inexperienced researcher in qualitative methods I chose thematic analysis partly because of its ease to learn and conduct, there is a certain amount of flexibility which I felt crucial in this study to enable the data to ‘evolve’ and so that the study was not prescriptive in its expected findings. Thematic analysis in this case enabled key elements of stories to be drawn out which in turn can influence professional practise, namely those working with young people with CFS – teachers, physicians, psychologists, and other healthcare workers.

5.2.18 Links Between Analysis and Interpretation

These two processes are inextricably connected, as holistic beings we are in our everyday life continually analysing information that is presented to us (whether consciously or sub-consciously) and as such we process that information to enable ourselves to make sense of the world around us. During research analysis investigators inevitably ‘over-read’ and under-read’ that which is transcribed – we concentrate too much on aspects that may not warrant so much attention and dismiss other details that may well require more of our attention. As Holloway and Freshwater highlight, there are many influencing factors in the background of our minds when we process texts, including personal, professional and cultural aspects swaying our interpretation. We also run the danger of drawing premature conclusions as we read, for example making assumptions that the story will continue along a specific track and therefore making the information correspond with our expectations (a case of self-fulfilling prophecies), as opposed to remaining in a state of neutrality, (Holloway and Freshwater 2007).

As mentioned earlier **reflexivity** is an important tool that the narrative analyst must acquire and utilise in order that full meaning of the text may be obtained. During the writing-up stage it is necessary for the researcher to not only document the story that was told, but also his/her own reaction to it – in this way an interpretation can be made and reported. My own experience of CFS, both as a sufferer and somebody with close links to other sufferers, has granted me an insight into this specific world and given me tools necessary to understand and analyse the data that has been obtained by having my own personal background knowledge to refer to. When considering the transcript it is important for the analyst to look at it in its entirety as well as its parts, considering the cues given by the narrator as to what s/he feels is

important to convey, and his/her attitude and mannerisms when responding to questions. It is also helpful for the researcher to contemplate the way in which individual stories represent specific people groups and the larger societal narratives present.

Finally, there is a major onus on narrative researchers to act with respect and sensitivity throughout not only the information-collection stages, but also during analysis and presentation of the data. The emphasis is upon investigators to remain true to that which has been presented by the participant and appreciate the emotional vulnerability that the individual has experienced by way of allowing insight into their private world.

To Summarise

Narrative research is primarily about story-telling, something which everybody does on a daily basis as a natural part of their lives, something which makes us inherently human and allows others to understand and empathise with us, and we with them. This story-telling is an emotional process, it involves being honest not only with ourselves but with those around us in an effort to give insight into each other's lived experiences. Narrative research methods have become increasingly popular in recent years thanks to influential investigators such as Andrew Sparkes and Cathy Riessman who have presented compelling accounts of people's lives through the use of this type of qualitative methodology. As a mode of research it is only appropriate in small-scale studies, at the emphasis is not on quantity but about breadth, depth and quality of the data obtained.

Narratives are not only about *what* is said but, just as importantly, *how* it is conveyed – the communicative tools used, the language which is utilised and so on, narratives have a performative element in this regard; whereby the story-teller decides what details to include and what to omit according to the current audience. These stories also have a role in identity construction, not only of individuals but also of larger constructs such as cultures and societies, they help people to explain their situation and contextualise their lived experiences, particularly in the case of illness narratives.

5.3 The Use of Narrative Methods for My Study

My study has focused on narrative research methods, I have conducted eight interviews with adolescents; seven in person and one via email as she was too ill to attend the hospital or have me meet her in her own home. I have also conducted four email interviews with primary care-givers, these included few questions and the participants were asked to give as much detail as possible, they were encouraged to type as if they were speaking and I underscored the importance of their accounts being as full and frank as they could make them. Despite the technique this aim was achieved and the emails I received back from the four mothers were steeped in emotion and descriptive content, so although some may argue that email is not an effective mode of communication I would argue that in this case it was both the most efficient method of communication as well as being a valuable tool for the women involved to convey honest and expressive stories.

It is important to note that a fundamental characteristic of narrative biographical research, such as this study, is that the research is emergent with an evolving process *through-out*. No hypotheses are presented for testing. The research questions guide a descriptive focus using participants' stories.

5.4 Aims

Through this study my aim has been to identify gaps in the current literature and knowledge base of what it is like to experience CFS as a young person. Through listening to their illness experiences and the way in which CFS impacts upon normal life situations and the day-to-day experience of being an adolescent. My background experience of CFS, both as a sufferer and as a close relative to a young person very severely affected by it, gives me insight and sensitivity, as well as motivation to explore the effects of the condition.

5.5 Research Questions

- ❖ What are the personal experiences of young people with CFS – how does the condition affect their daily lives – including the educational, social and psychological issues?

- ❖ How does CFS impact family life – how does the condition influence not only the lives of sufferers but also those closest to them?
- ❖ Through open-ended interviews with this largely under-researched population, can the knowledge base be extended to help guide practise for those caring for the needs of adolescent CFS sufferers and their families?

Any study looking at Chronic Fatigue Syndrome (CFS) is of significance to health-care inquiry due to the largely unknown and misunderstood nature of the condition, further, the issue of adolescents with CFS is even less acknowledged and appreciated, both by the medical profession and the general public. Despite this the impact on individuals with the condition can be large, affecting quality of life dramatically. The amount of available research into adolescents with CFS is limited but has increased over recent years, my hope is that this project will not only contribute to the existing knowledge base in this clinical area, but also act as a pioneering piece of work by ‘giving a voice’ to those most affected, in many, if not all, cases, for the first time. This study attempts to break new ground in as much as medical professionals and researchers still largely shy away from CFS in young people as illustrated in the literature review. There is a dearth of literature concerning this age group of CFS sufferers, and very little qualitative research in the area. Narrative biographical research is highly appropriate in areas such as this, with little pre-existing knowledge. The characterisation of CFS in adolescence via narrative research methods is of significance for the healthcare profession to increase understanding and empathy with young sufferers and in turn improve patient-care.

5.6 Rationale

As already outlined, this research is necessary to gather information via narrative interviews about young CFS sufferers, in which they are free to speak openly without fear of judgement or pre-conceived presumptions being made. Despite its official recognition by the Chief Medical Officer almost a decade ago, the literature reflects that the diagnosis and management of CFS still today cause controversy and apprehension within the medical profession, and many still recoil from even acknowledging its existence, let alone exploring the depth and breadth of patient experiences. I feel it is crucial that this group of adolescents’ experiences are

explored and documented (perhaps for the first time) and in a way that attempts to capture their past experiences, present concerns, and future aspirations in order that a picture may be built up of the human impact that this condition has on young people's lives. Due to the significant breakthroughs made in the field of genetic CFS research in recent years much of the current research energies are being expended in this area. Also, the £8.5 million announced by the then Health Minister, Jacqui Smith, in May 2003 was allocated by the government to fund services specifically designed for CFS sufferers, this has led to crucial work being conducted primarily in the area of rehabilitation which has been of major importance. The genetics work and the rehabilitation services have meant that funding and literary reporting have concentrated on these two areas, which is both valid and necessary, albeit overdue! However, this has meant a distinct lack of work being conducted into more subjective areas of the condition, i.e. exploration of psychological and social aspects of the condition, in both adults and children, and this is a gap in the literature which I aim to help fill. Without my study, and other similar studies, the knowledge base concerning illness experiences will remain restricted which impacts the way in which healthcare professionals relate to and know best how to treat CFS sufferers, as well as the public profile of the condition remaining limited which increases the mystery surrounding CFS and does not do justice for those effected by it. Health service staff and policy-makers cannot deal with a condition that they know only a limited amount about, neither can patients receive the best care. Capturing and describing the experience of CFS may provide directions for supporting adolescents.

5.7 Significance of Proposed Research

As previously mentioned, this study is necessary due to the current lack of research about the experience of CFS for adolescents and therefore understanding within the field of CFS. The existing and recent work centres largely upon genetics or rehabilitation and thus the more qualitative aspects have not yet been fully researched.

5.8 Approach, Procedures and Process

I have conducted eight open-ended interviews with a sample of 11 to 18 year olds to explore their ‘stories’, to get an idea of how having CFS affects adolescents in their day-to-day lives. I have also conducted four email interviews with primary care-givers of these adolescents, to gain an understanding of how having a child with CFS affects families and in particular those parents who perform the majority of the care-giving role, in this case all are mothers. I have analysed the findings using generic qualitative thematic analysis in an attempt to draw out common and variant experiences from the participants’ stories, similar to those methods used by Cathy Riessman in her thematic approach to narrative study.

5.8.1 Summary of the Data Collection Process

I initially approached parents of young people currently registered with a specialist CFS Service located in the South of England, via letter which was mailed on with a covering note from the Lead Occupational Therapist at the Service. I invited responses from those young people who were interested in taking part in the research interviews, with the backing of their parent/guardian. Once contact was established I invited young people, (those under 18 accompanied by their parent), at a mutually agreeable time to attend the Clinic to take part in an interview. For one girl who found it difficult, due to distance and fatigue, to travel to the hospital I met her in her own home, and for another girl who was too poorly to even meet in person in her home we conducted an email interview. The interviews were transcribed, a pen portrait and participant story described, (a distilled version of the narratives are presented in Chapter 6), then the transcripts were analysed according to a generic qualitative process to draw out themes – both general and individual which emerged from the data. This type of thematic analysis involves the drawing out of ‘codes’ from the data, this coding is then applied to the data to extract and group together statements or topics which are similar in nature and fall under the original umbrella code/theme. I have presented these four major themes, along with their sub-themes, to provide insight into how CFS affects this particular population group.

Due to the encouraging responses I received from the mothers who accompanied their children to interview I also approached a selection of primary care-givers offering a chance to tell the story of their experiences, I did this via email due to financial, practical and time restrictions, and analysed the data in a similar way to the

face-to-face interviews. The variant and generic themes which emerged from the care-givers' stories were incorporated into the themes drawn from the young people's narratives to be presented in diagrammatic form as well as prose.

5.8.2 The Sample

Sample Size

I conducted interviews with eight young people and email interviews with four primary care-givers, the number of participants included in the study reflected the initial aims of the study. The sample did not need to be large, as in quantitative research, because the emphasis has been upon the quality of information gathered as opposed to the quantity of individuals taking part.

Access

The majority of participants involved in any research need to be accessed via a 'gate-keeper', in my case this was the Lead Occupational Therapist who runs the Adolescent Clinic within the specialist CFS Service. She provided a covering letter and mailed my invitation to participate in the study out to the current members of the Service. Ethical considerations linked to access include that participants volunteer willingly and that they are not coerced into taking part, this was of course upheld. All stipulations laid down by the Research Ethics Committee and research governance department of the hospital were met, an honorary contract was put in place to enable me access to the hospital and patients, and CRB criteria was met. A paper trail for the ethics and research governance stipulations can be found in Appendix B.

Inclusion and Exclusion Criteria

I chose 11 to 18 year olds as the inclusion ages for the interviews with adolescents due to a number of reasons; (a) this is the age bracket for secondary school education which is largely considered as the cut-off between childhood and adolescence in this country, (b) 18 is ordinarily the age within the NHS when young people are passed from paediatric to adult services and therefore serves as a sensible upper boundary, and finally, (c) this is the age group classified as 'adolescence' for the Specialist CFS Service, from which I have sampled. Within this homogenous sample the key exclusion and inclusion criteria were that (a) all individuals had been given an official medical diagnosis of CFS, (b) all were registered with the Adolescent Clinic

attached to the Specialist CFS Service, i.e. all had been given a referral either from a GP, a paediatrician or a specialist to attend the Clinic and (c) all young people were aged between 11 and eighteen years.

5.8.3 Extending the Sample

My initial sample was intended to be the eight young people to participate in face-to-face interviews, mine has been a homogenous sample based on individuals similar to each other with the same characteristics for the purpose of the study's aims and focus, that is collecting information regarding the personal experiences of young people with CFS. As the research developed however, it became clear that including another element of experience, in the form of the four parents' stories would enhance the study and so this element was added in, thus including a second homogenous, purposive sample of individuals. The participants' stories differ according to the duration and nature of their CFS experience and so vary in content, however they are all information-rich cases, that is they have typicality – they represent a particular strata of society with specific knowledge and experience of the phenomena of having intimate personal knowledge of CFS, as either the parent of; or an adolescent sufferer. I do not claim generalisability of findings to the CFS population at large, or even to the universal adolescent CFS population, however the intention was to explore the life experiences and meanings of this particular group of people.

One issue which must be considered within narrative research is that participants must have the ability to coherently articulate their thoughts and feelings in order that their experiences can be conveyed in a form that can be related to by others. In face-to-face interviews (and in email interviews due to subsequent replies being bounced between researcher and participant) the investigator can provide prompts to assist individuals to tell their stories, however this isn't always possible or easy if the individual finds it difficult or is unwilling to express themselves clearly. The importance of establishing a relationship to allow participants is crucial, and the researcher must build a rapport with them in order that they feel at ease and thus allow them the freedom to communicate intimate experiences and emotions. (The importance of relationship-building is explored further elsewhere).

5.8.4 The Interview Process

The adolescent interviews were conducted face to face as far as possible, this was to enable a building of relationship and rapport with not only the young person but also their parent who accompanied them, through this relationship I could establish an element of trust and empathy which gave the young sufferers the freedom to speak openly about their past experiences, present situation and future hopes and aspirations. The interviews were conducted within a quiet room in the Clinic and lasted for an hour or more. My initial introduction gave an overview of what I was hoping to achieve, i.e. that I could build up a picture of their own individual experiences in order that other people could learn the impact of having CFS as a young person. I found that the opening few minutes of the interviews required a few questions to facilitate the narrative flow of response from the participants, however after this initial stage only a minimal number of questions were needed from myself, aside from affirmative statements or responses, and those questions were mainly necessary to keep the interviews 'on track' or explore/clarify points further.

One girl was too ill to attend the Clinic and she was unable to cope with an interview in her own home either so I decided, so as not to lose out on her participation, I would conduct an email interview with her. I travelled to the home of another girl, who was also too unwell to make the journey to the Clinic, however there were practical drawbacks of being in a family home such as issues of noise and interruptions. I found that having the mothers present for interviews with under-eighteen year olds did not detract from the information provided by the young people, as I was apprehensive that having a parent present would possibly make the adolescents less inclined to speak openly, however with one boy it aided the interview as he was particularly shy. In other interviews the mothers' presence enhanced the flow of conversation between themselves and their child as it allowed them to reflect together on circumstances which built up a fuller picture of the way CFS impacts everyone within the family home, I observed them 'batting off' each other sparking each other's memories and thus encouraging the conversations to continue. Three of the older children were unaccompanied as they were all over the age of 18 and did not require or opt to have a parent present. I found that the girls were more open and 'chatty' than the boys and relaxed much more quickly. The boy who was more timid in character displayed a number of anxiety traits and from speaking to his mother afterwards it appears that it was not the interview situation

that made him apprehensive, but that he simply is shy. Another boy who participated was older and, in stark comparison, very confident and eager to speak, however the content of his conversation I felt was fuelled in part by an eagerness to impress me, and that made me feel slightly awkward. I felt the need to readjust the flow of conversation on a couple of occasions to keep him focused on his experiences rather than peripheral irrelevant information. Throughout the course of the interviews I tried, as far as possible to keep my questions to a minimum and instead to offer words of encouragement or reiterate what the individuals themselves had just said in my own words in order that the flow of conversation continued and they felt that I agreed with what they were saying and felt comfortable in continuing. In this way my participation in the conversation was kept to a minimum allowing the participants freedom to explore those issues they felt were personally important, without being 'guided' down particular paths. The fact that the narrators were adolescents and not adults I do not believe had a huge impact on the quality of data obtained overall, however there were issues regarding the male participants which may have been linked to their age, the first being that one was overly confident and showed a lot of bravado and the second being that the other boy may have felt intimidated due to lacking in confidence, something which is less likely in an adult. Generally my own experience of CFS aided the interviews as I had first-hand knowledge of the condition and did not require unnecessary interruptions with questions probing the participants as to what they meant.

Through gaining such individual accounts of experiences, opinions, concerns, aspirations and so on, a picture could be painted of the true nature of CFS in adolescence, which could enhance the existing knowledge base, uncovering that which is considered important to the patients themselves and in turn providing insight for individuals involved in practise.

5.8.5 Concluding Thoughts about Data Collection Linked to Narrative Interviews

The three main reasons that I chose to use narrative methods were as follows:

- (1) I have been concerned with the *whole* story not simply its broken down parts
- (2) I wished to capture individuals' subjective experiences
- (3) I have been focused on the individuals' perspectives on their life history

In order that I could adequately address these issues narrative was the more efficient and appropriate form of research method, also I believe that working with an under-researched population of individuals who are minors and therefore less confident than adults, it has been important to keep the power differentials weighted towards the participants – as narrative study primarily does. The type of narratives I have been collecting is that of the *Lived narrative*, i.e. that which is concerned with ongoing sequences of everyday situations.

There are many ethical considerations to be accounted for in narrative study which I have had to remain mindful of. It is not a mode of research which is conducive to many of the stipulations demanded by ethical committees, for example the requirement that narrative study develops or evolves over time has meant returning to the Ethics Board on many occasions (see Appendix B for paper-trail) in order that substantial amendments be submitted and approved as the research has unfolded. Also there are implications regarding informed consent and confidentiality issues which are often more difficult to adhere to during narrative work and can mean the need for an ongoing approval process between researcher and participants. There can be long-term repercussions for participants involved in narrative studies as it is an intensely personal process involving the private lives of individuals, and the experience can have both positive outcomes (for example, assisting the cathartic, healing process and allowing contextualisation of experience) and negative implications (such as uncovering traumatic memories), researchers need to try and limit the negative possibilities as far as possible by acting with sensitivity and respect. There are ethical issues for researchers also, such as the need for emotional involvement – this was an issue I encountered as an ‘insider researcher’ with an emotional investment in the situation. Emotional involvement is important during all stages of narrative study due to the ongoing need for reflexivity to ensure validity, this is particularly crucial during the latter write-up stages in order that researchers do not simply document findings but also consider their own reactions to the data to aid the interpretation process.

The narrative interview was the most appropriate method of data gathering for my study due to the research aims and rationale, by allowing individuals the freedom to

offer their own personal stories with limited interruption and focus-setting from myself meant successful gathering of insights into private worlds and personal representations.

5.8.6 Additional Data Collection

As the project evolved I realised that a different, but significant element, of the CFS experience is that of the primary care-giver who could not only provide insight into their child's daily struggle with the condition, but also describe the wider impacts on themselves as primary care-givers and the rest of their family. I therefore chose, in addition to the face to face interviews conducted with young people, to include a select number of interviews with primary care-givers, (in this case, all were mothers). The most efficient form of communication, for the reasons described below, was that of email, (an example of one email 'script' is located in Appendix D).

5.8.7 Email Interviewing

In this age of technological advancement the World Wide Web (WWW) and Email (Electronic Mail) have provided new methods of data collection. In 2008 Government statistics show that 16 million (65 per cent) of all British households have internet access, that is an increase of just over one million households since 2007, (National Statistics Omnibus Survey, 2008). The term 'computer-mediated communication' (CMC) has been coined to label such methods. Email has been used for a diverse range of projects from research into psychological effects of the 9/11 attacks (Nielsen and Levin 2005) to questions about intimate issues such as sexual health (Ross et al. 2005). It has been found to be a particularly efficient and productive mode of research in those with chronic illness, (Kralik et al. 2000). Studies have been conducted into the effectiveness of email and internet related research methods compared to traditional methods of data collection and have found there to be little difference in efficacy between the two, (Gosling et al. 2004; Ross et al. 2005).

5.8.8 Building a Relationship in E-Interviewing

At the outset, establishing a relationship is very important in email interviewing, the researcher should attempt to build good rapport with the participants prior to

interview commencement and continue strengthening this bond through-out the email exchange, (Hunt and McHale 2007; Kralik et al. 2000). In this way, not only will the provision of participant information be of a high standard, but also participants are more likely to ask the interviewer questions or ask him/her to address concerns. This relationship should aid the flow of conversation, as well as encourage participants to continue the process through to completion. Kralik et al discuss the importance of an equal relationship between researcher and participant;

The relationship between researcher and participant was reciprocal rather than hierarchical...a woman wrote to the researcher: "What I have found so nice about your study is that along the way you have revealed yourself, and that you are not just an academic asking questions", (Kralik et al. 2000, p. 910).

This was an issue I felt important during my research and so was open with some of my personal experiences of CFS when I felt it applicable and this aided the relationship of trust to be built, especially with the mothers involved.

5.8.9 Advantages of Email Interviewing

There are a number of advantages of using email interviews (Hunt and McHale 2007); **Cost** - there is no travelling involved for either participant or interviewer, no need for recording equipment and no transcribing costs, (Meho 2006). Also, a criticism of transcription is that it effectively 'tidies up' what has been said which endangers the precise details of what has been said (Seale 1999), and there is the question of **Transcription Reliability** (Kvale 1996), or **Reduction in Transcription Errors**, (Kralik et al. 2000), both of which are removed in email interviewing as the email communication itself is printed and used as the transcript. The **Range of Participants** is increased, those who would ordinarily find it troublesome to travel to a face-to-face interview venue (in this case, individuals who do not drive needing to travel from the far side of the locality to the Clinic in order to participate), are accessible. **Time for Reflection**; both interviewer and interviewee have the opportunity to reflect upon what has been asked or said, and can take time to formulate responses. The email interview is conducted within a single script, despite occurring over a small number of exchanges, and so it allows either party to scroll back to past 'conversation' within the script and reflect upon what has been spoken

about previously. Kralik, Koch and Brady comment on the reflective process involved;

There was the opportunity for the participant to shape and re-shape her stories before they were told. As the writer shaped her thoughts into a written text, complex and recursive patterns were elicited. The writer moved back and forth between thinking and writing, writing and thinking, creating a web-like pattern that re-shaped initial ideas into a new meaning, (Kralik et al. 2000, p. 912).

Interviewer Effects, during face-to-face exchanges both participant and interviewer may be affected by visual characteristics or actions of the other person – this problem is eliminated during email interviews. As a follow-on from the last point, email interviews allows increased **Freedom**, the impersonal nature of email interviewing can act as a benefit, allowing individuals the ‘distance’ to say things that they may have found intimidating or embarrassing to speak about in person. Email interviews are less intrusive than in-person interviews for participants, they are not meeting with someone in a room so personal characteristics such as appearance and dress are not revealed. It is this anonymity which provides individuals with the sense of liberty that comes with being ‘hidden from view’, this acts as a safety mechanism and often provokes participants to communicate personal, private or intimate emotions, thoughts and feelings that may not be readily disclosed in a face-to-face encounter. As one study highlights;

The feeling of anonymity that comes with correspondence allowed the women to express themselves openly and honestly. There was an anonymity about writing that made it easier to be absolutely candid, (Kralik et al. 2000, p. 913).

Email interviewing allows researchers to **Work with Numerous Interviews Simultaneously** (Hunt and McHale 2007; Meho 2006), subsequently the collection of data can occur more rapidly (especially without the need for waiting for transcriptions), and there is the advantage of interaction between interviews, e.g. if something interesting arises during one interview the researcher can use this information in other interviews that are currently underway. Care must be taken when conducting a number of interviews simultaneously that participants’ information does not become confused, it is recommended that the past email ‘script’

be read over prior to sending new questions, to avoid confusion and repetition. In face-to-face interviewing there is a dimension of **Power Differentials**, with the researcher being the one with the tape recorder and therefore the authority and the participant who has no influence over the recording, this is not so in email interviewing, (Hamilton and Bowers 2006). Similarly, presence of a recording device during in-person interviews may be regarded as intimidating, (Hamilton and Bowers 2006), this too is eradicated in email interviewing.

5.8.10 Concluding Thoughts about Data Collection through Email Interviews

Research into the efficacy of email interviewing compared to face-to-face dialogue has found that email interviewees remained more focused on the questions asked, and offered more contemplative explanations and stories within their answers than those interviewed in the traditional way, (Meho and Tibbo 2003). A point made by Kralik et al that I agree with is that ongoing email communication (i.e. that which occurs over two or three sessions of correspondences) provides a more consistent view over time compared with face-to-face interviews that gather information relating to a particular moment in time, (Kralik et al. 2006). It is this depth of experience I aim to obtain from participants to enable a more encompassing picture of their lives.

Email interviewing, as a methodology, was better suited to the task of interviewing primary care-givers in my study who had already expressed an interest in contributing to the project for a number of reasons, listed below:

- the lack of travelling involved alleviated problems for at least two of the potential candidates who lived many miles from the specialist CFS centre
- a relationship had already been established with those parents who expressed an interest in participation, through meeting with them at the interviews already conducted with their children, and there had been some limited email communication before and after the interviews conducted with their children
- this is a self-funded PhD and I was trying to keep costs to a minimum, the lack of transcription and travel costs linked to email interviewing was an important consideration for the continuation of the project

- those parents who had already expressed an interest in participating were in part or full-time employment, email interviews by their very nature enabled participants to respond to questions at a time most convenient for them, without the need to take time out of their lives to travel to interviews
- for those parents who are full-time carers for their ill children the opportunities to travel to the Clinic to participate in a face-to-face interview were scarce if not impossible, email eliminated that issue.

Email interviewing provided an efficient and financially viable method of collating information from participants who may not otherwise have been readily accessible, it offered an alternative form of communication to traditional methods of data collection which could be employed quickly and still generated large amounts of high-quality information. As with any method of data collection there are inherent drawbacks however with careful thought and attention to detail these could be overcome, as I have outlined. It was the most convenient and efficient medium for my participants.

5.8.11 Data Sources

The origin of the data collected in this type of study is people's individual narratives, the stories of their own unique experiences. I have tried, as far as is possible, to not stray from the reality of the participants' transcripts (see Appendix C for one example adolescent interview transcript), I have not attempted to 'clean them up' but have used multiple quotes as reflections of the individuals' own words and feelings and acknowledge my own personal biases and influence over the research. Influenced by Riessman's work I have endeavoured to stay as close to the participants' words and stories as possible keeping them as holistic accounts;

Unlike traditional qualitative methods, this approach does not fragment the text into discrete content categories for coding purposes but, instead, identifies longer stretches of talk that take the form of narrative – a discourse organised around time and consequential events in a 'world' recreated by the narrator, (Riessman 1990, p. 1195).

5.8.12 Analysis of the Data

The interviews were transcribed, I then developed a pen portrait for each individual to give a sense of context and history to the reader. Following this I developed a description of the young person's CFS journey, the purpose of which was to illustrate their unique story, I then subjected the entire transcript for each participant to generic thematic qualitative analysis.

Once an interview has taken place the recording has to be transcribed, this is a lengthy process and involves recording not only the words that have been spoken but also other characteristics such as pauses, giggles and so on, these are crucial elements of the overall interaction and allow further insight into the true emotion and meaning behind the participants' words. The analysis process which I conducted involved firstly reading through the transcript several times to familiarise myself with what had been spoken, remind myself of the underlying plots of the stories and at times even allow me to grasp things which I had not picked up on during the interview itself. I then worked through the transcript sentence by sentence, and paragraph by paragraph making notes as to my observations. Next I re-constructed the stories into a coherent whole, organising the information into a logical progression through the story in places where the interview had jumped around from subject to subject and back again. When I had done this to all the transcripts I began to notice themes emerging – some were common among all the stories, others were unique to specific individuals, I then began working through all of the narratives pulling out the themes and creating an overall picture of CFS for this group of individuals. I do acknowledge that my own background and personal perspective influences the way in which I have analysed the data, again in recognition of Riessman's words, echoed from earlier;

Those who read narratives are themselves positioned, they enter the narratives imaginatively and participate in constructing their meanings. Interpretation is inevitably rooted in intersubjective realm, (Riessman, 2002b, p. 205).

The emergent themes are listed in Box 12.

These themes will be revisited in the Findings and Discussion chapter.

This is an exploratory study which seeks to gain in-depth description of young people's experiences of CFS. The study is not attempting to generalise to all adolescent CFS sufferers and their families, however the findings may be transferable and may suggest implications for health, social and educational professionals working alongside these individuals.

Box 12: The Major Themes to Emerge from the Findings

1. Adolescent CFS experienced as having to adapt to debilitating physical symptoms
2. Adolescent CFS experienced as living with changes in family relationships and member's life experiences
3. Adolescent CFS experienced as living with isolation and a disruption to a full and satisfying teenage life
4. Adolescent CFS experienced as feeling misunderstood and judged



Overarching theme:

Adolescent CFS is experienced as having to put life on hold

5.9 Limitations of the Methodology

5.9.1 Inclusion and Exclusion Criterion

The careful inclusion and exclusion criterion applied in this study could be seen as a limitation of the project, a progression of this study could be to replicate the interviews with a group of individuals from a wider sampling pool, for example another county, to see if differing themes emerged within the CFS experience.

5.9.2 Sampling

A potential weakness of the project is that the 'pool' from which I have sampled could be considered to have inherent bias due to the nature of parents who seek further medical care for their children. It is widely accepted that individuals from a middle-class background with a relatively high level of education are more likely to

seek services beyond that of their own GP when pursuing medical care, (Rangel et al. 2000b), and this is true for parents attempting to secure care for their children. All of those participants who responded to the call for interviews are white British nationals with English as their first language, all are from a financially stable, middle-class background. Had other individuals from differing backgrounds offered their participation this may have produced a different range of findings in the themes that emerged.

5.9.3 Being an ‘Insider Researcher’

It could be argued that being a service user myself is a limitation of the study, and although I will have biases in my approach as a consequence of my own experience, (as discussed in other chapters of this thesis), however I believe that the strengths of ‘insider research’ outweigh the weaknesses as my prior knowledge of the situation has allowed me a personal insight and empathy with the participants which has not only enhanced the building of trust and relationship, but also driven the research and understood the need for it.

5.9.4 Disadvantages of Email Interviewing and Possible Solutions

As with any data collection method there are naturally inherent limitations or disadvantages, but there are also guidelines within the literature for dealing with such issues. **Sample Problems**, there are problems associated with sampling techniques when recruiting online (a frequent way of recruiting for email interviews) such as selection bias, however those are not applicable to my study as I have already ascertained the individuals who will be participating. Participants do however need to be literate and physically able to correspond, (Kralik et al. 2000), they also need to be familiar with and capable of articulating themselves via email, (Bunting et al. 1998). Whereas the implementation of email interviews may be seen to cause selection bias against those without internet access or who do not feel competent using computers or the internet, it could be argued that in-person interviews contain an inherent selection bias against those with mobilisation difficulties, (Kralik et al. 2006), as is true for many people with chronic illness one example of which is Lisa in my study.

The online environment has created a new space for discussion, with the potential of involving people who may not otherwise be able to participate in research, (Kralik et al. 2006, p. 220).

One issue of difficulty linked to email interviewing is **Mistaken/Concealed Identity**, (or as one article labels it ‘research participant fraud’, (Hamilton and Bowers 2006), one recommended way of ensuring that the individual responding to emails is indeed the person they say they are and the intended interviewee is through obtaining signed consent by post, thus providing an address check, (Hunt and McHale 2007). **Ethical Issues** related to interviews are the same whether the exchange is conducted face-to-face or via email – e.g. informed consent; avoidance of deceit and right of withdrawal. These issues are easily negotiated by providing individuals with detailed information of the study and their roles as a potential participant, as well as allowing them opportunities to ask further questions (by email or telephone) and explaining their right to withdraw at any time. As with other methods of data collection feedback should be offered upon completion if requested. During an in-person interview the researcher has, to a large extent, authority over how long the interview will take, an issue with email communications is that **Interviews May Lose Focus/Take too Long**. When interviews are conducted over several days, or even weeks, participant’s (and researcher’s) enthusiasm may deteriorate, it is appropriate to set time-limits for the return of answers from participants in order that the interview does not drift on for long periods (Hunt and McHale 2007), e.g. it is advisable to agree at the outset of the process that both interviewer and participant will always respond to the other within 48 hours. This situation may result in a partial interview script which the interviewer must then make the decision of whether or not to include incomplete data. The failure to reply could be due to practical issues such as illness, going away on holiday or their computer being broken/inaccessible, or it may be that they feel upset, bored or no longer wishing to participate in the study. Participants may decide to withdraw simply by not responding and may fail to explicitly inform the researcher of this decision, if this situation had arisen my decision was to follow guidelines about email interviewing and send one further email to check that the participant had decided to withdraw, failure to respond to that email would have been taken as decision to withdraw, (Hunt and McHale 2007). I supplied a telephone number on initial paper correspondence to allow participants an alternative contact method

should a problem arise with their computer for example. If withdrawal occurred part-way through the interview process my decision was to attempt to obtain permission to use the information already collected, if permission had not explicitly been granted the data would have been destroyed and not used within the write-up. All email communication for this project was conducted through the Bournemouth University email system which is secure – all access is password protected and no-one other than myself, the researcher, has access to the email address which was used. All ‘email scripts’ will be kept for the same length of time as interview recordings and transcripts and then destroyed in the same way. (Current policy for keeping research data, according to Bournemouth University's guidelines, under the Data Protection Act, 1988, is as follows: (a) electronic data – 2 years after completion of the research study, and (b) hard copies of transcripts and analysis – 5 years).

Closure, to avoid misunderstandings it is advisable that when there are no further questions to be asked and all necessary information has been collected the communication between participant and researcher should be brought to a close by the researcher informing the participant that an end-point has been reached, thanking them for participation and asking if there are any questions or comments s/he would like to add.

Missing Non-Verbal Cues such as voice intonation, facial expression or body language are all visible to the interviewer during a face-to-face exchange and will be received either consciously or sub-consciously and subsequently affect the flow of the interview. Also, email lacks the assuaging benefits of voice during personal conversations, without this element of communication messages may appear too direct, rude or even offensive, (Bunting et al. 1998). Many email users overcome the loss of emotional cues by choosing to use ‘emoticons’, for example a happy ☺ or unhappy ☹ face, and abbreviations such as ‘LOL’ for ‘laugh out loud’, ‘ROFL’ for ‘roll on floor laughing’ or ‘OMG’ for ‘oh my goodness’, (Kralik et al. 2000; Meho 2006). Such ‘short-cuts’ provide symbolic representations to add emphasis or help avoid confusion in written statements.

Failure to Embellish on a point made during the email interview log when probed by the researcher could be seen as a disadvantage of not being in the same room as the interviewee, however it could be argued that this situation may arise just as easily in a face-to-face interview when a participant refuses to elaborate further on an issue which the researcher tries to pursue, (Hamilton and Bowers 2006).

5.10 Ethical Issues

All research involving living beings must adhere to an ethical framework, there are ethics panels and boards which scrutinise research proposals to ensure participants are protected and not violated in any way. However, narrative research stretches the investigator in different ways to other types of research projects as it is perhaps more personal, inquiring about and probing individuals to explore their thoughts and feelings in relation to their own private world. A pragmatic perspective on this issue may state that all research will break some type of ethical codes as it is necessary to expose details of people's lives, to look beyond that which is readily available to the public, and explore what is underneath and perhaps largely hidden. It is the job of the investigator to ensure that their participants are treated with respect and that any information is handled sensitively so as to maintain the moral obligations necessary to guard those involved from harm. After all, the investigator is being put in a position of privilege, having been 'invited' into the inner sanctums of personal experience. Often there is a need for ongoing approval of data, as opposed to a one-off agreement to participate – this entails the returning to participants with sections of text or questions about interpretation, which demonstrates respect for the individuals' own accounts by striving to ensure correct analysis is occurring. Adam Newton, in his book *Narrative Ethics*, draws attention to the need for a revolt against the traditional context-free ethical framework which is traditionally used in research and towards a more suitable structure which acknowledges the 'uniqueness of the moral situation', (Newton 1995). This issue is explored further in Riessman's work *Exporting ethics: a narrative about narrative research in South India*, in which she illuminates the risks with the traditional approach, saying:

(There are) inherent and practical risks associated with ethical universalism – applying 'universal' moral principles that have been constructed...in one cultural context and exporting them, without modifications, to another, (Riessman 2005, p. 473).

In this instance 'culture' may refer to different people groups according to nationality or indeed different social subgroups within the same nationality, for example linked to age or religious belief, in my study the subgroup is adolescence. Any narrative researcher will recognise with trepidation that medical ethics boards do not

necessarily understand fully the need for flexibility in this arena, instead such panels adhere strictly to the 'rules' of ethical practise and as such make ethical approval very difficult. It is often difficult to emphasise to those who have not explored the implications of narrative inquiry that some amount of reflexivity is required and that an inherent aspect of such research is its requirement to develop or 'evolve' as the study progresses as opposed to following a predetermined structure. However, a prerequisite of beginning research in medical institutions is the fulfilment of ethical approval without which the study may not legally commence, this may mean narrative investigators having to achieve initial approval and then returning to the board with amendments to the study and further ethical approval as the study's path takes different twists and turns. Riessman comments;

Committees have been guiding investigators with universal propositional ethics; many of us in the field need alternatives – an ethics-in-context, grounded in the exigencies of settings. This is not the same as ethical opportunism, but a situated ethics needs to provide room for particularities that unfold during fieldwork, (Riessman 2005, p. 487).

Ethical principles are not simply restricted to issues of confidentiality and informed consent, there are wider implications for example the longer term repercussions on participation, that which occurs after the Dictaphone is switched off; hands have been shaken and participants have been thanked for attendance. There is a balance to be achieved, between the overall benefits of the study and the rights of the individual, this is something which should be at the forefront of the researchers mind throughout the course of the study. Elliott divides this area of concern into (a) the ethical and (b) the political:

The 'ethical' is used to describe those issues that relate to the relationship between the researcher and the participant, and the impact of the research process on individuals directly involved in research, while the term 'political' is used to describe the broader implications of research in terms of the impact it may have on society or on specific subgroups in society, (Elliott 2005, p. 134).

This is a helpful way to look at the researcher's responsibilities as it neatly divides the process into two categories. The relationship with the participant is an intimate one, narrative research provides insights that other forms of research do not,

specifically because it involves the investigator entering the private domain of individual lives. Riessman makes this comment about narrative relationships being;

A relational practice that occurs in an evolving (and often intimate) conversation between teller and listener; the performative context can make demands on participants to 'say more'. Listeners, in turn, can be deeply affected by the narratives they hear, experiencing emotions that are sometimes difficult to bear, (Riessman 2005, p. 474).

5.10.1 Ethical Aspects of the Researcher's Experience

In her writing Riessman explores more fully the effects that listening to people's stories, especially those stories which are traumatic or abusive can impact on the researcher, (Riessman 2002b). This demonstrates the way in which ethics in narrative work is more diverse than simply attempting to protect the participant from harm, there are also major implications for the investigator. Riessman highlights the fact that ethics boards are more commonly concerned with protection of participants and less concerned with possible danger to researchers;

Review boards and professional associations have attended primarily to one side of the dialogue in developing guidelines for human subjects' protection. Protecting investigators from harm is rarely part of the conversation... Beyond physical danger, fieldwork can unsettle, even traumatise an investigator when she witnesses gross inequalities, or when informants communicate details of atrocities, (Riessman 2005, p. 476).

I found that despite the stories I heard not being traumatic in the sense that they did not describe violence or death, they did describe suffering that is familiar to me and as such affected me personally, in my thoughts and emotions.

As has been previously touched upon, narrative inquiry does provide an opportunity for the participant to retain more power in the social interaction as s/he dictates the route and speed the conversation takes and what information is revealed. Although this extended domain of participant influence is true it is not something which can be automatically assumed and the investigator must still remain vigilant as to their ethical and moral responsibilities. In face-to-face interviews of any type there is more taking place than simply the words that are spoken, for example; body language, physical appearance, facial expression and tone or intonation of voice are

all perceptible to the researcher. In interviews conducted in less neutral territory than a clinic or hospital, such as a participant's home this wealth of possible observations is further expanded.

There is inherent debate within the narrative field as to whether it can be a positive or negative experience for participants to take part in research, and in some situations it may be a mixture of both. On the one hand, the sharing of an emotional or emotive subject such as illness experience could produce or exacerbate feelings of upset, vulnerability, anger or anxiety, conversely this reiteration of experience may act as a method of healing or therapy. I ensured that there were contact details in the consent forms which participants kept, that should any distress or need for further support occur certain individuals could be made available to them.

5.10.2 Informed consent

Naturally, all participants signed a consent form which accompanied the Participant Information Leaflet they were given to keep (see Appendix A for example copies), however it must be acknowledged that consent is a complex issue in this area of study simply due to the fact that narrative research involves people's accounts of private, personal autobiographies. Elliott highlights the difference between participating in a narrative study and other types of data collection;

Unlike data such as reaction times or scores on memory tests that are routinely collected in psychological research, or information about occupation, hours worked, marital status, etc., that is elicited in sociological surveys, personal narratives deal with the meaning of one's own life experiences and thus touch on issues of personal identity, (Elliott 2005, p. 140).

With this in mind a certain reverence and respect is owed to the information obtained through narrative methods and as such the researcher must treat what is discovered from participants with delicate consideration. If the information is not treated sensitively it may be seen as emasculating the stability of identity that individuals strive to maintain. This is an issue which has remained at the forefront of my mind during the data collection and analysis stages, retaining as much of the personal tone and feeling expressed by individuals and remaining true to an accurate account of the stories told.

This ties in with the issue of confidentiality. Although confidentiality is integral across the board of research with human participants and particularly in the field of health and illness, due to the nature of narrative inquiry it becomes more difficult for anonymity to be upheld. For some participants this is not a crucial requisite, they do not mind their identity being revealed or their information being identifiable, in fact for some having their story heard is a positive, possibly even empowering experience. However for others and maybe in certain more intimate or sensitive areas of healthcare the participants certainly would object to not being able to keep their identity private. This can, to a certain extent, be overcome through the obtaining of informed consent; clear explanation of the research being provided and techniques such as the use of pseudonyms, changing the gender of the participant in the write-up, and so on, although again the investigator must remain mindful of the participant's rights. Riessman draws attention to the fact that not every eventuality can be provided for in the informed consent process, (Riessman, 2005). This is an issue that arose during my study and I returned to the mothers of the young people on a few occasions to ensure that they were happy with portions of text that I had written and to gain their consent more than once for the inclusion of data from their stories.

The investigator must remain vigilant to his/her moral duties and ensure that participants are treated respectfully and that all information is handled sensitively and with discretion. There is the issue of difficulty when asking people to volunteer in a task when they do not – or can not - understand the full implications of what it entails, as in the case of an incident involving a participant in a study by Sue Estroff, (Estroff 1981), who upon receiving the publication of the research recognised the portrayal of herself and was troubled by it. Estroff was affected deeply by the participant's reaction. In response to this situation Estroff explored issues related to the ethics involved in qualitative research and the responsibilities of researchers within this field, she writes of the conflict researchers encounter – between being a scholar and the need for 'accuracy, authenticity and disclosure', and the demands of professional ethics of 'dignity, autonomy, privacy, and well-being', (Estroff 1995). Participants have no real control over the way in which their information is going to be recorded in research findings, so having made themselves vulnerable during the

narrative recounting they are then powerless to influence how they will be presented, and thus perceived, by readers. The responsibility of the researcher to protect the best interests of participants is crucial in regard to his/her reputation as an investigator as well as the potential impact on those participants having the faith to volunteer in research again. The first task I undertook in presenting the participants' stories was to give pseudonyms to all involved and attempt as far as possible to omit all identifying data. I have sent large sections of text to some of those that took part to ensure that they have felt satisfied that I have presented them in a fair and accurate light and that they do not feel violated in any way, this enabled them the opportunity to object to or alter information provided in the final write-up.

Due to the characteristics of the population that I chose to study I did encounter ethical issues which needed to be addressed. Individuals under the age of eighteen are considered children rather than adults, and as such fall under the bracket of being a 'vulnerable group' within society, this means that there additional caution is exercised when Ethical Committees are presented with studies sampling from this population. Also the fact that narrative study is a research practise not commonly presented to the Ethics Board whom I had to seek approval from meant that there was a string of communication back and forth demanding very detailed explanation of every aspect of the study, which I had to provide in order that the board were 'convinced' that this mode of research is credible, viable and 'safe'. Finally, as highlighted earlier, the nature of narrative study demands that the research is free to 'evolve' as the data unfolds, this is not a conducive method of investigation for NHS medical committees who demand prescriptive, detailed accounts of the process and plan of the study prior to the start of the project and require that the original protocol must not be detracted from during the course of the project. Through the submission of multiple Substantial Amendments to the Sub-Committee for Research Ethics throughout the various stages of the project, and by including copious amounts of supporting documentation from University staff who are experienced in the various methodologies that I implemented, I achieved ethical approval for the various stages of development that the study went through.

5.11 Relationship Between Researcher and Participants

Narrative research is unique in its observance and acceptance of the need for a relationship between researcher and participant, the need for an intimacy and acknowledgement of emotional responses, a depth of trust is necessary in order that a true picture of experiences can be achieved, as previously quoted from Oakley reiterates this point;

The mythology of 'hygienic' research with its accompanying mystification of the researcher and researched as objective instruments of data production (must) be replaced by the recognition that personal involvement is more than a dangerous bias – it is the condition under which people come to know each other and to admit others into their lives, (Oakley 1981, p. 58).

5.11.1 Building a Relationship

Relationship is important not just for practical reasons, but also for ethical ones, it is vital that individuals feel at ease and safe in order that they speak openly about their life experiences. One of the benefits of my position was that I am a student with CFS myself, I am not intimidating in the respect that I am not a healthcare professional with a set agenda and therefore information given by participants could in some way be 'wrong'. My own personal experience of CFS helped build rapport amongst participants, especially the mothers, who intimated that they could trust me to be sensitive with their children and give due respect to all of the stories gathered, this trust generated reciprocity in the respect that my frankness and honesty was responded to by an openness from the participants. However, no matter how strong the rapport between myself and the individuals who participated was perceived to be it must still be acknowledged that I retained an element of power within the situation, I was the one instigating the original questions and the person responsible for writing up the stories in a respectful manner which reflected the true content of the narratives, the onus always remained on me to not exploit the vulnerability of the participants who opened their lives up for me to explore. For many, if not all, these interviews were the first opportunity they had been given to explore and articulate their own stories, without fear of prejudice or hidden agenda, I hope that this acted as a cathartic process allowing them freedom to explore their own thoughts and emotions about their experiences.

5.11.2 Difficulties Within the Research Relationship

The narrative research relationship is always a tenuous one, it has inherent complexities which must be acknowledged. For example, the issue of gender, the girls spoke easily with me and emotions were expressed openly, the two boys were not so easy to communicate with, one did not articulate himself fully relying on either his mother to speak for him or only giving very short detached statements - however without her presence I feel the interview would have achieved almost nothing - the other I felt awkward with, he was older and I got the distinct impression that he was in some way trying to impress me, this detracted from the openness of the exchange. Generally the age difference and my being an adult conversing with adolescents several years my junior did not seem to hinder the interview process.

5.12 Conclusion and What This Means

My agenda throughout this project has remained linked to that which I felt would make an important contribution to this field of knowledge, in order that gaps in the literature may be plugged and new insight learnt, this in turn may assist practitioners in their understanding of and interaction with young CFS sufferers and their families. The aim of the study 'to give young people a voice' has remained broad enough to enable a wide range of data to be gathered, but focused enough to allow examination in depth of the overall concept.

My choice of methodological approach has been due to three main focuses;

- (1) Narrative approaches are concerned with the *whole* story, not breaking them down into segments in order to analyse differentials, and I believe that the only way of transferring the participants' stories to the wider public was through capturing a holistic picture in its entirety. I agree with a viewpoint expressed in an earlier chapter;

Unlike traditional qualitative methods, this approach does not fragment the text into discrete content categories for coding purposes but, instead, identifies longer stretches of talk that take the form of narrative – a discourse organised around time and consequential events in a 'world' recreated by the narrator, (Riessman 1990, p. 1195).

It is this real 'world' which I have wanted to access.

- (2) One of my aims has been to capture a *subjective experience* from the individuals who volunteered, not just an overview of a vague collection of

issues but a true and tangible picture of the impacts of having CFS which have been influential on their lives, I believe a narrative approach best achieves this.

- (3) Narrative is also concerned with individuals' perspectives on their own life histories, matters which have affected them, either positively or negatively, issues which have been troublesome or rewarding linked to their own story which have evoked personal anxiety or growth – I have been interested in all of these matters because these are the things which can promote understanding and empathy, and further knowledge about this particular group of people.

Chapter 6

Findings and Discussion

6.1 Introduction

In this chapter I firstly include the pen portraits to illustrate the full range of participants' backgrounds, I then present the personal CFS journeys of the young people through distilled narrative summaries from the interview data of their experiences of the condition, followed by a summary of what can be learnt from the narrative. The rationale for the inclusion of a pen portrait and a distilled version of the story the teller told, is linked to section 5.2.6 in the previous chapter, which speaks of capturing the key elements of narratives as far as the *story* (*what* is being said), the *plot* (the sequence of events leading to causation) and the *narrative* itself (*how* the story is portrayed by the teller). Each participant has been allocated a pseudonym and identifying details have been removed for ethical reasons. For those young people whose primary care-givers also took part in the research, I have included the mother's story directly following their child's, in this way a clearer picture of family life can be gathered by the reader. I then present the findings from the thematic qualitative analysis. The key findings are discussed in the context of available literature. Another source of rich description I draw upon, in order to compare and contrast to my findings with existing literature, concerns poetry. I include some examples of poems compiled by the Tymes Trust (The Young ME Sufferers Trust) to illustrate the themes which emerged from the data.

During my reading around the topic of adolescent CFS, I have come across several sources of poetry, compiled by the Tymes Trust (The Young ME Sufferers Trust) into a book titled *Young Hearts*, (Tymes Trust 2004). Poetry as a form of story-telling allows tellers to convey complex, intimate and abstract concepts in an artistic format, which is simultaneously accessible to the reader. It is different to other forms of expression and more traditional methods of communication as it crosses sensitive boundaries and gives readers a window into the otherwise very private world of an individual's experience. Poetry permits the teller a sense of freedom by concurrently enabling them to be both emotionally vulnerable and yet hidden from view at the

same time. It can be cathartic in allowing individuals to express deep-seated emotions and states of mind, and is recognised as being a form of ‘therapy’ in this sense. As adolescence is a time of emotional experimentation and growth, poetry is apt in that it can act as a medium for communicating a newly discovered sense of self and emotional ability to communicate with the outside world. Poetry is particularly effective in conveying stories of suffering and isolation, as it crosses emotional boundaries, as stated above. I have included some examples of poems written by young adolescent CFS sufferers which coherently and concisely articulate some of the themes I have found reflected in my study.

Following a discussion of the main findings, I discuss the overarching theme to have emerged from the data and then put this in the context of what is relevant to healthcare and educational professionals. I then offer what I feel my contribution to the field has been through this research, discuss being a ‘part insider’, give my stance on the usefulness of the study and finally draw the whole chapter together by summarising what all of the findings and discussion actually mean.

6.2 ‘Amy’

6.2.1 Pen Portrait

Amy is a 16 year old white British female who has had CFS for approximately 10 months. She lives at home with both parents and one brother. Amy’s Mum attended interview with her and the closeness of their relationship was very obvious. Her mother works part time in an administrative role and her dad runs his own business. Amy was given a CFS diagnosis a year ago by a GP and a specialist. She also suffers from asthma, she takes no medication and there are no other health conditions in the family.

Amy continues her Year 12 attendance at school although allowances, such as a shortened school day and revisions to the timetable, have had to be made to accommodate her condition. She believes that she catches illnesses more easily than others her age and takes longer to recover from them, although her mother disagrees on both of these points. The CFS was triggered by Glandular Fever and severe mouth ulcers. She describes being physically active as resulting in making her more tired

than usual and has had to forego attendance at out of school activities (including dance), due to fatigue. Amy believes her fatigue started rapidly over 24 hours, although her mum recalls this as being more gradual – over two to six months. Amy lists her worst three symptoms at the beginning as being mouth ulcers, extreme fatigue and lack of energy - her mum agrees with the first two but adds sore throats as the third. Her worst symptoms now are mouth ulcers, that she tires easily and her lack of energy according to Amy, her mum lists mouth ulcers, fatigue and mood swings. Both agree that Amy's symptoms change over time. If she rests, Amy says some of her fatigue goes away and the time needed for that to happen varies, she describes her condition over time as having “good and bad periods”, her mum believes Amy's fatigue is improving over time. Amy believes she falls into the bracket of ‘Moderately Affected’ according to the AYME Functional Ability Scale (see Appendix E) and rates herself as 70% on that scale.

6.2.2 Amy's Story: Adolescence CFS is...*Being Forced to Relinquish All I Once Held Dear*

Amy arrived at the Hospital accompanied by her mum who remained with her during the interview. The two of them appeared very relaxed in each other's company, they both spoke openly about their thoughts and feelings in a way which would suggest they spend a lot of time together and have an open and honest relationship.

Amy first became ill in the summer of 2006, the CFS was originally triggered by Glandular Fever and in the beginning she was very poorly indeed. We spoke a little about the symptoms which Amy has found most difficult and she told me how she had struggled with very large mouth ulcers. Her mum, ‘Charlotte’, (this is a pseudonym for anonymity purposes), described the situation to me;

*The initial glandular fever she had was so bad she couldn't swallow, she couldn't even swallow her saliva. She was lying in bed, unable to move because she was just so poorly and it took the doctor a while to even test for glandular fever. She couldn't swallow; she relied on things like Complan, milkshakes and chocolate mousse just to try and get her to swallow something, and then she started to get sores on her face where her saliva was just dribbling out, where she couldn't swallow it...She looked so ill; big black bags under her eyes, she looked really so ill – and even the doctor was saying “You don't look well”, but there was nothing ...*pause*.. You keep going in, hoping that maybe there's an antibiotic that will clear it up and then feel*

deflated 'cos you come away with nothing – exactly the same way as when she went into the GP. (CHARLOTTE).

It took eight months before Amy was given a conclusive diagnosis of CFS, during which time her school attendance became increasingly sporadic. Amy and her mum told me how they felt frustrated by the ongoing cycle of visits to the GP who kept telling them ‘to be patient and she would improve’, but in fact her health deteriorated rather than improving. Eventually a teacher at the school suggested that Amy may have CFS at which point they returned to the GP to pose the question whether this was the reason that she wasn’t improving. The GP made a referral to the CFS clinic and Amy recalls feelings of relief that she had at last found someone who recognised and understood how she was feeling. Amy was obviously visibly very poorly at the beginning and this must have been a traumatic time for both her and her parents. However, the worst thing they found was the fact that they had no diagnosis of what was actually wrong with her, it was the frustration of feeling totally clueless about the problem and therefore incapable of finding a solution. Once they were given a diagnosis of CFS the whole family felt relieved that they now had something to work with – a name they could research and try to adapt to and find help for. Charlotte speaks about the situation at that point in time;

*...actually someone saying “yes, this is an illness, there is something physically wrong with you”, rather than thinking...not that she was going mad, but because she couldn’t understand why she was feeling like that, to have somebody give you a diagnosis *pause*...then we could deal with it, because up until then we didn’t know what we were dealing with. (CHARLOTTE).*

Her mum explained that still now Amy often needs to sleep late in the mornings;

Going into school at 10 o’ clock rather than going first thing helps ‘cos it takes her a while to get herself motivated in the morning – I don’t mean just motivated but to get the adrenalin going. Like today, we were going into town to do some shopping but this morning she just didn’t have the energy, so we came straight here. She didn’t get out of bed ‘til 10,15. but I know now that when I go into her in the morning and say it’s time to get up, the response I get if she’s having a good day or a bad day. Initially I would try to force her – “You’ve got to get up now” and try to force it, but now I know that if she needs to sleep, if we give her that extra half an hour or hour, and let her come to gradually herself it’s far better. She then has a better day, than trying to force her up when she’s not ready for it. (CHARLOTTE).

Although Amy experienced some issues with insomnia in the early stages she now feels that her sleep pattern is regulating and this has made daily life much easier.

Up until the point that Amy became ill with Glandular Fever, she had generally always been well aside from normal colds and coughs, and mild asthma. She found it a huge shock to suddenly feel unable to participate in any of her normal activities. Amy had always worked hard academically, achieving consistently high grades, as well as attending many extra-curricular activities several times a week. Her mum describes Amy at that time;

She was an 'A' grade student and when she was poorly she would really sort of force herself into school knowing that it was going to make her feel even worse but school was everything to Amy, because she was very intelligent and very bright and knew exactly what she wanted to do. At the first interview we had at the (CFS) Clinic the OT actually said: "What's more important – your health or school?" and Amy answered "School". So we had to kinda change that slightly because it was her GCSE year so it was exceedingly important. She had exams, it was important to Amy that she was at school and all her coursework was completed and that was just adding more pressure, and that's when we sort of hit a stone wall. She was trying so hard to do all these things and it was making her worse. We had to say, "Well you can't do all this, something has to give, you've got to ease back". For Amy that was one of the hardest decisions I think she has ever tried to make. (CHARLOTTE).

Amy's Mum said that if anyone had asked her what CFS was prior to Amy getting ill and them learning about it she would have said it was just for hypochondriacs. They knew nothing about it and never expected to have to face something so utterly life-changing. Amy said she felt scared when she was first diagnosed with CFS because she had formerly been so physically active, socially able and academically successful. Despite meaning to cut back her school work significantly she still managed to achieve nine GCSEs, although she had to stop Dance and two others as the workload was too heavy. Amy's parents are incredibly proud of how well she has done despite the barriers she has had to face and overcome. Amy's school was supportive throughout her GCSE years, allowing her a flexible timetable and to spread the work according to fluctuations in her energy levels. The teachers offered her time to speak with them when she needed to and she was allowed the freedom to pace herself because they knew she was genuinely ill and that she desperately wanted to still achieve high grades. Having achieved good GCSE marks Amy is now

studying for A' Levels, she started doing four but found she was unable to cope with the stress and workload, so she has cut down to two subjects. When asked about her school friends' reactions to her illness Amy told me;

At first I would suddenly have to say "No, I can't go out", and so they didn't really invite me to do anything, but now they can see that I'm going into school more and so they invite me to do stuff more. When they sort of understood it they would invite me to do stuff even if they knew I would like say "no". Then sometimes they would come round my house and then go out, or just sit and watch a film and get a takeaway or something. (AMY).

The understanding of her friends has obviously been of major importance to Amy. The acceptance of her being ill and efforts to accommodate the restrictions she has to live by has been of great significance to her feeling of still being a recognised member of the social group. Amy has a boyfriend who is a couple of years older than her - he has only known her since she has been ill. Amy says she gets insecure within the relationship, as she is unable to do all of the things she would like to and that her boyfriend sometimes gets annoyed at that. When asked why she feels insecure she replied;

..'cos he goes out at weekends and stuff. I don't know really why I am insecure, I never used to be. When I speak to the psychologist that I go and see, she says because now with ME I'm just like on a one track thing, so if something bad happens it feels catastrophic rather than thinking "Oh well, it's only little, just don't worry about it", but I'll just be worrying about it all the time. (AMY).

Amy understands this explanation for why she reacts to situations the way she does and tries to distract herself by listening to music or watching television, rather than allowing herself to dwell on negative feelings.

Amy has two siblings, an older married sister who doesn't live locally, and a younger brother. Amy's mum explains that there has been some tension in the relationship between Amy and her brother, as he is active and sporty and able to go out a lot. Amy readily admits to feeling jealous that her brother is free to live his life the way he wants to but her health restricts her from doing the same. Her mum explains;

She is jealous, because he can continue with all his activities and she can't and that has caused a little bit of friction. Every now and again, nothing major but yeah, it's sometimes very difficult, and she'll take her frustration out on her brother...until she sees the error of her ways and then they'll apologise and get on and live. (CHARLOTTE).

The jealousy is felt in reverse too as her brother sometimes feels difficult about the amount of attention Amy receives, Amy explains that initially her brother struggled to understand her being ill and that he thought she was making it up but now understands more.

Amy and her mum both feel their relationship has become a lot closer, but Charlotte has struggled with her own feelings of being unable to change Amy's situation;

From a mum's point of view it's been very very difficult, watching her go through it; knowing there is absolutely nothing I can do. Ummm, and then when I've done as much as I can, or done my best or whatever, and then she screams at me or whatever. I keep thinking "Oh, what if I'd...", but I can't physically do any more. (CHARLOTTE).

Amy recognises that she often takes her frustration out on her mum simply because their relationship is so close. As they sat together and talked me through their situation it was very obvious how deep their feelings of love and respect are for each other. Amy's mum cried at one point as she attempted to convey her feelings of frustration about being powerless to treat the CFS, or protect her daughter from the negative impact it has had on her life. She also spoke openly about how proud she is of Amy, both her academic achievements and the way she has learnt to adapt her lifestyle and expectations in accordance with the limitations she now faces.

Amy believes she has learnt a great deal about herself having had to cope with CFS;

I don't regret getting ill. In a way I'm sort of glad 'cos I've learned so much about myself, and now I'm closer to mum. In a way; 'cos I know I will get better so I know I can take it as, like, an experience and be ok about it. (AMY).

As with other participants in this research Amy has a mature outlook on her life and present health situation. She has learnt to accommodate the restrictions that poor

health has imposed upon her and rather than getting angry about it, she has adopted a matter-of-fact attitude towards it as simply an experience she has to accept and deal with.

Her mum has adopted similarly pragmatic approach to their current situation. She said;

It affects the whole family, the whole household, but we are normally all quite positive people so rather than let it pull us right down...we have managed (I don't know how!) to sort of say; "Yeah, it's not something I'd recommend that people go out and try but it's happening, so like deal with it and deal with it the best way we can". Sometimes we don't get it right and sometime she will have bad days; feel weak when she is really bad, but we just sort of do all this each day as it comes along as best we can. (CHARLOTTE).

The effect on the whole family seems to have been quite extensive, possibly because Amy was such an independent high-achiever. Suddenly the family dynamics changed and they have all had to learn to accommodate the differences in lifestyle, but they appear to have a realistic attitude towards the situation and have learnt to live within the new set-up well. There has, on occasions, been a divide caused within the family due to Amy's health, whereby her dad and brother spend time doing things that are too active for Amy, and she and she has spent that time with her mum. As Amy's health has started to improve they have found that they can return to doing activities as a family. Her mum explained;

*Because Amy is actually getting better now, we can go back to doing things all together, and there is one thing this has taught us: that family life is precious and when we do have time to do things together, like the four of us, then we will sort of try and make time to go bowling or something. The four of us together doing something that we can all do, rather than her dad and brother going off and Amy and I going off, so ***pause*** it's not all bad. (CHARLOTTE).*

Amy having CFS has altered the family dynamic, it has changed the way in which they have been used to running family life and impacted upon all of the relationships. Inevitably the relationship between her dad and brother has become stronger and Amy and her mum have grown closer. Amy comments, (as other participants in the

study have), that she has found her mum can often understand her condition and health limitations better than she can herself;

*As time has gone on I can understand what things I can and can't do, and can sort of predict when I'm going to feel bad. So mum sort of says; "well, I don't think you should do that", 'cos she knows what's gonna happen, but because I want to do it, I'm like, getting in a bit of an argument, but then afterwards I realise "oh, I should've listened to mum!". *laughs*. (AMY).*

This seems to be common amongst the participants, that as child and mum have spent more time together due to ill-health the adolescents have inevitably become more reliant on their mums – possibly more so than they would have done had they not become ill – and whereas the children know they have limitations due to their energy levels they still push themselves beyond those limits at times. This could be due to frustration at not feeling able to do everything they once could, or could simply be an act of adolescent defiance not to miss out on activities they wish to do. The trend that mothers (who are, within this sample, the primary care-givers) are more able to monitor their teen's health and behaviour and identify times when they need to rest or slow down could be an insight learned due to the situation of having an unwell child, or could simply be part of being a mum. Whatever the reasoning behind it, it must present some difficulties in the parent-teen dyad as the very nature of adolescence is to begin listening less to parents in an attempt to become more independent and self-sufficient.

Amy has found that meeting with a psychologist from the Specialist CFS Service has been beneficial in helping her understand CFS, how it affects her and the consequential feelings she experiences. Her mum agrees that Amy having access to a trained professional has been of benefit as Amy is more likely to listen to someone outside of the family set-up with no 'personal agenda' in advice that is given;

*I think because you know what the illness is and you know what to do in the everyday and how to cope with it, but the actual feelings and what's going on in her head *pause* although we're really close, it's like sometimes I don't know if what I am saying to Amy is right or wrong, or making things better, and seeing Sue, having someone she can actually talk to about her feelings ummm, has been really good...That has been the turning point, when she started seeing Sue and she could understand why she was feeling like that, because I don't understand why she was feeling like it and especially when*

she seemed to take all her frustrations out on me. I've got really wide shoulders and I'll take it and then go off and cry, but wouldn't let Amy see that. She knows now that sometimes I get as frustrated as she does because I can't do anything to help, you know, I just don't know how to do it, but speaking to Sue and knowing what she's going through and what she's feeling is perfectly normal. (CHARLOTTE).

For Amy the psychologist has provided a sense of legitimising that the way she thinks and feels – her frustrations and worries – are all part of having CFS as an adolescent. Adolescence is a period of new-found angst and introspection anyway which is further compounded by the frustrations and limitations imposed by a chronic debilitating and misunderstood illness.

Amy continues to explain the way that being ill has altered her thought processes;

...it was like, quite a black and white thing – so if something is good then it's good, but if something is bad then it's really, really bad and I just think the whole world's gonna end. (AMY).

It is unsurprising that when an individual's entire framework for living has been radically changed in ways they cannot control that their outlook becomes more pessimistic. Amy's mum relays the process to this point;

*Before, everything she loved and held dear, like her school-work, her dancing, her social life, ('cos she was very very popular), was all being chipped away at...so everything she loved had gone and it had just left ..*pause*..well, it had left nothing. She had no social life as such, she had no outlet because she couldn't dance. The main subjects she wanted to do at school being dance GCSE, she couldn't do. Everything was just being chipped away and she didn't seem to be getting anything back and all she said was: "I had to give up so much", and that was really, really difficult – very difficult. In fact it was quite devastating for Amy. (CHARLOTTE).*

In particular, the physical effects of having CFS affected Amy dramatically, reducing her capabilities and impacting her lifestyle significantly. This change has obviously caused distress to Amy and vicariously also to her mum, who empathises with Amy's disappointments and upsets. All loving parents want what is best for their children; in a relationship where child and parent are obviously close, such as that of Amy and her mum, the feelings of frustration and despair are exacerbated. During the course of the interview, Amy and her mum were both very candid about their

relationship, feelings and experiences, there was a sense of real affinity between the two of them, which was almost tangible. Their frankness and honesty about their lives was reflected in their emotional vulnerability – they were tactile, not afraid to laugh at themselves and each other, and at one point her mum cried as she explained how difficult it has been for her watching Amy suffer over the months, and how much her respect for her daughter has grown. At one point Charlotte told me;

We speak about our emotions together, exactly how we are feeling...
(CHARLOTTE).

With a sense of sadness she relayed the changes she has witnessed in her daughter over the time she has been ill;

*I just want Amy back, I want the old Amy back *long sigh*. It's coming gradually, but it's not the old Amy, it's a new Amy.* (CHARLOTTE).

I felt the emotion in Amy's mum's voice as she made this statement, it was with a real sense of longing and sadness at the amount Amy has had to sacrifice – the experience of having CFS has enforced a premature maturity, and it is obvious that Amy has had to forsake many of the things she once enjoyed. Her life has changed dramatically: academically, socially, emotionally, her aspirations have had to alter and her expectations have been reigned in. Having said that, as Amy and her mum spoke they each demonstrated true tenacity of character. Amy relayed the way she now tries to look at her life;

a It's not all gone. I can pick it up again in the future and I think it will be like new Amy – I will have more knowledge about things and it will help me in the future. (AMY).

This is a mature attitude to take and one which is obviously serving Amy well. As a family they seem to have adjusted their thought-patterns in an attempt to look at Amy's life in a pragmatic way. Her mum tells of the way in which they have had to adjust their expectations and values;

It's become about enjoying the things that she could do, although it was very little. If it was sitting curled up on the sofa drinking hot chocolate watching a

really weak movie – that was good; she got some enjoyment, it was about taking pleasure in little things. (CHARLOTTE).

When speaking about school-work and the A' Level courses she is currently taking, Amy explained that she originally opted for maths, further maths, chemistry and psychology, but she had to pull out of the maths and science subjects as the workload was too heavy. Although she has always wanted to be a Forensic Scientist she now knows that it may take longer to achieve that goal than it would have done had she been well. She has also had to re-prioritise her academic choices to accommodate her depleted energy levels - this at times has meant making difficult decisions which have left her "feeling like a failure". She explained that she felt she was failing because she knew she had the intellectual capacity to achieve high grades and continue the full remit of subjects she had started but physically she just wasn't well enough. It has been with the support and advice, not only from the school, but also from an Occupational Therapist at the Specialist CFS Service, and the unrelenting backing of her family that Amy has come to terms with academic disappointments and learnt to accept the position that ill-health has left her in. She explained that with the help of her support network, she has been able to make plans and contingency plans, should her original aspirations be unattainable.

Amy and her mum told me how speaking with a psychologist and learning to be adaptive and fluid within the restrictions that CFS imposes has helped her overcome depression, whereas at one time, prior to the psychologist sessions Amy felt 'down' a large proportion of the time, but is now feeling more positive. Her mum said;

*It is actually a very emotional illness. Some days it would be absolutely hell, she would have no physical energy; she wouldn't be able to get out of bed. We'd just sit there and hug and ..*pause*..we'd both be in tears because it was just so frustrating, 'cos we just didn't understand what was going on. There didn't seem to be, like a penicillin out there that was going to make her feel better. It was emotionally draining some days. (CHARLOTTE).*

The fact that Amy and her mum have been forced to overcome difficult, upsetting, frustrating experiences perhaps indicates how they have become so close and yet that closeness doesn't appear to be stifling or unhealthy for either of them, but more of a mutual respect and admiration for each other.

Amy has not taken any prescribed medication whilst being ill, she tried a couple of different homeopathic remedies that people advised her may help her symptoms, but didn't find anything made a dramatic difference to how she felt. She has a healthy, varied diet including fresh fruit and vegetables, fish and pasta, and felt no need to experiment with diets that excluded certain food groups as some CFS sufferers do. This is despite the fact that there is little evidence to suggest that exclusionary diets work in reducing symptoms in CFS, rather, the general medical advice is to eat a varied, healthy diet - high in fresh produce and low in fats and refined foods.

6.2.3 Amy's Story - In Summary

One of the main things that can be learnt from Amy's story is how important a solid support network of friends and family is for a young person with CFS - that understanding, compassion and patience are all major players in aiding management and recovery of the condition. The support of an individual's school (or other academic services) is also of significance as it makes the child's life less stressful in knowing that they have sympathetic teachers and also the reassurance that timetables are adaptable and subjects can be caught up on at a later date.

The physical symptoms of CFS can be many and vary significantly between patients, there are some that are common among virtually all individuals, but others can be very individualised, this is oftentimes linked to the trigger illness that led to the CFS starting in the first place. It is possible to see from Amy's recollections how draining and demoralising multiple trips to the GP before a diagnosis is found, can be to the patient and their family. However, it is also significant just how much of a relief it is when a diagnosis is decided upon, even if that diagnosis is a new illness they have no knowledge or understanding of. It is the act of diagnosis which alleviates the feelings of 'being in limbo' without anyone knowing the root cause of symptoms, and initiates a new 'chapter' in the healing process where research can be done and management of the condition be decided upon. The holistic approach to medical management of adolescent CFS appears to work well according to Amy's experience, the combination of a GP, Occupational Therapists and a Psychologist working as a team to address Amy's needs as a young person, is a successful one.

Amy and her mum clearly explain the way in which CFS affects the whole family, not just the individual with the condition. It causes pressure on family relationships, sibling jealousy, distress for parents helpless to alleviate their child's suffering, disruption to primary care-giver's working life, and the inability to conduct family outings, holidays and so on as before. A positive impact Amy's CFS has had, is the close bond that has formed between herself and her mum. They have clearly benefitted from what has been a negative situation and gained a major positive in the form of a close mother-daughter tie, which would possibly not have been so at this point in their lives, had they not been flung together in such a dramatic way.

From a social perspective, Amy's narrative identifies the major impacts that CFS has on friendships and peer group associations. The feelings of being 'left behind' while her friends 'move on' with their lives has not been an easy one for Amy - she has felt that her life has remained stagnant as theirs have flourished with new experiences and freedom linked to being a teenager, which she has been denied. She and her mum recognise the way in which she has lost a great proportion of what is considered normality for this important, socially active part of her life, she feels she has had to forego all of the activities that she once cherished and enjoyed. However, Amy has developed socially too - she has become mature beyond her years and has learnt to face the negative parts of her health with a pragmatism that she possibly would not have learned had she not become ill.

6.3 Narrative of Amy's Mum 'Charlotte'

Charlotte works part-time in an administrative role, her husband works full-time. As well as Amy at home, they also have a son, Daniel, who is slightly younger than Amy.

Charlotte told me that prior to Amy becoming ill she knew very little about CFS, she said that she considered it a condition for hypochondriacs and a way of people attracting attention to themselves. After several weeks of Amy being ill, a teacher at her school suggested that CFS could be the cause, at which point Charlotte began researching the condition on the internet and felt recognition at the illness she was reading about. Upon finally receiving a firm diagnosis of CFS Charlotte describes

feeling relieved that Amy had a recognised condition and that they, as a family, could now start managing it. Prior to that point they had felt lost, as they were dealing with the unknown. Charlotte relays;

It was a bit of a relief to know that what she was suffering was a recognised condition and that help was available, not knowing what she was suffering from was really difficult, as all sorts run through your mind. At one stage I even thought that she was suffering from a terminal illness, knowing that it was CFS (although difficult) made it easier to deal with. (CHARLOTTE).

Prior to understanding the true cause and nature of Amy's condition, Charlotte obviously felt very concerned, worrying that her daughter could have almost anything – the unknown was terrifying and her mind ran wild with possibilities.

In the very early stages, before, and just after diagnosis the feeling of utter despair at being unable to help and having to watch my daughter suffer was extremely difficult. I felt totally lacking in control and totally unsupported by our GP, many was the time that I would break down when I was on my own (not wanting my daughter to see how worried I was, and trying to put a brave face on things by pretending that I was coping relatively well, when in fact this was far from the truth, (CHARLOTTE).

Not only did Charlotte feel powerless to change her daughter's situation or relieve her suffering, but she also felt unable to show her anxiety as she wanted to protect Amy from further worry. Amy's family doctor has been unsupportive throughout her illness, Charlotte describes the situation;

My daughter is still experiencing physical symptoms, recurrent sore throats, mouth ulcers etc and our GP has basically told her to "live with it", this is sometimes quite distressing for her as the symptoms are often debilitating and she requires time off college. It amazes me that there are no "remedies" for this, (CHARLOTTE).

Possibly one of the most disappointing and unusual aspects of CFS compared to other chronic conditions is the lack of 'cure' or even effective treatments for the symptoms. For most conditions there is some universally recognised medication that

will alleviate symptoms, if not remedy the condition altogether, but this is not so for CFS and is all the more upsetting for CFS sufferers and their families.

Despite the negative experience that Amy has had with her family doctor, both she and Charlotte have felt great benefit from attending management sessions at the CFS Service. They believe that applying suggestions from the Occupational Therapist into Amy's lifestyle has triggered a clear turning point in her recovery. They have also felt that the sessions with a psychologist at the Clinic have really helped Amy, and subsequently the rest of the household.

Upon receiving a diagnosis, both Amy and Charlotte felt they had reached a turning point; knowledge became power within the situation and they could start being *pro*-active as opposed to *re*-active.

Charlotte believes that the whole family has been impacted by Amy having CFS – both corporately and as individuals. She explains;

Our whole family life has altered dramatically. On a family level, when my daughter was first diagnosed and in the initial stages of her illness everything we did revolved around her. We could no longer plan trips out as a family as more often than not she would be too poorly on the day, this would sometimes cause friction as my son would be looking forward to the trip and would be annoyed that it had been called off. Sometimes it would mean that my husband and son would go off and do things together and I would remain home with my daughter. My daughter sometimes felt angry, jealous, and frustrated because she could not join in, (CHARLOTTE).

It is easy to see how Daniel would have felt irritated by the situation, as a boy in his middle-teen years it would be difficult for him to understand and empathise with his sister's situation, and his parent's need to construct family life around her needs. In many ways CFS was dictating the way they functioned as a family.

Charlotte goes on to describe the way in which the situation impacted her

relationship with her son, she felt that she was missing out on quality time with Daniel as he spent those periods with his father;

At the time my relationship with my son was pretty scant, mainly in the fact that the majority of my time and energy was spent looking after my daughter, and his needs were met mainly by his father, this meant that I missed out on attending a lot of his sporting activities and felt that I was "missing out" on seeing the relationship that he had with his father, (CHARLOTTE).

Charlotte felt she had no choice but to pour herself into her relationship with Amy as her daughter's needs – both emotional and practical – were great. However, by doing this she felt the mother-son relationship was being denied the attention it deserved. Charlotte also relayed problems of jealousy between Amy and Daniel, her son feeling 'all the attention' his sister was receiving to be unfair, and Amy being envious of the activities and freedom she was being denied due to her health that her brother was able to continue. Charlotte continues, explaining that family life improved as they began to understand and manage Amy's condition more effectively, she also comments that as Daniel matured and became more aware of the nature of CFS he better understood his sister's needs and felt more sympathy towards her. As a family they made a conscious effort to sit down and discuss the situation and their feelings about it. It was then revealed that as much as Charlotte felt she was being denied the relationship she desired with Daniel, her husband mirrored those feelings about his relationship with Amy. They agreed that Charlotte would spend more time with Daniel, and her husband be more involved in meeting Amy's needs and the situation began to resolve itself. It is fortunate that, as a family, they communicate well with each other and are prepared to make the effort to speak about their feelings, as with doing so they have achieved more harmony within the household.

Charlotte's social life was 'put on halt' for some time as the care of her daughter was her number one priority. Her working life remained largely unaffected, as she only works part-time – she also felt that at times work acted as an 'escape route' away from the stresses at home.

Amy's education has been severely disrupted by her having CFS and this has caused her mother anxiety also, Charlotte explained;

as Educationally my daughter suffered a great deal, being a straight A student about to take 14 GCSE's was extremely difficult, rows and tantrums ensued she was forced into dropping some of her subjects which she was not at all happy about, (CHARLOTTE).*

Amy's frustration and disappointment at having her school prospects derailed are understandable especially being such a diligent student, and this must have impacted family life as she vocalised her feelings. Charlotte would have had to deal with, not only Amy's emotional upset at that time, but also her own vicarious feelings of disappointment at what was happening in Amy's life. Charlotte relayed that the school were, by and large, supportive, although Amy did encounter one teacher who said she did not want 'quitters' in her dance class, which was very hurtful for Amy as this was one of the classes she excelled at prior to becoming ill and felt distressed at having to give it up. Charlotte is proud of her daughter's achievements despite Amy herself feeling 'quite angry' that she has only managed 10 GCSEs and therefore not reached her full potential. It was evident from the interview with Amy that she is a hard-working and conscientious pupil and that, despite achieving a high number of very respectable grades in her exams, she has still felt robbed of what could have been.

Generally, apart from the negative comments made by one of Amy's teachers and feeling unsupported by their GP, Charlotte has found other people to be accepting and understanding of the condition once it has been explained to them. Friends and family have been sympathetic to the effects CFS can have on plans and have understood when visits have had to be cancelled at the last minute.

Charlotte believes that the mother-daughter dyad has altered, but in a positive way;

Initially I suppose I was "just mum" to a teenage daughter with the usual ups and downs that this relationship can have at the best of times, however the most important factor to come out of this is the incredible relationship I now have with my daughter. It has brought a closeness to us that is very difficult to describe, we shared a lot of extremely low times, cried together, argued and eventually laughed and to have come through this with the bond we have today makes me extremely proud. An example of this would be when on an extremely tough day during a session with the Child Psychologist my daughter admitted that she was only coping with her illness due to the

relationship we shared, but had up until that time not mentioned this to me, (CHARLOTTE).

The bond that Charlotte describes was evident when she and Amy came for interview together, they are emotionally vulnerable and open with each other and it is this honesty that has brought them closer together. Their willingness to be up-front about their feelings, disappointments, anxieties, and so on, has forged an alliance between them – it is possible to see the journey they have both been on and the positive end result they have achieved.

Charlotte believes her role as a mother has been impacted in a positive way by coping with Amy's CFS, as tough as it has been at times;

I am now a bit more relaxed in my attitude to life, initially I felt total despair because I was unable to help my child, I did not know what to do to help her get better, along with having to watch her suffer and being at a total loss as to how to help her. At the beginning I suppose I was extremely protective towards her and the pressure to keep "everything together" (work, family etc) was tremendous and very stressful. However having gone through this together has highlighted the fact that "stress" can be exceedingly damaging and we now as a family (myself in particular) try to avoid it, (CHARLOTTE).

To a mum, whether your child is six or 16, there is an overwhelming need to protect them from harm and suffering, to alleviate their pains and concerns, and a willingness to sacrifice yourself in the process, if this is what is required. Charlotte has experienced those feelings, despite her daughter being in her late teens, and through that experience learnt important things about her own life and character. Her honesty in admitting that there was a desire to 'try and hold everything together' in order to be a success, is mirrored in Amy's character and the pressure she puts on herself to achieve the highest possible standard in whatever she turns her hand to. Charlotte has learnt that stress can be destructive and has adapted her attitude to life to avoid such situations wherever possible.

In conclusion, it is possible to see how destructive CFS can be on family life, however, Charlotte and her family's deliberate efforts to remain candid about their

feelings, has brought a positive outcome to a negative situation. As a unit they have learnt to adapt to the new situation and remain mindful of retaining the closeness within their relationships.

6.4 'Lisa'

6.4.1 Pen Portrait

Lisa is in her late teens (over school age) and lives at home with both parents and one sister. Mum works within healthcare and dad works full-time. She has had CFS for four years. There are no other health problems in the family. Lisa's CFS started with an infectious disease and she recalls her fatigue as starting over a one month period at the beginning. She doesn't think that she catches illnesses any more easily than her peers or takes any longer to recover from them. Her three worst symptoms at the beginning were fatigue, dizziness and nausea (plus associated loss of appetite), her three worst symptoms now are: fatigue, muscle pain and poor memory, her symptoms change over time. Lisa's mum recalls her initial worst symptoms as being fatigue, dizziness and muscle pain and the three worst now as fatigue, muscle pain and cognitive problems. She needs to limit her activity to stop the fatigue worsening - if she rests some of it goes away, but if she stops resting the fatigue returns. She describes the length of time needed to rest after activity as "ages", and describes her fatigue over time as "having good and bad periods". Her mum took time to comment on the fact that although her daughter gets support from the ME Clinic she feels there is little or no support for the rest of the family. Lisa rates herself as between 25% and 30% on the AYMME Functional Ability Scale.

6.4.2 'Lisa's Story: Adolescent CFS is Experienced as...*Isolation*

Lisa has been ill for a little over four years - she says the trigger point was an unknown viral infection. She believes the worst times during those four years were when she was first diagnosed and currently, as she has recently relapsed and her health is worse than it has ever been. Lisa was eventually diagnosed by a Paediatrician and recalls that prior to this her GP was not helpful or supportive as he didn't believe that there was anything wrong with her. Lisa underwent a series of blood tests, an ECG and a 24 hour heart monitor (as she was suffering with palpitations), before being given a diagnosis of CFS. She remembers feeling relieved

when she was told that she had CFS (possibly because she was finally given an answer and was no longer discounted for pretending to be ill), but that she had no other advice offered to her or her family. She felt scared, as she did not understand what CFS was, had never heard of it prior to diagnosis and was unsure where she could go for more information or support before making contact with her local Specialist CFS Service. She has learnt through the advice offered there how best to pace herself and to avoid a 'boom and bust' cycle (i.e. on days she had more energy she was tending to do too much and then suffering more afterwards as a consequence).

Lisa shares her home with her two parents and younger sister, she believes that her being ill has impacted the whole family as they are no longer able to all go out together, neither can she be left alone at home for extended periods. She believes that the relationship with her mum has grown closer than it would've been as she is Lisa's carer and helps her with many things. Lisa's mum works part-time hours to fit in around her husband's working hours but her employer knows that if Lisa needs her at home she may need to leave work early. Lisa believes that her having CFS has had a detrimental effect on her relationship with her sister, they argue frequently and are jealous of each other, they do not spend a lot of time together as her sister is either at school or the stables. Lisa mentions that she and her sister are jealous of each other, which is a point raised by other participants in the study. When individuals have had their freedom restricted and their opportunities reduced due to ill-health and are no longer able to lead the lifestyle they were accustomed to pre-CFS it is unsurprising that they feel envious of siblings who continue to live their lives as normal. It is also understandable that siblings of individuals with CFS feel jealous if they feel that their brother/sister is receiving more attention from parents, or being excused from activities such as school or chores. This has been a cause of tension raised by a few families in this study and presents a fine line for parents to have to walk, in order to accommodate the needs of all their children and maintain some measure of family harmony.

Lisa uses the AYME site daily to keep in touch with friends she has made on there, through the message board, she has also used the site as a resource for obtaining information and her mum has rung the helpline a few times for advice. The

organisation AYME (Action for Youth with ME) has been widely spoken about within the study, with many participants expressing how helpful it has been to make contact with other people of similar age, experiencing the same illness. With a condition such as CFS, which is widely misunderstood, support agencies such as AYME provide a vital role in legitimising what young people with CFS experience. They have an outlet to communicate with others without the need to justify being ill or having to give lengthy explanations of symptoms, because other people have personal experiences of the same struggles. For some young people who access AYME, it is the only source of interaction they have with peers, having lost school friends and other social relationships. Many describe it as a 'lifeline' out of their isolation. Lisa says;

I have made lots of friends that have supported me. Also, it's somewhere I can have a rant. It's helpful to get people's advice and opinions on things,
(LISA)

Lisa's use of the word 'rant' indicates her feelings of frustration about her situation, and perhaps without the friends she has made through AYME she would feel even more misunderstood and cut off.

Near the end of Year 10 and into the beginning of Year 11 Lisa began to fall behind with her school-work, she was home-tutored in Year 11 for Maths, English, Science and Music, and finally left school having taken her GCSEs twice. She describes herself during that time as having felt 'down' and wanting to be in school, she didn't like falling behind with her work and missed her friends. This characteristic of enjoying school and wishing they were able to attend is one described by many participants within the sample, who feel frustrated and disappointed that they cannot continue their academic life as normal. The school showed understanding towards her and had some prior experience of pupils with CFS. Lisa lost touch with the majority of her school-mates and has only one with whom she has stayed in contact - she has only one friend that she still sees and even that contact is limited as her friend has now moved away to university, she lives a very isolated existence. She has friends that she 'chats' to from AYME, either by email, on the website, or via text messaging, she only feels well enough to speak on the telephone very occasionally. It

is difficult for a healthy person to comprehend feeling so poorly that even speaking on the telephone is an overwhelming prospect, and this indicates just how restricted Lisa's life is. When asked to describe how CFS affects the way she interacts socially she said;

I worry about how I'm going to be when I see someone, and it also stops me from meeting some of my AYME friends as I'm not well enough, (LISA).

Lisa's apprehension about meeting with other people is sad, she feels anxious as to how others will perceive her if she does not look or act the way they expect her to. This anxiety prevents her from meeting up with her friends and adds to the seclusion. The physical, mental and emotional reserves necessary for meeting someone when you feel devoid of energy are not something you consider if you are well, as it is a natural part of everyday life. However, having to get washed and dressed, then leave the house and travel to a destination with all the different sensory bombardments of being in a public place are hard enough, without then finding the capacity to make conversation in a socially acceptable way. Finding interesting things to talk about despite living a very limited experience, are all a major strain to an individual with CFS, especially those more severely affected such as Lisa. When Lisa does leave the house she may go on a short drive with her parents to somewhere local, she doesn't go out with friends socially and isn't well enough to go out alone. Her social life and social opportunities are very limited. All of the 'normal' experiences of interactions which are part of being an adolescent are out of reach for Lisa. She is reliant on her parents in the same way a much younger child would be, which must be frustrating and disappointing for somebody in her late teens. When she does go out she relies on the use of a blue disabled badge in her parent's car, but is only able to travel short distances as travelling in a car makes her feel ill. Lisa has in the past used a wheelchair to allow her more freedom outside the home but is not currently well enough to even do that. Even with access to a wheelchair she feels too ill to leave the house, this is an insight into the debilitating nature of CFS. She says she was scared and embarrassed about using the wheelchair initially but had to get used to both that and the blue disabled badge, if she was to have any freedom at all. Lisa had to overcome fear and embarrassment about how she may be perceived by others for using a wheelchair. Despite Lisa's feelings of apprehension she soon realised that

without a wheelchair her life would be extremely restricted and she would be confined to home permanently – she felt no choice but to accept the changes her health imposed upon her.

6.4.3 Lisa’s Story – In Summary

Lisa’s story demonstrates just how isolating and lonely CFS in adolescence can be, especially for those individuals more severely affected. There is a real sense when reading her words that Lisa doesn’t so much ‘live’, as simply ‘exist’ at the moment, she has put her life on pause. She has no freedom without the company of her parents. She is unable to leave the house alone or with friends and has no social life to speak of other than that played out online with her AYME contacts. I felt a real sense of regret for Lisa, sadness that she is not experiencing all of the things that other people her age do. For the vast majority of eighteen year olds life is just beginning with either university or the workplace beckoning. At this age most young people are enjoying an active social life with their peers, meeting new people and enjoying new freedom apart from their family, but a young person with CFS such as Lisa does not have the opportunity of that spontaneity or liberty. The need for a blue disabled badge and a wheelchair reflect how debilitating CFS can be, without such aids Lisa would be virtually house-bound and has had to accommodate them into her life despite the apprehension and embarrassment she has felt having to do so.

A positive thing that can be obtained from Lisa’s story is just how effective and vital support agencies such as the AYME (Action for Youth With ME) website, with its message board and pen-pal facilities as well as information pages, is at helping those who are isolated in their homes feel less lonely. The ability to identify with other people of a similar age from the comfort of her own house, or even bed, enables Lisa to feel that other people truly understand what she is going through, it is a tool which enables legitimisation of her symptoms, thoughts and feelings which many other people who do not understand CFS may be unable to provide her with.

6.5 ‘Jack’

6.5.1 Pen Portrait

Jack is a 14 year old, white British male, who lives at home with both parents and two younger siblings – one brother a couple of years younger and a two-year old

sister. Mum works part-time and dad is a full-time worker. Jack was given a CFS diagnosis 10 months ago by his GP having failed to recover from an infectious disease, he has no other medical conditions and takes co-codamol for headaches and vitamins due to reduced food intake. There are no other family illnesses. Jack seems very young for his age and displays observable signs of nerves (hand-wringing and facial tics). There is some pressure within the family due to his CFS, for example, his brother's resentment of extra attention paid to Jack, plus the need for certain practical accommodations of illness, such as lifts to school outside of normal school hours when the bus could take him. Jack's GP was not helpful in providing information post-diagnosis, but his parent's research led them to the CFS Clinic, which has been very helpful in liaising with school and family, and improving CFS level via the use of routines.

Jack is in Year 10 at school and although he attends every day he is timetabled to either arrive late or leave early each day. He doesn't believe that he catches illnesses more easily than his peers or that he takes longer to recover from illnesses. He says that physical activity makes him much more tired than usual. Jack says that he continues activities as normal, although his mother disagrees with this. When asked the cause of his fatigue Jack says it is due to "lots going on around me", his mother (and primary caregiver) believes it to be due to CFS, both he and his mother agree that the fatigue started rapidly – within 24 hours. Jack recalls his worst three symptoms initially as headaches, sore throats and stomach aches, although his mum recalls them as being extreme tiredness/sleeping, not eating or drinking and sore throats. Jack lists his worst three symptoms currently as being tiredness, headaches and itchy eyes, his mum says they are difficulty getting up in the morning, extreme fatigue in the morning and headaches. Jack doesn't believe that his symptoms change over time, although his mum disagrees with this. He says that he needs to limit his activity to prevent the fatigue getting worse, and believes that if he rests for approximately one to two hours, the fatigue will lessen. He says that his fatigue will return if he stops resting and starts a new activity within this time-frame and describes his fatigue as "improving over time". His mum commented, as follows: *"Jack attends school daily, most of the time but doesn't go in until later in the morning, missing first two lessons which equates to about five or six days a month. He is under a programme to manage his ME, which is why he starts school later. He*

has strict times for rest, going to sleep and waking, including a wind down time before he goes to sleep and a wind up time before he actually gets out of bed which we have found has helped him tremendously". He has just started back at school after the summer break and hence getting back into a routine and he is suffering more than he was at the end of last term, which I was expecting. He has given up subject at school so as not to stretch himself. He doesn't participate in any physical activity, not even at school. Jack's CFS started with a cold and sore throat. His main symptoms currently are fatigue and headaches although some references were made towards poor concentration at times and aching in arms and legs, plus a loss of appetite. He feels that the physical symptoms are worse for him than mental ones.

It was a difficult interview as Jack was only willing to give mono-syllabic answers – I cannot be sure if this would have been the case if his mum hadn't been present, but suspect so. I gained more information from his mum than from Jack, although she was careful to always ask for his agreement on her comments. He came across as disinterested but the more we spoke the more I think this was his timid and nervous nature – he displayed certain tics repeatedly. Mum appeared quite an anxious individual too, she obviously leads a hectic life juggling family and work and a poorly son. She even commented herself that she is a 'highly stressed person'. From comments made before, during and after the interview I had suspicions that Jack is suffering from some degree of depression. He appears somewhat isolated, obviously speaks little to his parents about how he feels and so on, and his social circle don't seem to be the type to discuss their feelings and thoughts.

The family consists of both parents at home, a brother of similar age and sister who is a toddler. Grandparents are very involved and extended family on both sides are supportive although know little about condition. There has been some tension within the household at extra pressure that CFS has put on all of them, for example having to accommodate getting Jack to and from school as the school bus does not run at times when he attends. Also, his younger brother complains about the extra attention Jack receives, and that he doesn't have to go to school full-time.

Jack's GP was not particularly helpful providing information or advice post-diagnosis of CFS, his family had to research it themselves and have benefited greatly

from support and treatment methods provided by the Specialist CFS Service. The school have tried to be as flexible as possible, allowing Jack to drop a GCSE so as to cope better with other subjects, also allowing him to attend slightly fewer hours in the school day (a member of the Adolescent Service visiting his school with the family has helped this process). Hanging out with school friends outside of school is very important to Jack - not being allowed on a recent residential school trip has disappointed him, despite him knowing that he probably wouldn't have been able to cope with it anyway. Jack believes he is 'Moderately Affected' (70%) by CFS according to the AYME Functional Ability Scale.

6.5.2 Jack's Story: Adolescent CFS is Experienced as...*Struggling To Keep Up With My Mates*

Jack and his mum turned up at the hospital to meet me together, he chose for her to remain in the room during the interview. She came across as busy and is leading a stressful life by her own admission, but is anxious to seek the best possible care for her son. Jack was not easy to communicate with, displaying nervousness such as avoiding eye contact. Jack's answers to my questions were largely monosyllabic which his mum was aware of and attempted to encourage him to expand more on his opinions and thoughts. I am unsure whether Jack was stressed, shy or disinterested, however his mum assured me that he had been positive about responding to the request for an interview. It is possible that he was simply displaying personality traits common to boys in their middle-teenage years.

Jack has had CFS for approximately 10 months, the first week of which he was too ill to get out of bed. In the last eight weeks or so he has begun working with the occupational therapist at the Specialist CFS Service and he has been improving, he attributes the improvement to adhering to a routine of rest and activity. He has managed to keep attending school and hasn't missed any prolonged periods, but his timetable has been adapted so that he starts later each day. His Head of Year has been understanding and he has explained that he struggles with concentration. Jack no longer participates in sports lessons but doesn't find mobility around the school buildings an issue. He was struggling significantly with memory and concentration

issues but this has improved since he discontinued a subject as he was not coping with the amount of GCSE coursework. When he was first diagnosed Jack's Form Tutor explained the situation to his class who were subsequently supportive. However, since the start of a new academic year with new class members he feels his peers understand less about the condition, making comments that he is 'lucky' to have CFS, presumably because allowances are made for him within school. He says he is not bullied or criticised for being excused from some lessons and says that his classmates' opinions do not bother him but he doesn't sound convinced or convincing on this.

Jack had to stop doing his paper-round as he was too tired to cope with it and says that the fatigue is the symptom which he struggles with the most, he also suffers with headaches which he was prescribed co-codamol for as paracetamol was not strong enough. The initial CFS diagnosis was made by a GP following a particularly severe cold and sore throat. Jack comments that following the GP giving the diagnosis of CFS there was no offer of further follow-up, support or advice. Jack's mum researched it and discovered that there was more help available through the Specialist CFS Service so they approached the GP for a referral to the clinic. Jack and his mum explained to me their feeling of abandonment when, post-diagnosis, their GP failed to provide them with any further information, advice or treatment plan. When Jack was first diagnosed they knew little about how it would impact him or them all as a family unit. His mum, Sue, recalls;

I remember when we walked home we said, "oh, it's a good job that it's not glandular fever 'cos he would have been really tired for six weeks if he'd had that!" ...of course I'd heard about it but didn't really know that much and then we found out that ME lasts a lot longer, (SUE).

Jack has two younger siblings, a sister who is only a toddler and a brother close to his own age. When his brother could see that Jack was very ill he sympathised and understood but as things have begun to improve he is less tolerant, complaining that Jack is ok really and just 'putting it on', he is jealous of any allowances that are made for Jack. It doesn't help family relations that the advice offered by the local Specialist CFS Service encourages a strict routine of lifestyle management, which obviously impacts on the whole family as it restricts activities, holidays and so on.

Jack's mum says that her youngest son does not speak about Jack's condition frequently, but that he does harbour some resentment for the 'preferential treatment' Jack receives. Jack's mum feels that learning more about the nature of CFS has allowed her and her husband to appreciate elements such as the 'peaks and troughs' in energy and activity better, but that her younger son has not been educated about it in the same way and therefore does not, and cannot, fully appreciate the true impact on Jack. Jack's condition has also affected his mum, who is his primary care-giver but also works part-time and has two other younger (one very young) children to care for. The practical aspects, such as changes to Jack's school hours – although altered with the best intentions of attempting to ease the pressure on him, can prove stressful for his parents. The school has altered Jack's timetable to allow him to start later in the mornings and although this is helpful in many respects it does mean that he now leaves the house too late in the mornings to catch the school bus, so alternative arrangements must be made for transporting him to school. As Jack's mum works part-time and his dad full-time, and they also need to organise their other two children the family often need to rely upon Jack's grandparents. His mum told me that she often feels awkward with her work colleagues as they feel she is 'taking advantage' because she needs to make allowances for her home situation;

You're in a situation where people don't understand and just think you're abusing or taking a liberty, (SUE).

Both sets of grandparents have been supportive, they were concerned when they saw Jack's health deteriorate rapidly in the early stages and made themselves available to help care for him at home, in order that his parents could keep to their work commitments. Jack is conscious of the extra pressure that him having CFS puts on his mum in particular and tries his best to alleviate as much stress as possible for her, even if that means pushing himself beyond what he feels manageable health-wise. Jack's mum recognises and appreciates the help that she has received from the extended family which has been ongoing throughout his illness. She often receives snippets of information or newspaper articles they may have seen linked to CFS, and if Jack is at his grandparent's house they remind him of his routine and when to take rests.

Jack has found it a struggle to continue an active social life with his school friends as he has been unable to continue going out with them as often as he did before he became ill. He admits that sometimes he pushes himself beyond his energy levels so that he can enjoy himself with his friends, but afterwards suffers for it needing to spend the following day in bed feeling exhausted and lethargic. Jack had to stop regular swimming sessions as he no longer has the energy. He also used to play in the garden with his brother and at the beach, but his parents have noticed a marked decline in his desire to do those things believing he now has too little energy to initially want to participate. This change in desire to play with his brother may also be due to his age, what he found enjoyable last summer may not necessarily be so this year. Jack's mum spoke more openly about his limited ability to socialise now, compared to pre-CFS, pointing her question at him for my benefit, to which Jack agreed;

...with your friends, you find it quite hard keeping up – walking from shop to shop and cafes and whatever, you find that quite difficult and that's one of the reasons you don't do that quite as much now, isn't it? (SUE).

Jack relayed how many of his friends are understanding, but implies that not all are - he appears reluctant to speak about having CFS with them more than he absolutely has to. It seems important to him that he is not seen as 'different' amongst his peers, which is perfectly natural for a 15 year old boy, as adolescence is a time of striving to fit in with those around you.

Jack has coped well with his school-work, managing, by and large, to keep up with his classmates, he has only needed to stop one GCSE, but says this allows him free-periods in which he can catch up with any work he may have fallen behind on in other subjects. He plans to take A' Levels and has aspirations to become a teacher. The school, and Head of Year in particular, have been very accommodating to Jack's requirements and this understanding has alleviated stress on the family. The Lead Occupational Therapist from the Specialist CFS Service attended a meeting with Jack, his parents and the Head of Year at the school to discuss the way CFS impacts Jack, and how best to juggle his academic requirements and his health. Jack has a positive attitude towards all of his GCSE subjects apart from French as he says he is not keen on the teacher. At this point his mum elaborates more than Jack is prepared

to, explaining that the French teacher prevented him from participating in a residential school trip, which he was very disappointed about. The teacher believed that Jack would have been unable to cope with the demands of the trip, and although he understands that it may have been challenging, he still appears resentful that he missed out on the opportunity and was made to look 'different' once again among his peers. Despite this Jack tells me that he did go away on a school skiing trip and really struggled with the week; only managing two out of five days skiing, but thoroughly enjoyed the social aspect of being away from home with his friends. Jack's mum tells me, at this point, that her and her husband struggle with decision-making sometimes, as they don't want to impede Jack's opportunities more than is necessary;

It's a difficult one 'cos you don't want to say "no, you can't go" 'as you feel like you are penalising them for having something that is really not their fault...but then again, you don't want to force them to do stuff that is going to make them worse, or make them feel embarrassed or difficult because they can't keep up, (SUE).

Jack feels that his health is now steadily improving and he attributes this largely to the advice from the CFS Service and the routine of activity and rest timetable that the Occupational Therapist worked out with him. His main symptoms now are fatigue, generalised aches and pains and headaches. His mum made reference to his loss of appetite and that if he wasn't reminded to eat, he probably wouldn't.

The concluding comments from both at interview was that Jack is slowly returning to his pre-CFS health and that as long as he is sensible and structures his time to include rest periods he can maintain his attendance at school.

6.5.3 Jack's Story - In Summary

Jack and his family report a very positive outcome having had access to the CFS Service, the management strategies and specialist care has enabled Jack to feel he can start to have some control over his health and recovery. There is also a very important element of legitimisation for the patient and family provided by such clinics, especially where family doctors cannot or do not offer ongoing support. Such

gains reflect how critical such centres of specialist expertise are, especially for conditions which are widely misunderstood.

Jack's parents are obviously supportive and empathetic to Jack's health needs, but the added support of his grandparents eases some of the pressure for his mum. This support network is particularly beneficial in a family with more than one child as the burden of responsibility of care is spread over more adults. One thing that Jack's mum and dad do struggle with is the decision-making process on behalf of their son, recognising that there is a delicate balance between making the appropriate choices for his physical and social needs, so that his health does not suffer detrimentally but neither is he denied the things he enjoys doing.

There is an undisputed amount of ignorance surrounding CFS within the public domain due to lack of knowledge, however it is interesting to note from Jack's story that both he and his mum relay incidences of this about their own peers groups. Jack's classmates pass flippant comments about him being 'lucky' that he has CFS so that he can be excused from PE and so on. Jack's mum describes feeling that she is 'taking a liberty' within the workplace as certain allowances have to be made for her to accommodate her son's health. Both situations reflect the misunderstood nature of the condition.

Jack's narrative, as with others in the study, demonstrates that children with CFS and their siblings often display signs of jealousy. This jealousy is sometimes mutual – the child with CFS is envious of their brother/sister being able to continue activities which they are now restricted from due to their ill-health, and the brother/sister is resentful of the extra time and attention paid to their ill sibling.

It is clear to see from Jack's story that he is often unable to physically keep up with his friends when he goes, this is probably true for many young people with CFS. It may well lead to him hiding how he feels or pushing himself beyond his energy capacity to the detriment of his health in order that he does not appear set apart from his peers.

6.6 Narrative of Jack's Mum 'Sue'

Sue, Jack's mum, also has two other children – a son, Tom, who is a couple of years younger than Jack and a little girl of pre-school age. She works three days a week and her husband works full-time, which means that life is both busy and stressful for Sue, juggling the demands of being a working-mother as well as catering for Jack's extra needs as a result of having CFS.

Sue had little prior knowledge of CFS before being faced with it within her own family;

There had been a girl (late 20's/early 30's) working in my office who had been diagnosed. I was aware that she suffered from severe tiredness and occasionally fainted but that was all really. I feel really bad now that I was so ignorant, (SUE).

Having experienced first-hand the debilitating effects that CFS can have, Sue has been faced with the reality of the condition and how destructive it can be.

Sue and her husband found the time prior to Jack's diagnosis a worrying and frustrating period, they felt – and still feel – largely unsupported by their GP surgery and struggled to get answers as to the nature, cause and prognosis of the illness. Sue recalled the day the family doctor gave a definitive answer as to why Jack was not improving;

The initial diagnosis by the GP was very vague - he said 'Luckily Jack hasn't got Glandular Fever, he has ME. If he had Glandular Fever, he could have been ill for more than 6 weeks.' Not knowing much about ME then, we weren't too worried then, thought it was just some virus, (SUE).

Sue and her family's lack of knowledge about CFS and the lack of understanding demonstrated by the GP lulled them into a false sense of security. Rather than having the diagnosis and prognosis accurately explained to them, they were instead falsely reassured. Now with hindsight Sue looks back with some annoyance on the confusion that the GP invoked;

Looking back, I feel very angry with our GP Surgery as we got nothing from them. We didn't ask at the time because we assumed Jack would recover in a week or so - how wrong we were! (SUE).

Sue not only felt let down but also misled. She conducted her own research on the internet in the absence of any advice from her doctor's surgery, she found out about support groups and CFS telephone help-lines. Sue feels that the first person who was helpful in their quest for support and advice was the school nurse, who told them to get a referral from the GP to a general paediatrician, this request was passed onto a paediatrician specialising in CFS who, at the consultation, linked them up with the Specialist CFS Service. The whole process – from first tentative GP diagnosis to speaking with someone knowledgeable and helpful took four months, however the Occupational Therapist management therapy really proved to be a turning point in Jack's recovery, teaching him self-management skills and advising on activity/rest routines.

The impact on Sue's entire family has been major; emotionally, socially and practically. She conveys how difficult it has been;

An enormous impact, one we could never have imagined. At the start, when we did manage to get Jack out of the house, we couldn't drive more than 2 minutes in the car without Jack falling asleep. If we went to visit anyone, Jack would tend to lie on the floor and just fall asleep. We had to (and still do) plan and prepare for any social engagement. We obviously understand a lot more about the peaks and troughs, (SUE).

Spontaneous decisions to go out have become a thing of the past, Jack's fatigue means that things have to be planned carefully in order than he can cope and often social engagements need to be postponed or cancelled at the last minute, this obviously impacts the entire family. Tom, Sue's younger son, has been particularly affected by Jack's CFS;

I personally think it has affected our second son very much. Jack is the oldest - Tom is 2 years younger and now Jack gets so much attention. Tom has never said anything to suggest that he is jealous of the attention Jack gets but I'm sure he is affected by it. Jack gets taken to or picked up from school every day as he only does part time schooling - Tom has to go on the bus and

spend all day at school - it must be very hard on him. Jack gets to stay with his grandparents so he can get a good nights sleep and in the morning, if Jack is on a late and is staying at home, it's always 'Shh, Jack is sleeping!' Previously Jack and Tom shared a bedroom Just before Jack became ill, we moved them into the largest bedroom and decorated as a 'lads room' with 'Day Beds' to enable them to use the room to socialise with their mates. Suddenly the room was out of bounds for Tom as a social area as Jack was either resting or sleeping or would have a severe headache. If we do go out to a social event, we usually have to leave earlier than we would do if Jack wasn't ill. It's really hard on Tom and I feel for him. (SUE).

It is evident that Sue has a delicate balancing act to contend with in order that family life remains harmonious for all. This, no doubt, causes additional pressure for her. She understands that Jack's needs can be many and yet feels sorry for Tom and the sacrifices he has had to make on account of his brother's ill-health.

Sue feels that her eldest child has in some ways been reduced to a toddler in as far as the amount of extra attention and care that he requires, far more than a young man his age ordinarily would;

To be honest, it has claimed a huge part of my life. In some ways, its like having a toddler again, checking how much he's eaten / drinking, ensuring he gets to bed at the right time, gets rest periods and waking him up in the morning which can take some time! Jack has problems with his weight, mostly due to the fact that he finds it very difficult to eat breakfast and lunch when he is at school. Obviously, this is very worrying for me - everybody is told how important it is to start the day with a good breakfast but yet I'm lucky if Jack will have a cup of tea, and suffering with ME, it's so important to eat to increase his energy levels. He won't take a packed lunch to school and won't have anything from the school canteen. I hate looking at his super skinny arms. People say 'loads of teenagers are tall and skinny' and I know that is the case but Jack is skinny because he doesn't eat enough food. Our cupboards are full of different foods that I have bought to try and entice him! I have to cook 3 different meals as Jack is so difficult to cook for and as far as Jack is concerned; the phrase 'if he's hungry, he'll eat it' doesn't apply! (SUE).

Jack's lack of appetite is clearly a great worry for his mum, it is something she is constantly mindful of and causes her extra work within the family set-up to address it. The extra foods in the cupboards and cooking three different meals is an added burden to an already busy and stressed mother, however, she – as any caring and anxious mum would be – is prepared to do whatever she can to improve the situation. There is also the extra daily issue of transporting Jack to and from school as his

timetable has been adapted to make allowances for some of the symptoms he experiences, however this means him needing to arrive at and leave school at times outside of those catered for by the school bus;

Having to take to or pick Jack up is quite a strain, time wise and financially. It's over a 6 mile round trip to school and every day he either needs to be taken in later or picked up earlier. Luckily, my parents do help out when they can, especially when I am at work but that's still a strain because I feel guilty relying /expecting them to do this, (SUE).

Even with the extra help to meet the practical demands she faces caring for Jack, Sue still has the emotional burden of guilt that she is delegating responsibilities which she feels she should be meeting.

Sue has experienced some difficulties at work, despite explaining her home-situation to various managers. She feels disappointed that having been committed to her job for many years, she is now facing demands which she will struggle to meet considering the extra responsibilities she has caring for Jack.

Jack's academic life has been impacted greatly, which has affected his mum's life also, both practically and emotionally. He has been moved down from one of the top sets for one subject; had to stop another GCSE altogether and is unable to participate in any sport. His school day does not begin until 11.40 am to allow for a later alarm call, a quiet start to the day and a rest before leaving the house – this obviously affects his school timetable significantly. Jack's Head of Year has been helpful and understanding and has agreed to meet with Jack's Occupational Therapist from the Specialist CFS Service, in an effort to work out a school schedule which accommodates Jack's academic, health and social needs. The understanding of the school and efforts by the Occupational Therapist to liaise directly with teachers have alleviated some of Sue's anxieties. Not all special compensations have been totally successful however, as Sue explained;

In January this year, he sat his mocks. He was granted an extra 25% time to complete the exam in which he found helpful when he had a lot of writing to do but found it very difficult when he had one exam after the other, Ironically, this is when the extra 25% is a disadvantage as it leaves him less time to recover between exams. He ended up taking the following week off as

he dipped. I am worried about how the GCSE timetable will be for Jack; having one exam after the other but hopefully it will work out ok, (SUE).

There appears to be only standard things that schools can put in place to assist pupils with health needs to manage exams, however the nature of CFS means that these 'allowances' at times cause extra problems.

Sue recognises the changes that have occurred in Jack socially;

Jack has obviously been affected. He used to enjoy having his mates round, especially on his birthday and at Christmas, having parties, usually with a couple of mates sleeping over - he can't cope with this any more. He also never sees his school friends out of school any more as he can't keep up with them. I feel for him but he's ok. He keeps in contact with a couple of girls from his previous school and will maybe catch up with them once every 3 or 4 months. He says that it's sometimes a bit difficult at school because he's not there all the time and so doesn't have any really close friends, (SUE).

Jack's health has meant that his social life has suffered, which is as important as other aspects of his life during adolescence, and Sue is aware of this.

Sue also feels that she has to nag him to do things which she wouldn't have to do if he were well, for example, making sure he goes to bed at 9 pm or ensuring he rests before and after a social event, in order that he gets back on to an even keel with his energy levels. This not only means Jack demands more of his mother's attention than he would do if he were well, but also must cause some friction within the relationship.

Sue describes her feelings as to how Jack having CFS has affected her as a mother;

I wish Jack didn't have ME. I wish we were the family that we were. It's hard - I'm sure I've aged 10 years in the last 2!! Doing anything now seems to take so much planning. I worry about how Jack will cope holding down a job....not doing a full day or taking the old two or three days off as he isn't feeling too good is ok when you are at school but I can't see that being accepted by an employer. I feel a lot more tired than I used to....I suppose that's something to do with knowing that I have to 'look after' Jack and also being aware that Jack does get more attention and so trying to give Tom similar attention to balance it all out. And then there's my 4 year old daughter who by default gets lots of attention because of her age! It's hard trying to balance everything. And I worry that Jack is missing out on things

that 15 year old boys should be doing, but saying that, at least I haven't got the worry of not knowing where he is! (SUE).

Sue's work, family and social lives have been impacted by her son's condition, resulting in more for her to have to juggle on a daily basis. She is also anxious – not only for the present, but for the future too. While Jack is still at home and attending school there is a good proportion of flexibility that he has, along with his parents taking responsibility for his needs, this will not necessarily be the case in the future and Sue is aware that at some point in the future if he does not recover from CFS he will have to learn to manage having CFS more independently.

Sue believes she is much closer to Jack than she would have been had he not become ill and that is, in part, a reflection on him not maturing as quickly as his peers due to his ill-health;

I suppose in some ways I am closer to Jack - I don't think there are many mothers that have their 15 year old son saying 'can you lay with me please for a while?!' And I suppose you've hit the nail on the head - Jack is 15, 16 in two months yet he is still a child, not in his development or looks but just because he hasn't got the independence. It's a difficult thing to explain He wants to go to university to train to become a teacher but wants to stay living at home. That's lovely for me but not right really. He won't be enjoying the social side as he should be, if he's living at home, (SUE).

Sue again reiterates her fears for her son's future and recognises that because of the CFS he may miss out on experiences that would be open to him ordinarily, she is anxious that he has all of the opportunities that anyone else his age would have.

Sue told me that she has felt powerless during the time Jack has been ill, she has not felt that she can control what is happening to her son, however she does feel that she has learnt to recognise signs better than she once did – she can now read Jack's health better and is able to see a pattern of behaviour in his symptoms;

I don't think I have ever really felt in control with Jack's ME - I think that Jack is getting better and then bang, he relapses, not to the extent of the initial stages but its still upsetting. But, saying that I'm noticing more of a pattern now as to when he has relapses, like nearing the end of the school term etc, (SUE).

This familiarity with Jack's health pattern demonstrates a journey that Sue has been on. She may not be able to control Jack's CFS experience, but she is now better equipped to manage it.

The entire family unit has been impacted by Jack's condition and life has changed as a result – the things they could once do together are now restricted;

We don't do as much as a family as we did before Jack became ill. We can't really go for days out as it's too long for Jack. Travelling is difficult for him as well. If we do go away, we have to ensure that there are days before and time after to enable Jack to catch up e.g. when we have managed to take a summer break, we have to ensure its in the middle of the summer holidays, to enable him time to wind down from school and to give him time to get himself back into a routine ready for school, (SUE).

Lots of careful planning has to go into family activities now, not only of what they can do together but also when. The after-effects of any outing must be considered so that Jack has time to recover. Sue sums this up by saying;

So yes, its hard work having a child with ME, making excuses why we can't attend certain events, why we have to leave early but that's the way life is now, (SUE).

As difficult as the adjustments have been - and will continue to be - to make, there is a certain amount of acceptance, or maybe just resignation in this statement. Their lives have altered since Jack has been ill, they have all had to make adjustments to their lives, so in effect the CFS has affected them all.

Jack's grandparents have been very supportive and help out practically whenever asked, as well as being of emotional support to them all. Their involvement has eased some of the practical burdens that Sue has to juggle on a daily basis, and for this she is grateful. Family friends have been understanding too, however the thing that outsiders struggle to comprehend is the lack of clear prognosis, they sometimes forget that although Jack doesn't always look ill, that is not necessarily an accurate representation of what is going on inside;

The bit I think the majority of people don't understand is that there isn't a set time when he will be better! Plus, like I said above, when you have got it under control, Jack seems normal so people forget that he needs to stick to his routine - they may stay to late when they come round for the evening or make comments when we leave events early, which is not ideal, (SUE)

Anyone without first-hand experience of a family member with CFS is bound to struggle to understand the nature of the condition; the lack of definite prognosis is difficult for anyone to contend with – it is more a necessity to accept the vagueness but remain positive and take each day as it comes, as many participants and their families have commented upon.

Sue's story demonstrates how difficult juggling family life with a poorly child can be for a working mum, with other children to care for. Sue recognises that CFS has halted her son's social and emotional development and this has exacerbated the burden on her. Having two other younger children has meant trying her hardest to meet their needs whilst attending to Jack's, at a time when her eldest son – according to age – should be becoming more independent.

6.7 'Liz'

6.7.1 Pen Portrait

Liz is a white British, 16 year old female living in a rural location with her mum and two sisters, (one slightly older and the other a few years younger), she admits she is not emotionally close to her mum but is close to her sisters, she leads a fairly isolated life only mentioning one friend. Liz's mother is a retired healthcare professional, her dad was not mentioned. The initial triggers of Liz's CFS were whooping cough and pneumonia. She was given an initial CFS diagnosis three years ago by a GP, who referred her on to a specialist for confirmation.

She has no other medical conditions, takes no medication and there are no other family illnesses. Liz believes that she catches illnesses more easily than her peers although her mum disagrees, they both agree that she takes longer to recover from illnesses than others her age. Physical activity leads to her feeling much more tired

than usual and she is unable to do any activities other than her school work. Her fatigue started over two to six months and she lists her worst three symptoms in the beginning as tiredness, muscle aches/pain and lack of sleep, her mum recalls her original worst symptoms as fatigue, restlessness and lack of sleep. They are both in agreement that her current worst three symptoms are fatigue, lack of sleep and muscle aches/pain. Although Liz believes her symptoms change over time, her mum disagrees. She has to limit her activity to stop the fatigue worsening, if she rests some of it goes away but if she stops resting and returns to activity the fatigue returns. The length of rest time she needs varies and she describes her fatigue over time as going through “good and bad periods”.

Liz’s mobility outside the home is restricted due to fatigue. On the few occasions, (maybe once a month), when she does go on short shopping trips Liz needs to use a blue badge and wheelchair, she struggled to get used to the chair at first. Liz struggles with ‘sensory overload’, (noise and hustle and bustle of lots people), when out in a public place. She is conscious of other people’s assumptions about seeing her in a wheelchair and feels anxious that she is in people’s way. Liz says that the lay-out of shops is poor for wheelchair users and that often she has to be pushed a long way round a shop as she’s in other shopper’s way. If she goes to a café or restaurant she has to sit with her feet on a chair as her legs ache, again she is self-conscious. Sometimes she stands up from her wheelchair to reach something from a shelf and feels people whisper about why she needs to be in chair if she’s obviously not disabled. Liz leads quite an isolated life socially. She spends time with her sisters who are both supportive and one family friend who lives in close proximity, she has no other friends. Her schoolmates did not keep contact – this was not something she wanted to talk about.

Liz has missed school from age 13 onwards, to date, if she was attending school Liz would now be in Year 10. She has been home-tutored throughout but estimates to miss approximately five to six days of that tuition per month due to being too poorly. Having been home-tutored since May 2005 Liz now feels recovered enough to consider returning to school, her mum is campaigning for a place at a local private school which is in close proximity to their home, but funding is difficult to achieve. She has progressed consistently with tutors and achieved two good grade GCSEs.

Liz is quite able academically, and is keen to start the small private school which is local to home as they are willing to accommodate her needs – such as give her a room to rest or catch up on work in if necessary. Liz appreciated the new Headmaster’s honesty about knowing little about CFS but being willing to learn. She is slightly apprehensive about returning to a school environment, especially the social aspects this will entail.

Liz feels that being long-term ill has meant she has needed to mature more quickly than she would have done had she not been ill, she feels she has had more to cope with than her peers so has grown up quickly emotionally but thinks she’ll be socially less mature due to being so isolated for so long. She doesn’t make long-term goals as she feels too overwhelmed and doesn’t want to risk the disappointment of not achieving her aims. She takes life ‘one day at a time’.

Liz feels that she did not benefit greatly from the Specialist CFS Service as she believes her family did not adapt to the suggested routines. She uses AYME daily and finds comfort in knowing there are other people her age with the same issues to deal with. According to the AYME Functional Ability Scale Liz rates herself at 50-60%.

6.7.2 Adolescent CFS is experienced as...*My Friends ‘Moving On’ Without Me*

Liz was not well enough to travel to the Hospital for interview and therefore I travelled to her home, which is in a small pretty village in the country. I was met at the door by Liz’s mum who had interrupted a telephone call to answer the front door and then resumed her phone conversation in the kitchen while I spoke with Liz in the living room next to it. This was the first interview I had conducted and I was a little nervous, however Liz was friendly, albeit quiet and relatively shy, and we soon settled into talking about her life. The over-riding feeling I got from Liz was that she leads a fairly isolated lifestyle, if it weren’t for her two sisters and a friend who lives close by she would have no social contact whatsoever with people her own age. The social life that she does have is conducted online with people of a similar age who also have CFS, this is a real support for Liz. I got the impression that Liz was nervous about speaking openly with her mum in such close proximity and this was confirmed when her mum finished on the telephone and went upstairs; Liz instantly

became more confident, her voice grew louder, and she visibly relaxed. During the course of the interview Liz did mention that her relationship with her mum was not as close as some mother-daughter dyads are, although she has a warm bond with her sisters. Although Liz has been very poorly over the last few years she now feels on the road to recovery and is excited, albeit with slight trepidation, at the thought of returning to a school environment. She is keen to pursue the rest of her education and is looking into ways she can achieve the goal of returning to school which are manageable even though her health is still not one hundred percent.

Liz first became ill in 2004, she had whooping cough compounded by pneumonia. She missed most of the school winter term, only managing approximately 15 days of school attendance during that whole period. Her GP originally referred her to a specialist who diagnosed CFS early on, she and her family had never heard of it prior to the diagnosis and she recounts it being 'strange' to have an illness that she'd never heard of before and knew nothing about.

Liz is close to her sisters but is otherwise fairly isolated. She has two sisters – one older and one younger – the older of which Liz tells me struggled to comprehend her condition initially, although Liz feels this to be understandable as Liz herself didn't understand it either. She began home tuition in May after a lengthy battle fought by her mother to get the arrangements in place. Liz told me that she lost touch with her school friends, she laughed nervously as she told me, perhaps indicating that this is a difficult topic of conversation. Her explanation for the loss of contact is that people have moved on with their lives;

Umm, I think that people have sort of moved on...changed...and I haven't, 'cos I wasn't able to be out and about seeing people..., (LIZ).

Liz's body language intimated that her social isolation was something that bothered her. Adolescence is a time when she should be investigating the world and experimenting with new ideas and social opportunities outside of the family unit, but instead of that she is restricted to her home by and large, and dependant upon her mum to assist her and accompany her if she does ever venture out. Her friends have, understandably, moved on with their lives, making new connections and exploring

new prospects – this is not insensitivity on their part, simply them being ‘normal’ teenagers. ‘Friendships’ during the adolescent years are somewhat fickle anyway and can be broken easily, it would have been surprising if any of Liz’s classmates had remained committed to a friendship unless it was based on several years of contact and they lived in close proximity.

Liz has one good family friend who lives in close proximity within the same village, who is around the same age and is also friends with Liz’s sisters. Liz admits to being lonely at times and says she would like sometimes to have friends other than her sisters. When thinking back to the time before she had CFS and reflecting upon the period that she’s been ill Liz said;

It feels a long time ago. I dunno...it feels.....it’s kind of odd because it must have been when I was about thirteen when I first got ill. So it was quite a big change from thirteen to sixteen, quite a big gap to miss from school. And like people have like grown up quite a lot. So that’s kind of like odd and my little sister is in the same school year as I was when I left, it’s really weird I think I’ve made progress.Umm, I’m definitely better than what I was. But it’s still kind of weird to think that I’ve missed that huge gap, (LIZ).

I had a real sense of Liz feeling that she had missed out, that she had a ‘huge gap’ in her life when she hadn’t been living a normal life, as though she had been robbed of what should have been, and instead had to live within a framework dictated to her by her health.

Liz has a few friends from AYME (‘Action for Youth with ME’ an internet-based support network for young people with CFS/ME), but does not see them in person, only keeps contact online. She does however appear to gain a lot of support from the site and takes solace in other people’s recognition and understanding to help beat the feelings of isolation. She says;

*It’s nice to know that what you’ve been trying to explain to everyone is not just you thinking crazy ***laughs***. Everyone else is sort of feeling it too which is nice..., (LIZ).*

Liz utilises the AYME site daily, where she communicates with people via a message board and also uses MSN to 'chat'. This is her main access to a social life with people her own age. When describing the benefits of AYME she said;

It stops me feeling isolated. It gives...it's nice to have people going through the same thing as you. It's nice to be able to say "I'm feeling really bad today" and have one of your friends say "Oh, me too!" They think about me too and...it's nice... (LIZ).

The site has helped her access others in the same situation which has been comforting to her, and given her a sense of legitimising her symptoms and feelings, which stops her feeling so isolated. When describing her relationship with her mum – her primary care-giver – Liz said that having CFS had impacted the situation;

*Being with each other like all the time, like everyday ***small laugh*** it's a bit odd. Not many people my age do that ***small laugh under her breath*** and sometimes I've like hated it but...it's strange and sometimes I tend to get... ***tails off*** but it's alright..., (LIZ).*

At this point her mum leaves the next room where she has been on the telephone and goes upstairs (out of ear-shot) after which Liz appeared to feel more relaxed.

Liz very occasionally manages to go out on a short shopping trip, she uses a blue disabled badge so that her mum can park close to the shops and is pushed around by her mum in a wheelchair. When she is in a public place she struggles with sensory overload; different noises and close proximity of strangers in particular. She finds her legs tire and ache in one position, whilst seated in the wheelchair, so if they stop in a café she sits on one chair and rests her legs on another, she finds this necessary but embarrassing. She considers herself to be in other people's way when using a wheelchair and comments that the lay-out of shops do not make wheelchair access easy. She has been very aware of people noticing and whispering about her in a wheelchair and comments that if she does stand up to reach for something people jump to conclusions, perhaps think she is only pretending to need the chair;

...people just assume things and are wrong about them. I can feel people watching me and assuming things about me and sort of saying "Oh, what's she doing? What is she thinking? Why is she in a wheelchair?" (LIZ).

Liz is reliant upon her mum to push her in the wheelchair if she goes out as she is too weak to propel herself in it, she seems uncomfortable with this and believes this encroaches on both her own, and her mum's freedom, she enjoys it when she can go out with her sisters helping her and is grateful for the 'space'.

She has been home-tutored for the past three years. At first she did very small tasks in her lessons such as a simple maths game in which she had to colour the answers as this was the limit of what she could cope with, after a year with her first tutor she felt some improvement and has now achieved two 'B' grade GCSEs in maths and English. She is proud of her achievement as it wasn't an easy process and it has opened up new avenues to gain funding to continue the home-tuition, without the GCSE attainment the tutoring would have been stopped. Liz tells me that she has been 'back-yearred' in order that she can continue working for GCSEs and is now studying for English literature and textiles. She finds that the one and a half hour sessions are a long time to keep her concentration level high and explains;

If I'm bad and someone's trying to talk to me and I'm tired, I can hear what they're saying but all the words don't really make sense, and they sort of jumble all up. They get quite...confused and I can't really make sense of it. So that's quite difficult as people think it's 'cos I'm not listening (LIZ).

Liz finds it frustrating that she makes simple errors and believes that if it weren't for the CFS she wouldn't have such problems. She was doing well at school prior to getting ill and still has aspirations for the future wanting to do A' Levels at sixth form college. Her mum is currently campaigning to achieve the funding necessary to get her a place at the nearby private school because the only state school is 12 miles from home and she would be exhausted from the journey alone to get there before the academic day even began. Liz believes that the private school within the village could accommodate her needs as it is a school where some pupils board and could provide her with her own room containing a desk and a bed where she could rest or work quietly alone during the school day. She has obviously thought a lot about it and considered her options, and although she is nervous at the prospect of returning to a busy school environment, she is also excited at the thought that her academic and social spheres will expand.

Liz came across as having a mature disposition, she appears to have learnt to adapt her outlook on life in an effort to avoid feeling overwhelmed;

I think with having ME I've sort of learnt not to think too far ahead. So I only, like, think sort of short bits of time, not too far in the future. and so then I've found it more achievable and feel like I'm making more progress... I think that the ME's sort of changed my values on things a bit really, 'cos obviously there's sort of like a bit of a big change and I couldn't do some of the things I wanted to. So I think that now...not in a bad way, but in a positive way, I think it's best to sort of see how things go, not to make these sort of huge future plans or anything..., (LIZ).

Liz thinks that although in many personal and emotional ways she has had to grow up quickly, but feels that she is probably less mature than her peers socially, and will only discover the extent of that when she returns to a school situation.

When Liz visited the private school close to her home and spoke with the Headmaster she appreciated the fact that he admitted his knowledge of CFS was limited but was willing to listen to her explanation and be as flexible as he could to address her needs. She believes that the fact that the school has fewer pupils means it has more flexibility to accommodate individuals with particular requirements.

6.7.3 Liz's Story - In Summary

Liz's story demonstrates how disruptive the cognitive symptoms of CFS can be, impaired memory and concentration cause immense frustration and feelings of being overwhelmed by sensory input can be disorientating and upsetting, this is something which needs to be taken into consideration by tutors of students with CFS. Another cognitive impact can be a sensitivity to incoming stimuli, when someone spends a large majority of their time alone or only surrounded by a few close family members and then has to go into a public place such as a shopping centre or school environment, the barrage of novel incoming sensations can be very stressful.

Again, this narrative suggests just how isolating and lonely having CFS can be for a young person who has been confined to the home and no longer able to attend school. feelings of being 'left behind' whilst people move on with their lives can be

caused by something as obvious as peers moving away to university, or something as basic as no longer being familiar with the current fashion or music trends. Such experiences may leave young people feeling less inclined to try and make the effort to see their peers because they are apprehensive about looking foolish. This is also a consideration when they start to feel well enough to return to school as there is a lot of catching up to do in order to try and fit in socially, as well as the academic side. Returning to school having been absent for many months or even years can cause apprehension, as Liz mentions. She has a sense of excitement about her social and academic lives starting up again, but is also anxious about being back in a large gathering. It is the role of schools who are welcoming back a child with CFS who has been absent for a long spell to try and make that transition as easy as possible, to accommodate their needs and be willing to listen to the individual with regard to how best the school can serve those needs. Liz is appreciative of her new prospective Head-teacher's attitude, who despite knowing little about CFS - and being honest about this fact – is prepared to listen to Liz's account and accommodate her anxieties and practical needs as much as is possible. This gesture of openness and flexibility seems to be facilitating Liz's return to a school environment in such a way as to make it easier.

Liz believes that people who see her in a wheelchair are silently questioning why she is in it, whether her perception of people's attitudes is accurate or not what is significant is that Liz feels self-conscious. Many individuals with CFS believe that other people do not take the illness seriously because there is nothing visible to see, a broken leg in a plaster cast is an obvious disability; somebody who to all intents and purposes *appears* well often has the added burden of trying to explain or even justify what and how they feel.

Liz's relationship with her primary carer – her mum – does not seem to have developed in as positive way as some of the other participants recount their relationships to have done.

6.8 'Chloe'

6.8.1 Pen Portrait

Chloe is an 18 year old, white British female who lives at home with her mum, dad and older brother, she is over school age. She is an intelligent, motivated, cheery girl who has fostered a positive outlook on her condition and refuses to waste her limited energy dwelling on the negatives of her life. She has a good support structure comprising of her long term boyfriend, close family and friends. Her main external support has been AYME of which she's an active member: she writes for the website, is a pen-pal to severely affected members and is hoping to work as the representative for her county. Chloe's Mum runs a business from home and her dad works full-time also.

Chloe had an infectious disease which triggered her fatiguing illness and she was given a CFS diagnosis three years ago by her GP. She has no other medical conditions and there are no other illnesses in the family. She was initially bed-bound for three months but gradually improved, she returned to school part-time and completed her schooling. She now feels she's reached a plateau at a fairly high percentage of her former functioning. Chloe describes physical activity as making her much more tired than usual, and believes she catches illnesses more easily and takes longer to recover from them than her peers. She believes her fatigue started gradually over two to six months, although her mother thinks this time was much shorter – nearer one week. Chloe recalls the three worst symptoms at the beginning of her illness as being: extreme fatigue, sickness and headaches, her three worst symptoms now are: fatigue, muscle aches and nausea. Her mother described her initial three worst symptoms as fatigue, nausea and muscle pain, and believes this is still the case. Her symptoms remain fairly unchanging over time. Chloe occasionally takes herbal remedies for nausea. She limits or cuts back her activity to avoid the fatigue increasing, if she rests after exertion some of the fatigue dissipates, but if she stops resting and re-starts activity her fatigue will return. She has to rest for hours or days, depending on the activity, when she is fatigued. When asked to describe her condition over time she says "I have good and bad periods".

The CFS started at 15 years old, which is the beginning of the GCSE year – obviously this was not good timing academically. Chloe missed most of her GCSE years but went back into sixth form and did GCSE re-takes and A'levels, achieving

ten GCSEs and two A'levels. She has always been an A grade student, she comes across as conscientious and a hard-worker.

Chloe appears confident, intelligent and socially able, she has a happy personality, and is overtly positive about having CFS, saying more than once: there's '*no point sitting and dwelling on the negatives, you need to stop wasting valuable energy and focus on the good things*'. She is very motivated, determined and organised. Chloe gives herself short-term, (daily or weekly), goals written on a board in her room that she aims to achieve, she gets slightly annoyed if she doesn't achieve her aims, but just re-evaluates and re-sets goals for the following day/week.

Chloe has a good circle of supportive friends and a boyfriend who's stuck by her through-out, she is part of 'a tight-knit family'. Her mum works from home, and her dad works away. She has one older brother who is three years her senior.

Chloe was hardly ever ill prior to the start of CFS. She had a helpful GP, although it took some time to achieve a diagnosis. It became a cycle of repeated trips to the GP and many investigative blood tests. Initially she was thought to have Glandular Fever, but later this was ruled out via a negative blood test result. Her major symptoms initially were nausea (and associated weight loss), a persistent sore throat and exhaustion.

Chloe's main support/help has been AYME contacts and resources, plus positive experiences of the Specialist CFS Clinic's advice, routines and strategies. She now does charity work for AYME as a pen-pal to bed-bound girls, and writes for the website. Chloe believes that her current charity work will be helpful on her CV towards her future aspiration of becoming a writer, she is not convinced she wants to go to University as she feels that her family contacts in the media and her own work experience will be more beneficial to becoming a journalist than a degree would. She mentioned a desire to write a book about her own experiences of CFS. She feels she can rate herself as 70-80% on the AYME Functional Ability Scale.

6.8.2 Chloe's Story: Adolescent CFS is Experienced as...*Learning To Accommodate My New-Found Limitations*

From the moment I met Chloe for interview in the lobby of the Hospital I felt at ease with her, her bubbly, bright optimistic personality was evident from her demeanour and eagerness to chat. I would imagine that she communicates well with most people, she has a magnetism about her that makes her easy to be around. Chloe came across as not only socially able, she also appears quietly self-confident – not in a pretentious way but simply at ease with who she is, where her life is and her expectations and aspirations for the future.

Chloe became ill approximately three years ago, when she was 15 years old. She originally believed she had glandular fever, but after six months a blood test confirmed it wasn't that and after multiple trips to the GP and a battery of different blood tests she was told she had CFS. Six months in a young person's life is a long time – socially, academically, physically and emotionally. The process of multiple trips to the GP and consequentially multiple trips home again without any answers, must have been frustrating, disappointing, draining and worrying for Chloe and her family. From a parent's perspective the inability to change a difficult situation for your child is hard to bear, but then for an 'expert' that you have decided to entrust your child's health to who should be able to improve the situation is also clueless it must only compound the feelings of powerlessness. As a child/adolescent it must be difficult, living in a 'limbo-state' until someone decides what the problem is and you can discover the things you need to do to remedy the situation and begin living normally again. Part of the difficulty in gaining a diagnosis of childhood CFS is that often when patients book a doctor's appointment they see different GPs within the practise according to which one had availability on the day in question, therefore unless copious detailed notes are made on the patient's record which are read and taken into account on subsequent visits it can take a long time for all the pieces of the puzzle to be put together and a clear picture seen. Following diagnosis her GP was helpful providing her and her family with information packs and suggesting websites where they could find out more and get support, the doctor suggested she investigated AYME (Action for Youth with ME). She describes herself as originally feeling confused as she had never heard of CFS and wasn't sure what the prognosis was, but gradually accepted the situation. There was obviously an emotional process that Chloe had to go through which included confusion and therefore probably a

degree of fear and apprehension; followed by research into what CFS is and a sense of enlightenment; to finally acceptance of the situation.

Chloe missed most of Year 11 but her school was very supportive and based on her excellent academic history said she would be allowed to return to sixth form. She felt much improved when she took her GCSE exams and then returned to school part-time to do two A' Levels working within a flexible timetable which allowed her to start late or finish early each day in accordance with how she felt. Despite the absence from school and the restricted timetable Chloe achieved 10 GCSEs and two A' Levels. She has aspirations to one day be a writer and believes that working for a charity, as she is with AYME, will enhance her CV and overcome some of the academic gaps that may hinder her acceptance onto a media degree course. Chloe's academic results and aspirations for the future reveal a glimpse into how bright and ambitious she is, she has a clear focus of what she wants to do with her life. Her friends remained in close contact and made the effort to visit her at home, she acknowledges how fortunate she has been to have their understanding and support. Chloe has been fortunate to have such committed friends, which she herself acknowledges, this hasn't been so for some participants in the study. Chloe's persistent friendships may have been an indicator of the strength of the relationships or just simply the types of people Chloe and her friends are. Chloe also has a boyfriend who has remained constant throughout the time she's been ill, as well as a good support network within her close family, she is very thankful for this and believes that without this encouragement and backing she would not have been able to achieve what she has. Chloe's mum works predominantly from home so was always in the house when Chloe was ill, although she mentions that now she is regaining her health it gives her mum back some freedom not to have to worry about her all the time. Initially when the family knew very little about the nature of CFS they struggled to understand how Chloe could manage to go out on a Saturday evening and then be totally exhausted the following couple of days and be unable to get up for school the following week;

It was quite hard because for a long time obviously we didn't know what was wrong with me, so I'd go from going out at the weekend – say going to the cinema, and be fine, and then it would come to school and everyone would be

like “you’re faking this”, because obviously you don’t really know how to take it, (CHLOE).

This is typical of the ‘Boom-Bust’ cycle (as CFS healthcare workers call it) – i.e. doing too much when energy levels feel high and then suffering for it afterwards. As Chloe and her family began to learn more about CFS they understood better how to adapt her lifestyle to accommodate it. She believes that by making changes to her life as well as the progression of time she has improved greatly, from being bed-bound for the first three months, to then managing a few hours of school twice a week, to now having a virtually normal life as long as she is sensible. She acknowledges that she isn’t completely well and that she has to pace herself in order that she can live a relatively normal lifestyle, but makes allowances in accordance with her energy levels, for example, if she goes out on a Friday evening with her friends she knows she will have to set aside the following two or three days to rest before returning to an even keel. Despite recognising that she has made significant progress compared to how ill she was in the first three months, she recalls feeling scared at the beginning;

*It was quite scary ‘cos I hadn’t got a clue what was happening and because I was so into school my priority was “Oh my god, I’m missing another day of school”, which sounds really stupid as you health comes before education, but I’d be “Oh, I’m going to fail my GCSEs” and that would be a really big worry for me. It was scary ‘cos when they haven’t diagnosed you, they were saying all sorts was wrong with me and its horrible as all the doctors would talk **about me** as opposed to actually saying: “How are you feeling?”, (CHLOE).*

Fear prior to diagnosis is an understandable emotional reaction, nobody knowing exactly what is wrong is not an easy thing to accept. It was possible to sense from Chloe’s recall of events how frustrated she felt by the way physicians communicated with her and her family – not even acknowledging her feelings or symptoms. The one person able to ‘shed light’ on the situation is the sufferer, without including them in the consultations it is all guess work. this situation may have arisen due to Chloe’s age, with the GP feeling she was too young to speak with directly, however it appears that she felt patronised and isolated by this treatment.

Chloe feels she has become closer to her mum since being ill and that her mum can often ‘read’ her symptoms better than Chloe can read herself;

If I get back from shopping or something and I'm a bit grumpy and tired she'll (mum) say "Go and lie down, because you're going to have a bad day the next day", she knows my symptoms more, she can read me and sort of says "You're going to get a headache in a minute if you don't go and lie down...", (CHLOE).

Chloe recognises that not being committed to a university course or job means that she has the freedom of taking time out to rest which allows her to push herself harder temporarily if she really wants to go out and then having the free time to not do anything for the next couple of days. Despite this she admits to feeling frustrated at times that she has to plan her activity in accordance with her energy capabilities, without the freedom of living a spontaneous lifestyle – doing what she wants when she wants, without fear of negative consequences.

Chloe works part-time for AYME as a regional contact for the county but has used (and continues to use) the site as a social support network. She feels that utilising the site's message board and making friends with people her own age who are in the same situation has acted as a significant source of advice, support and reassurance;

...it's (AYME) been an absolute lifeline, you know, just to talk to people that are in the same boat as you are. You don't have to say "oh, I've been so poorly", because everybody feels poorly, (CHLOE).

The sense of legitimisation that AYME has provided Chloe with is palpable; she feels reassured that other people are in a similar situation to her and therefore doesn't need to justify or explain exactly how she is feeling. Chloe knows of about 20 people in her local vicinity with CFS who are registered with AYME, but these are predominantly girls. She believes that boys react differently to girls with CFS;

*ME is a really debilitating illness so I think for a man, a guy, it's quite a knock on the pride that, you know, for girls they just get on with it, but for a guy it is something you don't really want to say you can't do these things and so it might just be the case that they are sort of hiding away and not wanting to talk about it, *laughs* (CHLOE).*

The unequal gender split in participants in this study may support Chloe's theory, however it may simply be the fact that adolescent boys are reluctant to participate in

qualitative research. It has been suggested by a specialist working with young CFS sufferers (Doctor Esther Crawley, in Bristol), that boys with CFS present differently to GPs and therefore are not recognised in the same way. Whereas girls will speak of fatigue as a predominant symptom sparking doctors to consider a fatiguing illness such as CFS, boys tend to complain more of the cognitive/mental difficulties such as concentration and memory issues and therefore take longer to be acknowledged as potentially having CFS.

Chloe recalls seeing a photo of herself in the early stages of having CFS and being shocked at how ill she looked;

*There's a photo of me at a friend's birthday as I was getting better and you could see my ribs through my top...it was just horrible 'cos I didn't realise at the time I was so thin...I was like a little child; I had nothing *pause* just skin and bones! Horrible, my skin was sort of grey and my hair was dingy and thin... (CHLOE).*

She remembers that at the time of the photograph being taken she wasn't at her worst point, she was starting to improve a little but due to being indoors all the time and not managing to eat properly, (she could only stomach fruit and jelly due to the intense nausea), her appearance changed dramatically. She acknowledges that her mum must've been 'worried sick' about her at that time and although her friends, family and boyfriend has more recently spoken to her about how poorly she looked at the time they did not speak about it. It is a natural compassionate response to protect those we care about from information which may make them feel upset or worse than they already feel if they are struggling anyway, therefore despite recognising how ill Chloe was/looked her boyfriend chose not to burden her further with his own anxieties and only spoke of them with her when he thought she was better able to accommodate them. Chloe has visited a homeopath who has recommended alternative treatments to combat nausea and pain, she has also tried to improve her diet to include food rich in vitamin B12 to give her more energy – she tries to remain mindful of what she eats. She has considered trying acupuncture but didn't want to risk changing something and then suffering a relapse while she was studying. Chloe mentioned the Lightning Process and expressed her preference for

more ‘natural methods’ such as homeopathy, she knows of a friend who has spent a lot of money on the course and is now worse;

...her parents spent a lot of money on it and it just didn't work, which must be devastating 'cos she's been ill for six years now – completely bed-bound for six years. That must be heart-breaking thinking "Do we have a cure?" I think too many people when they hear about things like the Lightening Process think it's a cure but if it doesn't work it's all the more heart-breaking, (CHLOE).

Chloe believes her health is now almost returning to her pre-CFS level and has a pragmatic attitude about having been ill for so long;

I think that a lot of people sort of hole themselves away from ME, but I think that you just have to accept it, just think; "Yes, I'm ill but one day I'm going to get better – there's nothing you can do about it"... I think now that I know more and I know my boundaries and what it can do to me and stuff, I think my health has actually improved 'cos I know I need to take designated rests and I need to just get on with it. It's not going to just go away and I do just have to deal with it and there's no point kicking up a fuss and pretending it's not real, 'cos it is, (CHLOE).

Such comments as this reflect Chloe's optimistic and mature character, she has come to terms with the fact that this is the situation that she is in at this present time and believes she simply needs to deal with it as best she can.

Over the time that she's been ill Chloe's main struggles have been with nausea, extreme fatigue and generalised muscle aching. She hasn't experienced any significant cognitive symptoms, which she is thankful for as she believes physical symptoms are easier to deal with (for nausea she takes medication, for fatigue she can rest), but being unable to concentrate on reading a book, for example, would have frustrated her more.

Chloe has a board in her bedroom on which she writes her short and long-term aims – from sending a card to a friend, to finishing learning to drive. She makes sure there are small achievable things on the board which she can easily tick off so as not to feel too overwhelmed and so that she can feel encouraged that she is making progress. By constantly re-evaluating her goals Chloe feels she can retain a focus of

things she wants to attain, but she makes sure that she keeps realistic, for example, on a ‘bad day’ she tells me that her goal may be reading a couple of chapters in her book. Chloe believes that maintaining a positive mental attitude is very important;

*There would be times when I was bed-bound, when I wasn't doing things, you'd just sit and dwell on things and think about them and say; "Oh my god, this is really tragic". People get upset about it and I just think it's a waste of precious energy that you **have** got, (CHLOE).*

Chloe feels she has benefitted greatly from the CFS Service in her area despite at first struggling to adapt to the timetable of activity and rest. Now she feels that by sticking to a routine and ensuring she eats and rests regularly she can function much better, and even plan activity at the times she knows her energy level will peak. She still has to be sensible and pace herself, and when asked why she is considering applying for a blue disabled badge for her car she explains;

The stupid thing is that if I go to Tesco with my mum, walking across the car park makes the biggest difference to going. Around Tesco is fine and then you think "Well, I'm tired, time to finish shopping", then if you have to walk half a mile across a car park it makes the biggest difference – even just a small thing like that. By the time you get home you are completely shattered, (CHLOE).

The issue of CFS patients applying for blue disabled badges is a contentious one as the stipulation is an *inability* to walk; no recognition is made of the after-effects that such exertion can cause. It is therefore difficult for some CFS sufferers to be successful in applying for a badge, despite the potential of having one making their lives easier – this is an example of the misunderstood nature of the condition.

As part of Chloe's charity work for AYME she is assigned two or three people to keep in regular contact with, two of which are girls very severely affected. She ensures that she sends them cards by post and feels that this can serve as a real encouragement to someone who is isolated;

I know how big a deal it was with some of my friends when I was poorly, even though I saw them once a week if they came round, they'd still write me letters....so I know how important it is to have that shining light, (CHLOE).

Chloe recognises how much she benefitted from individuals making the effort to stay in contact with her when she was an unequal contributor to the relationship, and knows how small acts of kindness can help someone who is housebound feel slightly less isolated and lonely.

When speaking about her friends leaving for university she relayed;

When I hear “We went out and got completely slaughtered and it was hysterical!”, sometimes I feel I’m missing out, but then I think I’m so lucky with actually what I can do. There’s no point dwelling on it, (CHLOE).

Chloe seems to have adopted a very mature outlook on life and her positive attitude towards her present limitations and future aspirations is admirable. Rather than focussing on the things she may be missing out on, she has chosen to concentrate on those things she can achieve and look forward to a fuller lifestyle in the future.

6.8.3 Chloe’s Story - In Summary

One of the main things that was impressed upon me through Chloe’s story is that many adolescents with CFS are forced to mature very quickly, not just because they miss out on much of the social side of life as a teenager but also the way they need to be sensible about their lifestyle and outlook on life. Chloe, and others in the study, has displayed a very pragmatic approach to life, which she had to develop quickly faced with the boundaries imposed upon her by ill-health.

Chloe’s descriptions demonstrate quite succinctly the journey from anxiety and fear prior to diagnosis, to shock and confusion at diagnosis, through to understanding and acceptance when they begin to research what CFS is. This is a process that human beings have to go through when faced with a novel situation, but when it involves one’s health and well-being and when it is faced by individuals so young it must invoke an emotional roller-coaster of thoughts and feelings.

The ‘Boom and Bust’ pattern that Chloe describes is one repeated amongst many patients with CFS, especially prior to diagnosis. It is perhaps unsurprising that people around Chloe struggled to believe she was genuinely ill when she could manage a

trip to the cinema on a Saturday night but was then too exhausted to get up for school on a Monday morning. This cycle may be more comprehensible in an adolescent population where there is lack of projected thought about the consequences of their actions and more of a focus on impulsive desires to go out and socialise.

Having seen many young people with CFS, both participating in the study and seeing recordings of children and teens being interviewed for conferences and so on, there appears to be a pattern in visual appearance of this group of patients. The pale skin, dark rings under the eyes, lank hair and slightly haunted expression has become familiar to me. Another thing I have found is that when speaking for a time with the young people I have met, as they tire their physical appearance changes, it is as though the energy draining from them is visible in their face. Chloe expresses her shock having looked back at a photo of herself when her health was particularly poor and describes a picture similar to what I have seen.

Something that Chloe's story, and others, have told us is the strong desire by young individuals and their parents, to search for a cure. Many have researched homeopathic alternative medicines, not so much as a 'cure' but to ease the symptoms – Melatonin, St. John's Wort, multivitamins, vitamin B complex, Echinacea, Omega 3 and so on are commonly experimented with, as are exclusionary diets. There is little scientific evidence to support any of these as making a significant difference to the condition, however in some cases a portion of symptomatic relief is found.

Chloe's narrative described the negative experience she had when attending physician's appointments. She felt that she was talked *at* or *over* but not *to*. This act of dehumanising Chloe and her experience is frustrating at best, and damaging at worst. Even though Chloe is not legally considered an adult and did have parents accompanying her for appointments she is still the person to whom the doctor should relate in consultations, not to mention the fact that she is an intelligent and articulate young woman who is more than capable of liaising directly with adults. Without Chloe's explanation of her symptoms, thoughts and feelings outsiders, albeit ones trying to be helpful, cannot understand the truth of what is happening to her.

6.9 Chloe's Mum 'Claire'

Chloe's mum, Claire, has one other child – Chloe's older brother. Claire runs her own business from home and her husband, Chloe's father, works abroad and so is away from home for extended periods of time. Claire told me that she felt very emotional completing the email interview, she did not find it an easy process, as she was confronting deep-set feelings.

Claire said that her prior knowledge of CFS before receiving a diagnosis when her daughter was ill was very limited, she told me that she affiliated it with the negative conception of 'yuppie flu'. Claire relayed how receiving a diagnosis for Chloe's ill-health took repeated trips to the GP and that they spent a long time feeling confused by the situation. Upon receiving a diagnosis Claire relays having felt relieved to at last have an answer for her daughter's condition, however she also comments that she did not understand the implications of a CFS diagnosis in the early days, but their initial care strategy was bed-rest and dealing with Chloe's needs on a day-to-day basis.

Claire said that she found the GP of little assistance and felt alone and frustrated in her efforts to glean answers for her daughter's situation, they visited a homeopath which she felt of little benefit and eventually the family doctor referred them to the local CFS Service. In the absence of other advice and support Claire conducted her own research online.

Claire described how radically her life has altered in response to her daughter becoming ill;

My life has changed completely because of the ME, I was hoping to go back to the work-place full-time but because of Chloe's needs of taking her to school and back again at different times of the day I felt obliged to work from home, (CLAIRE).

Claire feels that her own freedom of choice and activity has been curtailed due to her daughter being ill, she has had to make contingency plans as far as work is concerned in order that she is available to meet Chloe's practical needs.

Claire goes on to describe the way in which Chloe's CFS has had an effect on other family members and the dynamics of the family as a whole;

My 21 year old son tried to help but he found it difficult to understand and accept the condition, my husband who works away from home has never really accepted the condition and becomes very frustrated when he returns home (he was never around when Chloe was having the really bad days), (CLAIRE).

It is fairly evident to see the way in which Chloe having CFS has brought added stress and strain to the family as a whole. Both her brother and father find it difficult to comprehend and acknowledge the characteristics of the condition, which must impact on the relationship between them. This difficulty in understanding felt by Chloe's dad and older brother subsequently puts added burden on Claire to try and meet the emotional and practical needs of her daughter, whilst balancing the rest of the relationships within the family unit. The absence of Claire's husband has meant he has missed out on experiencing the true nature of CFS and how it affects Chloe, simply because he has not witnessed the symptoms and their effects consistently through-out the course of the illness. An additional pressure in recent months has been Claire's discovery that she had skin cancer resulting in the need for surgery. The operation was more major than initially anticipated and therefore Claire herself required extra care and support from her family which she says Chloe was unable to provide due to the CFS. This situation led to further demands being made of Claire's son, who is only young himself, and as a mother Claire describes feeling guilty and frustrated at the position the whole family has had to contend with. Claire's mother visits the family home frequently but her lack of understanding and voicing of negative comments about Chloe's condition puts Claire in an awkward position of trying to explain things to her mother whilst simultaneously protecting her daughter's feelings. Claire also describes the inability of friends and neighbours to comprehend seeing Chloe go out for an evening with her friends and then 'crash' afterwards, again she feels the need to legitimise Chloe's decisions as well as explain the nature of the illness.

Claire describes the way in which the mother-daughter relationship has been altered;

My relationship with my daughter can be very volatile as I have trouble understanding her need to go out with her friends, then her crashing the next day, (CLAIRE).

In her interview Chloe explained to me how important it is for her to continue relationships with her peers and feel a sense of belonging and not being left behind, even when this means pushing herself beyond what she knows her energy levels can tolerate and being aware that she will need to rest for two or three days afterwards in order to return to an even keel. This adolescent need for a social life clashes with her mother's understanding of what would be a sensible decision to make and not go out with her friends. Claire relays her frustration;

We used to have a very healthy mother-daughter relationship but recently because of her inability (or as I see it an inability) to manage her ME it has put quite a strain on our relationship. I become frustrated that she can go out, shop, play with her friends, but simple demands that I give her she cannot do, so a void and anger and disappointment has crept into the relationship on both sides, (CLAIRE).

Claire believes that the negative emotions she feels are reciprocated by her daughter, however it is interesting to note that Chloe did not intimate towards any of these feelings of disappointment or resentment during her interview. This could be for a number of reasons, perhaps at the time that I met with Chloe the mother-daughter relationship was more positive than it now is, maybe Chloe omitted this feature of the relationship with her mum so as not to give me a negative picture of her family life as she felt loyalty towards the family unit or embarrassment at the situation, or perhaps the difficulties within the relationship have been felt more strongly by Claire than by her daughter. Claire has the benefit of years and wisdom as a mother to analyse the situation in a deeper way, and perhaps her maturity allows her to admit to the struggles she feels exist within the family's life.

Claire described to me the negative emotional effect that watching her child struggle through an illness has caused her;

It is very frustrating understanding the condition and not seeing her flourish and enjoy a 'normal' young person's life, she is a very intelligent, beautiful girl who turns into an angry depressed person which sometimes can destroy the relationship that she and I have, (CLAIRE).

The change in character displayed in Chloe is not surprising due to the frustrations and limitations that ill health has placed upon her, it is natural that these feelings are expressed within the family unit and perhaps inevitable that Claire bears the brunt of her daughter's feelings of exasperation. This pressure on the relationship is bound to leave residual feelings of negativity as not only is Claire having to withstand the full force of Chloe's feelings but also she is helpless to change the situation and stop her daughter's suffering. At one point Claire portrays her feelings of guilt and failure as a mother, saying;

I have felt I have not been a complete success in coping with Chloe or the illness so I feel I have failed as a mother to some degree. I am not very tolerant of the illness and very, very angry because of all the things I wanted for her, the lack of freedom for me, an adjustment to all the things I had planned for my life. This sounds dreadful as Chloe is the one suffering, but I want to fix it (as mums are meant to) and I cannot, (CLAIRE).

Claire's frustrations are two-fold – on the one hand she feels trapped and helpless that she is unable to alter the situation, unable to change Chloe's hardships and subsequently feels Chloe is being robbed of all the positive life experiences she had hoped for her daughter would have. On the other hand she feels resentful of the freedom she herself has lost and how Chloe's condition has had a negative effect on the way she would like to be living her own life. This latter 'confession' is made with some guilt; guilt that it is her daughter that is contending with an illness and that as a parent she should shelve her own personal disappointments. However, it is expected for a mother with children in their late teens and early twenties to feel that her time caring full-time for her offspring is nearing an end and that they will now be entering a phase in their lives when they become more independent of their mother and she would be allowed the freedom to pursue her own interests and desires once again.

Claire concludes her email by saying;

Throughout the illness I have felt upset, confused, all of the above, because it is out of my control and I cannot do anything to fix it. This was not on my life agenda and it is frustrating and all-controlling. The confusion is due to the lack of understanding of what is happening to her, if it was cancer of a physical disease then it would be easier to understand but I feel as if a second

person sits inside my daughter and I want it to go away or be controlled – as I am sure my daughter does too. I make excuses for her and they should not be excuses because she is tired, she is in pain, she is confused and she must be depressed, but it is fighting the unknown which is hard for me to do, (CLAIRE).

These thoughts that Claire articulates so well really sum up the depth of emotion she has felt throughout her daughter's illness, feelings of confusion, frustration, fear, anger, resentment and disappointment. Her helplessness to alter the situation – for the benefit of Chloe, herself or the rest of the family – is exasperating. As she says this was not 'part of the plan', none of them had anticipated such a disruptive force entering into all of their lives. Claire believes that if Chloe had an illness that was less misunderstood they would all cope with it more effectively. The fact is that current knowledge of CFS is so limited – there is no known cure, no definitive understanding of origin and no clear-cut prognosis, this causes great confusion and isolation for sufferers and their families. Claire's analogy of another (unwelcome) person sitting inside Chloe dictating her life, feelings, emotions, activities and abilities displays a concise mental image of the way in which Claire believes her daughter has been accessed by some force which is beyond all of their control. As a mum she believes she should be able to influence her child's life for the better – eliminate her suffering and allow Chloe the life she deserves, and yet her disturbance that she is unable to do this is tangible.

6.10 'Vicky'

6.10.1 Pen Portrait

Vicky is a 17 year old white British female who has had CFS for the last five to six years. She lives at home with her mum, who acts as her full-time carer, her dad is deceased, she has siblings who are much older than herself due to her father being relatively old when Vicky was born. Vicky received a CFS diagnosis four years ago by a specialist, she has no other medical conditions and there are no other illnesses in the family. She takes melatonin to aid sleep. She is much improved recently which she attributes to attending the Lightning Process course.

Vicky described her group of friends as being 'the weird ones' who don't fit anywhere else in the college social world. She was very close to her father as a

young child as he was retired and therefore at home full-time, and her mum worked as a teacher. Her mother commented that prior to Vicky's dad's death when she was eight Vicky had rarely been ill, after the bereavement she was often ill. At aged 11 when she moved to secondary school her health took 'a nose-dive' and she became ill in the October half-term of the first year. Vicky believes her fatigue started gradually over two to six months but her mum recalls it being more rapid, possibly a week. When her father died it changed her world dramatically, and she speaks of now being close to her mum, but that process taking a fair amount of time and effort on both parts. She believes she catches illnesses more easily than her peers and it takes her longer to recover from them than others her age. She recalls the trigger of her CFS being severe stress, her mum agrees with this but adds the presence of an infectious disease at the time. Her worst three symptoms at the start of the CFS according to Vicky were sore throat, tiredness and anxiety, her mum lists them as laryngitis, severe hip pain/weakness, (so fell easily), and fatigue. The worst three now according to Vicky are tiredness, muscle pain and lack of concentration, according to her mum they are residual pain, migraine and tiring easily. Both agree that Vicky's symptoms change over time but that generally her fatigue is improving over time. She has to limit her activity to prevent an increase in fatigue and describes physical activity in resulting in her feeling more tired than usual, although she does manage to continue extra-curricular activities in the evenings. If she rests some of her fatigue dissipates and she needs to rest for approximately an hour for this to happen, if she stops resting before this period her fatigue returns. Vicky rates herself as 92% on the AYME Functional Ability Scale, and believes she is well on the way to full recovery.

6.10.2 Vicky's Story: Adolescent CFS is...*Not Going To Be Permitted To Define Who I Am*

Vicky arrived at the hospital with her mum and a friend, they were on their way out for the day. Her mum and friend stayed in the waiting room while Vicky and I spoke in a side room. Vicky is a sweet girl, she comes across as eager to please and be liked. Speaking with her was easy and she was open and candid as she spoke about her life. Her recollections indicated that she is fairly introspective and the way that she has thought things through and communicates eloquently her feelings and

opinions indicate that she is intelligent and contemplative. She does, however, present as being fairly young for her 18 years of age. Over the past few years Vicky has led a fairly isolated life due to having CFS and missing school, she has spent the vast majority of that time with just her mum and grandparents and has not therefore experienced the normal maturation process that occurs during the teen years; learning the norms and mores of adolescent behaviour and communication. This segregation from a customary teen social context may explain why she is not as mature in her outlook on relationships as others her age.

Vicky is 18 years old now, she first became ill approximately seven years ago at the beginning of her senior school education. After only one half term of her first year she became ill with laryngitis and lost her voice for nine months, she tried to keep going to school but her attendance became increasingly sporadic. During the initial weeks she remembers feeling very tired and unwell, as well as frustrated and scared that nobody knew what was causing the problems. She tells me that she has had a good support network in her close family – her mum and grandparents. She lives at home with just her mum and her grandparents live next door. She has two half-brothers and sisters who live further away. When asked whether her siblings understand about her having CFS she explains that it's difficult as they only see each other occasionally;

I think they find it difficult to understand what it is, 'cos when I'm with them I feel more full of energy 'cos I'm happy, so they always see me at my best...so it's difficult for them to understand when I'm having a really bad day because they never see it, (VICKY).

Vicky is very grateful to her mum's support, both practical and emotional, and believes they have a much closer relationship now than they had in the past, or would have had had she not become ill. Her mum acted as a 'driving force' trying to ascertain medical help and answers, and fought to gain the help Vicky needed. When Vicky first became ill her mum believed that she may have been responsible for her daughter's illness. Vicky relayed to me feelings of guilt that both her and her mum experienced at that time;

I felt really guilty at one point because my mum blamed herself, 'cos when she was pregnant with me she had glandular fever and she thought that maybe that had caused it. For her, she thought that glandular fever was a short-term ME almost, she really did blame herself. I was like, "No, don't worry about it, don't blame yourself, please. I blame myself, it's me", (VICKY).

It is a natural response for any parent to try and discover why their child is ill and also oftentimes to blame themselves. It is a reflection of Vicky and her mum's lack of knowledge about CFS that led them both to the conclusions they reached. If the nature of CFS had been explained by a healthcare professional they possibly would have avoided these negative feelings.

As well as the throat problems Vicky also suffered with a great deal of pain in her hips and walking became increasingly difficult to the point she needed use of a wheelchair. She recalls that the school was very helpful and researched CFS themselves in an effort to provide Vicky with the best support they could. They worked hard to maintain contact and ensured that work was sent home. The school tried to alter Vicky's timetable so that she could attend alternate days but the logistics of fitting in around the rest of the class's lessons made it impossible for the system to work. At the end of Year eight Vicky started home-tuition for English and her mum helped her with the work. They found though that their relationship became strained and Vicky needed her mum more as a parent than a teacher, hence the need for home tuition from tutors coming to the house. Vicky achieved five GCSEs all at 'C' grade but describes it as having been 'hard work', especially the week of final papers when she needed to go to bed after every exam. The special needs teacher at the school was very helpful and organised it so that Vicky could take the exam papers at home and so that the examination process was broken down over the year on a modular basis, this way if she was experiencing a particularly 'bad patch' for one modular paper she could fall back on the other parts of the assessment. They also allowed her extra time for each paper so that she could take a break part-way through to rest should she need to. Vicky is deservedly proud of her academic achievement despite the barriers she has had to overcome. Vicky told me how enthusiastic she was about school prior to becoming ill;

Oh I loved school! I always really loved school and was really upset when I was ill 'cos I always wanted to be in school. I think it was probably one of the

reasons I would get really tired because I was always pushing myself really hard 'cos I wanted to be in school, to be with my friends...(VICKY).

In all, Vicky missed practically all of her secondary school education, which meant she lost out on many of the important social interactions which take place during this period, she told me her thoughts on this;

I missed out on all the experiences, especially the social ones. I didn't have friends. I haven't really kept any of my friends from secondary school, some of them stuck by me and I speak to them occasionally but I'm not in huge contact with them (VICKY).

The social side of school appears to be something that Vicky came to dread on the rare times she had any contact with her peers, she was teased by some and simply left behind by others who moved on with their lives. I was given the sense that this became a real issue for her, especially when she speaks of the friends she has now in College and how much she appreciates their solidarity.

As well as foregoing school, Vicky also had to stop the many extra-curricular activities that she did; tap and modern dancing, singing and theatre arts, swimming and some other sports, and piano lessons. Vicky has managed to continue with piano, thanks to a supportive and encouraging teacher, but has had to stop dancing and sports due to her hip and leg pain, and the singing when she lost her voice. She explains how difficult it was to stop those activities;

That hurt...I hated giving up the dancing, 'cos I love my dancing. I love doing shows, I'm very theatrical. I love doing things like that; I like musicals, I like to sing, I like to dance. It was heartbreaking having to give those up which is why I kept up the piano – I was determined (VICKY).

Vicky became virtually wheelchair-bound, only able to walk very short distances with crutches but requiring a wheelchair if she went to the shops for example. She had significant pain in her hips and legs which would result in numbness and her collapsing on the floor. As scans and tests ruled out any other cause she was told that her legs problems were due to CFS. Vicky struggled with the way other people looked at her when she was in a wheelchair;

What I found hard was the way people looked at me. People would look at me and think “Why is she in a wheelchair?” Especially since I didn’t have like a broken leg or anything obvious to show why I was in it and I would quite often sit there with my legs crossed, ‘cos it wasn’t like I couldn’t walk, it was ‘cos I couldn’t walk very long distances at all. I could just about walk to the toilet and back in my house. It wasn’t that I couldn’t walk so I could move my legs and people said “well, she’s not paralysed”, and would give me really funny looks, especially round town. That was really hurtful ‘cos you couldn’t go around with a sign on your head saying: “I have ME – I’ve got pain in my hips and this is why I can’t walk”! – it was quite embarrassing. (VICKY).

Vicky also commented on how she found it frustrating and felt she “had no life at all at that point” when she was reliant upon her mum to push her in her wheelchair. She was unable to go out with her friends and felt totally dependant upon her mum without any freedom. As discussed in previous chapters; adolescence is an important time in which young people begin to make the transition from dependence to autonomy, which involves the need for exploration of freedom and a shift from reliance on the family to a growing affiliation with different friendship groups. Some young people with CFS are deprived of this freedom which denies them the opportunities that their healthy peers have.

Vicky recalls being teased at school linked to the need for crutches and a wheelchair and her loss of voice. On occasions it was possible to be dropped off at the school doors by car and therefore only require the use of crutches as the distance needed to travel could be made without need for wheelchair, then other pupils would question her as to why sometimes she needed a chair and sometimes she didn’t, implying that her disability was not genuine.

It was so difficult to explain to them, partly because I didn’t know myself quite what was going on, all I knew was sometimes I could walk and sometimes I couldn’t. I didn’t know what was causing it, no-one could find any reason except for the ME, and explaining that to them was just too hard, as it’s quite complicated...some people didn’t believe me and would say “Get out of the chair” and I would say that I couldn’t...it was hard (VICKY).

Vicky found herself teased by many different people at school because they couldn’t *see* anything wrong with her and therefore didn’t believe that she was really ill. She relayed to me that sometimes she found it less pressure to stay at home and do her

school-work rather than have to put up with comments and questions from her classmates. She told me that she has been depressed in the past and was prescribed antidepressants at one stage. She particularly struggled with the transition into a wheelchair and although she was referred to a psychiatrist she found it easier to speak to her mum whom she now seems emotionally very close to. She took other medication to help with insomnia, as no matter how tired she felt she wasn't able to sleep. She tried a herbal remedy but stopped as she believes this gave her nightmares. The nightmares lasted about six weeks, and were so severe she would wake in the night shaking and screaming. This resulted in her approaching the GP for sedatives to counteract the nightmares.

Vicky explains that when she first went to college she found it a strain socially due to all the time she had missed from school;

I was quite socially inept. I found it difficult to make friends and to keep them. I made them to a certain extent, but not a lot of them, and then I got ill and so I lost them all again and that was quite hard. Being in that social atmosphere was tiring 'cos I wasn't used to that at all, I missed my friends and I wasn't very good at talking to people. I wasn't up with all the things that people talk about, like fashion, I was like "What? What's that about? I don't know anything about that". So it was quite hard, but I got better over time. (VICKY).

Although originally when Vicky started college and then had to stop because of her health she found the social interactions particularly difficult, now she is feeling much better, she has more independence and her friendship group has grown and she feels she now has friends which she will keep for a long time.

One major thing that struck me about Vicky throughout the interview is that despite being bright, bubbly and intelligent she is very young for her age. The way she speaks about her friendship group and her attitude towards boys/boyfriends is nearer what I would expect of a 14 year old, not an 18 year old. When asked if she had a boyfriend she replied;

*Not at the moment, kind of hoping for one though. The boy in our group; I quite like him *laughs* and my friend said "I'll ask for you" and I was like "No, I'll wait". But no, I kind of hope for a boyfriend, I asked a boy out. All*

the boys liked me when I had an electric scooter, 'cos I had one to get around school, and they were all asking me out 'cos they wanted a go on it! That was quite fun actually...I would like a boyfriend, I may get one. I think I could get one now, I don't think I could've before, but I could now... (VICKY).

I reflected on the way Vicky spoke about boyfriends and contemplated whether her 'social immaturity' is due to Vicky having spent a lot of time away from her peers. In many ways it would perhaps be unsurprising if adolescents were less mature when they have been isolated for lengthy periods and therefore missed out on experiencing all the 'normal' rites of passage of being a teenager, the cultural lessons which dictate how to act and speak and the experimentation with different types of relationships.

Vicky speaks about CFS as a person, she explained to me her reasoning behind that;

*I always talk about the ME as a person, like "I liked to sing and IT decided to take my voice away, and then it decided to give my voice back"; "I was still dancing and IT stopped me from dancing and then it decided to give me hip-pain!" *laughs* I always talk about it like a person, that's my way of talking about it. I find it easier to explain it as something. I've been told that it's something that's in your mind and stuff like that, and I was blaming myself a lot and I thought, if I can think of it as something with an identity then I keep myself – I don't BECOME the ME. I don't want the ME to be me, I want it to be a separate identity and some part of life that I can get rid of *laughs*. (VICKY).*

Vicky doesn't want her ill-health to define who she is or what her life can be, and therefore regarding it as some transient being allows her to believe in a future one day without it.

Vicky didn't know about AYME (Action for Youth with ME) – the national charity for young people with CFS, widely known about within the participants of this study, and didn't do any research of her own to find out about CFS. At the beginning she relied upon what her GP told her and what other people knew about it, she said she learnt more when she began attending the CFS Service...

I never really knew that much about it so I was a bit blind about it. To a certain extent I didn't want to know about it 'cos I didn't want to think "Oh, that's what I've got in store for me". I was a bit in denial, I didn't want to

admit it. I knew I had it but just went by what the doctor said. I didn't look anything up – I wasn't interested, I didn't care! (VICKY).

This attitude is different to anyone else I have interviewed, in every other case the individual or their family were eager to investigate further what CFS is and how best they could deal with it. Vicky's approach is nothing to be criticised, in many ways it could be seen as sensible not to project into the future about things that may or may not happen, it is simply a different way of looking at it, possibly a reflection of her personality and the family's approach to life.

Vicky began a childcare course at college, part of which was a placement in a nursery, she was totally exhausted by it and had no energy to return to college. She then began to catch infections and never seemed to get better. She eventually had to suspend her course altogether. It was at that point that she was told through a friend about an alternative therapy called the Lightning Process. She explains that she found the course a resounding success – she believes it enabled her to return to college, keep up with the workload, attend placements, she now has plenty of friends, is able to go out and has no need for a wheelchair or crutches. Vicky explained the Lightning Process to me;

It's basically a way of thinking; whenever you get a negative thought which makes you worried or upset you stop it and think about something nice and what you want for your life. You use this over a month to six weeks and slowly your body gets back into the way of thinking and you get rid of all the adrenaline and get better and better over time. (VICKY).

Vicky goes on to tell me that she would highly recommend the Lightning Process course to anyone with CFS. She also told me that the course leaders insist that you only apply for a place if you have total faith that it will work, if you are cynical in any way you need not apply as it is unlikely that you will be accepted. A little later when discussing something else Vicky explained a little more about the Lightning Process;

I still say that I have got the ME because I think it's always going to be there, it (the Lightning Process) just keeps it at bay; it just helps you to control it to a point where you don't notice it's there. Sometimes it does come out, like when you're really tired or when you get ill. (VICKY).

During her explanation of what she understands of the theory behind the process Vicky used the expression ‘mind over matter’ more than once, I probed further into what she meant by this, asking if it means that CFS is not a physical illness? Her response;

It's difficult. It IS physical 'cos it's your brain telling chemicals in your body to work, so it's the chemicals that are the physical bit that are causing the problems and the tiredness. But it's a way of thinking that helps to stop your brain from producing those chemicals. It's kind of mind over matter but yeah, I would always say that it's a physical thing definitely. I hated it when people told me that it was in my mind, it made me sound like a nutter! It makes it feel like it's not real and it's really annoying, and 'cos it makes you really upset you think "It really is my fault". (VICKY).

When asked about her future aspirations Vicky tells me that in the short-term she wants to learn to drive, but in the long-term she wants to pass her current college course with the necessary grades to be accepted onto a midwifery course.

6.10.3 Vicky's Story – In Summary

Something that could be taken from Vicky's story is the suggestion that when young people are isolated due to illness and forced to spend the vast majority of their lives confined to home, away from their peers and normal experiences of teenage life this may well influence the maturation process in terms of what is considered culturally correct. Vicky, despite having a reflective and intellectual ability of looking at her circumstances appears socially stilted and a lot younger than her 18 years with regard to those things that typically dominate adolescents' conversation such as romantic relationships, peer interactions, fashion and so on. The return to school or college for a child who has missed a large portion of their academic life is an intimidating prospect as Vicky explains, she feels nervous not only due to the academic pressure of school but also at the prospect of returning to an environment where she is surrounded by her peers whom she feels she no longer relates to as well as she would have done had she remained in school.

I am sure that Vicky is not alone in experiencing feelings of guilt concerning the effect her illness has on her mum. Sacrifices that mothers who have to return to being

full-time carers make may include having to give up work or resort to part-time rather than full-time hours, also it impacts their social freedom. One woman told me, outside of an interview, that she had been confined to home for such a long time that she actually felt slightly panicky on the rare occasions she visited a public place such as a supermarket, feeling overwhelmed by the number of people and amount of noise, she described it as having become institutionalised.

A significant point which is illuminated by Vicky's narrative is the overlap in roles that may occur when a child is unable to continue in full-time schooling. Vicky's mum tried to help her academically with her coursework and in turn took on the role of teacher, which impacted their relationship, resulting in them applying for home tutors to visit the house so that Vicky's mother could return to her primary position as parent which is what her daughter required of her the most.

One striking thing from Vicky's narrative is her need to separate off herself from her health-condition, she feels so strongly that she doesn't wish to be defined by the CFS that she refers to it as a separate entity to herself. This is interesting because it demonstrates the strength of feeling it causes Vicky. This may be due to the fact that CFS is a condition which is so poorly understood, its character and prognosis are so indefinite, and therefore there is a danger of the fear of the unknown becoming overwhelming for the individual. By segregating herself from it, Vicky allows herself the opportunity not to be consumed by it.

Something that Vicky's narrative allows us insight to is the distress caused by people's ignorance of CFS, she mentions having it said to her that it is simply 'all in the mind' which she has found understandably frustrating and upsetting. Equally, being teased by her peers for being 'different', for not fitting in with the crowd because of the limitations caused by her ill-health has been a source of anguish for Vicky.

Despite the best intentions of the school to accommodate Vicky's illness there is only a limited amount of flexibility they can show in order that they demonstrate equality and fairness for all of the other pupils. As learnt from Jack's story, allowing him to start the school-day late or finish early is beneficial to his level of fatigue, however it causes practical difficulties for the family as there is no school bus to

transport him at those times. Similarly, the attempts to alter Vicky's timetable did not ultimately make her school life easier as she found she was missing classes and therefore turning up to lessons unaware of what had been taught previously. The allowance of extra time or a scheduled break in the middle of exams is a good idea as far as easing the cognitive strain of having to perform under pressure, however it does mean that an already exhausted child is caused still more tiredness by having to remain in an exam environment for a prolonged period.

6.11 'Cassie'

6.11.1 Pen Portrait

Cassie is a 15 year old white British female, she is an only child who lives at home with both parents. Mum works part-time and dad full-time. She was given a CFS diagnosis by a specialist in 2004. She also has ADHD, Asperger's syndrome, anxiety and hyperthyroidosis. She takes a selection of prescription medications and some herbal remedies. There are no other medical conditions in the family.

Cassie is in Year 11 at school which she attends full-time, although she estimates that she probably misses approximately one day of school per month. She doesn't believe that she catches illness more easily than her peers but thinks that she takes longer to recover from them in comparison to others her age. She describes being physically active as making her more tired than usual. She has been able to continue her out of school activities which include dance and drama, and she doesn't believe she needs to cut back or limit her activities to stop her fatigue increasing, although her mother disagrees with this. Her fatigue started with an infectious illness which her mum remembers as starting over a one week period although Cassie believes this was longer, more like two to six months. When asked her three worst symptoms at the start of her CFS and her three worst now, she said extreme tiredness for both time periods but didn't give another two answers. Her mother described her three worst symptoms initially as extreme tiredness, headaches and stomach aches and now as tiredness, poor short-term memory and mood swings. Cassie believes that her symptoms change over time but her mother disagrees. Cassie says her fatigue improves after 15 minutes rest and won't return if she stops resting, her mum disagrees and to the former says the time needed to rest is variable and that the

fatigue does return if she stops resting and resumes activities. Cassie describes her fatigue as “improving over time”.

6.11.2 Adolescent CFS is Experienced as...*Battling To Be Believed*

When I first met Cassie and her mum at the hospital for interview and we talked together it became clear that she has spent a number of years battling against disbelief and prejudice regarding her daughter’s health conditions. Cassie’s mum is an individual who has fought tirelessly against negative opinion from healthcare professionals and even her own family concerning Cassie’s diagnoses of Asperger’s Syndrome, ADHD and CFS. She portrayed a picture of herself as at times being fairly isolated. Cassie has over the past few years been diagnosed with relatively misunderstood and controversial conditions – which could be seen as conflicting in nature – i.e. ADHD is primarily characterised by over-activity and abundant energy; conversely CFS is predominantly an illness of fatigue and inactivity. It is not difficult to see why Cassie and her mum have come up against difficulties when explaining Cassie’s health to other people.

Cassie has been ill since 2003, at which time, following a series of throat infections, she was diagnosed by a paediatrician as having CFS. In all, Cassie missed two years of school but is now entering her third year of being back in school, which she now manages on a full-time basis. Cassie’s school was supportive, they didn’t question the fact that she was unable to attend and continued sending work home for her to complete. When Cassie felt well enough to return to school for half days she found that she had very few friends and although she found it difficult she tried to not let it upset her and concentrate on her school-work. When she was well enough to return to school full-time there had been a transition of schools – from middle to upper school – and she returned to a new school and so began making new friends.

When Cassie was ill at home her main symptoms were tiredness and persistent headaches, she spent the majority of her time lying on the sofa and only left the house on rare occasions. Cassie’s primary carer is her mum whom she has always had a close relationship with. They believe that the strong bond between them is derived from the other health issues that Cassie has had to deal with over the years, which include ADHD, Asperger’s Syndrome and Anxiety Disorder. At the time

when Cassie was first ill her mum had only recently returned to work, which she subsequently needed to stop due to Cassie requiring her at home full-time. They report feeling that their GP was dismissive of them when they went to appointments, Cassie's mum, Deborah, explained;

*Nobody actually believed there was something wrong and when you've got a ten and a half year old laying flat out on the sofa with severe headaches and tummy aches and can't move – and this is an ADHD child! – and you've got a GP that won't listen ..*pause*.. that's the hard part. (DEBORAH).*

Cassie's mum recounts that they eventually “gave up” visiting the family doctor and began seeing the school doctor who referred Cassie to a paediatrician, at which point she was given a CFS diagnosis. Listening to Cassie's mum speak it is obvious to hear her frustration about the situation with the GP, she believes he delayed a diagnosis which made Cassie's life more difficult than it needed to be. Cassie's mum is no longer willing to see the same family doctor, despite still being enrolled with the same surgery. She says, with obvious emotion;

He wasn't prepared to listen, he was closed-minded - and then the appointment was over, and that was after having to wait ten days to see him. (DEBORAH).

Cassie's mum describes feeling relieved when her daughter was eventually given a diagnosis of CFS as they were then able to manage the situation more effectively, she had had suspicions that it was Chronic Fatigue Syndrome prior to the paediatrician's confirmation, so had already been caring for Cassie according to information she had read about CFS, but being given a conclusive diagnosis confirmed to her that she had been doing the right thing. As with other participant's stories the act of receiving a diagnosis is a very important moment, it is at that point that sufferers and their families feel more in control of the situation. They can then begin researching CFS, how best to manage it and who to seek for advice and treatment. This sense of relief is possibly in part due to the vague and misunderstood nature of the condition and the fact that symptoms need to have persisted for a number of weeks or months before physicians are willing to diagnose it having eliminated other possible causes of symptoms. The period of illness prior to diagnosis in any individual's life is a tense one, the feeling of 'being in limbo',

without anyone being sure of the cause and yet unable to function normally is a frightening and confusing time, possibly more so in a child/young person due to the huge social, academic and physical changes which are part of growing up.

Fairly early in the interview I began to form the impression that Cassie is relatively detached from her situation health-wise, when asked if she read about CFS herself or asked her mum questions about what she had discovered Cassie replied that she was content to let her mum do the research and that she just acted in accordance with what her mum said was the best things to do. Cassie didn't appear to have been anxious about her health at any point, nor did she seem eager to learn more about her diagnosis of CFS. Conversely Cassie's mum acted in the opposite manner – eager to research and find out more information via the internet, also she insisted that her daughter be seen by healthcare professionals who knew more about the condition. The lack of concern on Cassie's part may have been linked to her age at the time she originally became ill as she was only ten years old. Also, it could possibly be due to the fact that Cassie's mum has had to do a lot of 'campaigning' over the years with healthcare professionals in order that her daughter's other conditions – Asperger's and ADHD – be addressed. Cassie may well have become accustomed to her mum doing the research and communicating with doctors, and subsequently been more relaxed over the CFS diagnosis knowing that her mum was working on her behalf, at one point she stated;

When I went along to all of these things with the doctor, I just kinda sat there and let mum deal with it and didn't really do much, I was happy for her that she had all the information and knew how I felt anyway so she could put across how I felt, (CASSIE).

There is a huge difference between CFS and ADHD, in fact they may be viewed as being conflicting in nature, with the former rendering an individual exhausted, lethargic and unable to function normally, whereas the latter having characteristics of excessive activity and restlessness. Cassie's mum describes CFS as "very contradictory to the ADHD", and believes it is for this reason that she has been faced with more of a struggle convincing doctor's to take her daughter's health seriously. Cassie describes her need to pace herself at times, even now as she feels she is recovering from CFS, however she still participates in a different activity every night

of the week, including dance, spinning, music and drama. Prior to becoming ill she also had swimming and Taekwondo lessons, but had to forego these due to lack of energy.

Cassie believes that when she had to stop the more energetic activities she was doing she instead concentrated more on dancing and this has really become her focus, she even relays that having CFS pushed her in the direction of dance full-time.

I wasn't really completely focused on it as I am now, so I'm quite glad in a way that I did get ill, although I'd prefer to be without the CFS, (CASSIE).

As a family they have felt partial benefit from attending the CFS Service, but feel there is a lack of knowledge within the team about how to manage CFS alongside the rather contradictory ADHD. This lack of knowledge is perhaps understandable considering Cassie's mum acknowledged how unusual the combination of both conditions is and that she does not know of any other children in the same situation.

The pair explain there has been a lack of understanding from Cassie's extended family - grandparents especially, and that there is also tension between Cassie's mother and father over the way their daughter's health should be managed. Cassie's mum expanded on the difficulties that her Cassie's health has caused within the marriage, she explains that her husband struggles to understand the combination of ADHD and CFS with their two opposing sets of characteristics;

*I think generally the whole package has put strains on us – it puts a strain on our relationship and it's very ***pause*** no, it's not volatile at the moment – it's 'fragile', it's very fragile right now, (DEBORAH).*

The way the situation was described it has at times appeared to become 'Cassie and her mum against the world'; i.e. the lack of understanding from extended family members, the tension within the marriage which naturally impacts on the parent-child relationship, the fact that ADHD and CFS are both conditions which are largely misunderstood and relatively controversial, and therefore Cassie's mum has – by her own admission – felt the need to battle to be heard and taken seriously by healthcare professionals. Cassie's mum is swift to defend her daughter, she doesn't believe she

is well enough to carry out household chores for example, and does not leave Cassie unattended at home despite knowing that other 15 year olds have more responsibility and freedom. Deborah expresses her feelings of being isolated and misrepresented amongst her extended family;

I find it frustrating that family don't understand. I kind of expect it from others that aren't family 'cos they're not as close, but family – they should be a bit more understanding, (DEBORAH).

It seems that Cassie's mum feels let down let down by her family and isolated from them, on reflection I had a mental image of her descriptions as her seeing herself and Cassie as an island – whether this segregation is of her own making or not is not for me to comment upon, but I did feel sorry for her that she feels without support from those closest to her.

Cassie believes that she has *more* opportunities than her peers due to her mum's support and encouragement. This is a positive reflection on the way Cassie views the mother-daughter dyad, she appreciates the input and effort that her mum has made on her behalf and feels she has benefitted from that.

Cassie describes having CFS as not only affecting her physically but also impacting upon the way she is perceived by others;

Other people just see it as like a 'get-out clause' kind of thing. When I first started secondary school, although I was in full days I didn't do games. I told them the reason why was 'cos of the ME and they said "Oh, I wish I had that so I could get out of school and not do things". They just didn't seem to understand, (CASSIE).

Cassie describes her comments from her peers such as these about being excused from PE as “a bit hurtful” and says the situation makes her feel frustrated, especially when she was jeered at school and called a ‘liar’ (p. 17). To be mocked in this way by classmates has obviously not been easy on Cassie and it is perhaps understandable then why she reveals that she is reluctant to tell many people about having CFS.

Cassie and Deborah feel that Cassie's health is now improving, but her mum is concerned that Cassie is prudent in pacing herself in order that she does not relapse.

She describes Cassie as struggling towards the end of the previous school year as she was tired, had over-exerted herself and had the stress of exams to contend with. Cassie's mum describes the following – almost with a sense of panic in her voice;

She has lost nearly three years of middle school, and if she goes back down again now, well that could be sixth form out. That could be drama college/ acting school – whatever she wants to do later – it could all be gone. I think she needs to think seriously, (DEBORAH).

Cassie's mum relays that Cassie does not go to bed until the early hours of the morning because she is sat at her computer and has to be nagged to go to sleep. Cassie is clearly embarrassed at this point in the conversation and it appears to be a frequent argument that they have. When I suggest that such behaviour could simply be part of teenage rebellion her mum agrees but is clearly concerned that if Cassie does not take care of herself she will relapse and all of the time, effort and care that it has taken to reach this current good level of health will be undone. Deborah says;

*She went down with the ME, she's come back, she's doing exceptionally well now – despite the things that are going on for her – she's done exceptionally well and the possibility of losing it again 'cos she won't sleep *pause* I can't get that through to her, (DEBORAH).*

Cassie reacts to her mum's warning with little obvious regard, she again seems detached from the situation and her mum appears more anxious about Cassie's health than she herself does, however this could be due to embarrassment that it is being talked about in front of me.

Cassie is reluctant to speak about having CFS to her friends at school or at her out of school activities;

I don't tell people unless I have to – I don't feel it's necessary. I haven't about my anxiety disorder or Asperger's, I've told some people about my ME 'cos I've had to because of games but I won't tell them otherwise, (CASSIE).

It is unclear why Cassie doesn't want people to know about her health, it may be that she does not want to be regarded as different from the rest of her social group due to

embarrassment, or that she simply doesn't encounter many problems having the CFS and therefore it really isn't an issue for her.

Cassie spoke about her future ambitions and aspirations at which point her mum reiterates the need for her to focus and act sensibly about her health. Her mum again has high praise for Cassie telling me of her daughter's ability and potential, she does have concerns over Cassie's ability to move away from home at present, but thinks that in three years time when the decision has to be made (at the end of her sixth form) she will be better equipped - emotionally and physically. At this point her mum expresses (more than once) her apprehension about Cassie moving away to dance/drama school saying *she* wouldn't cope without her daughter at home. Her mum makes jovial references about accompanying her daughter in order that she can do her cooking and laundry, but despite the attempt at humour I think there is a real element of truth here. I feel that possibly Cassie's mum has spent so many years campaigning on her daughter's behalf for medical attention, and pouring copious amounts of time and energy into her dancing and drama pursuits that it has consumed a huge proportion of her time and the thought of Cassie leaving home will leave a massive void in her life.

Cassie feels she can achieve "possibly more" than others her age. She is very self-assured and has a high level of confidence in herself and her own abilities. She is not afraid to vocalise that confidence or how proud she is of herself, at which I am a little surprised at the lack of modesty when speaking to a stranger. Possibly her self confidence stems from the manner in which she has been raised – the fact that she is an only child who has undivided, unrelenting and seemingly limitless attention showered upon her, coupled with her mum's doting perception of her – always praising her and rarely seeing any fault in her.

At one point in the interview Cassie's mum made reference to the type of children she thinks get CFS;

just I did wonder if it wasn't the kids that are extremely active, not necessarily achieving but those that sort of are exceptionally active outside school...The one thing I do seem to notice is the kids with ME are not those that want to skive school; they're the ones who want to be in school, (DEBORAH).

In the small sample of young people that I have interviewed there does seem to be a general character trait of wanting to do well; working hard and achieving well at school. I have not found anything in the literature to confirm or deny this observation and I acknowledge that it is difficult to draw far-reaching generalities from such a small sample size, however it may be suggested that this 'high-achiever' personality trait that helped coin the label of 'Yuppie Flu' in the 1990s, implying that those in 'upwardly mobile' positions were more prone to CFS.

Cassie has not adjusted her diet in response to the CFS but is taking a large amount of medication – complementary and prescribed for the different conditions she has been diagnosed with.

6.11.3 Cassie's Story - In Summary

The over-riding theme which can be learnt from the account given by Cassie and her mum is the isolation and frustration that can be caused by having to battle to be believed, whether this is striving to convince family members or seeking acknowledgement by healthcare professionals, it can be a draining experience. A GP's reluctance to diagnose can make young people and their care-givers feel dismissed and this in turn can cause anxiety, as well as perpetuating the 'limbo state' it also adds pressure by abandoning the patient and family to research alternative sources of diagnosis alone.

There is a danger, as this story demonstrates, that when a young person's energy levels begins to improve they become too relaxed, almost careless, with their health and risk triggering a relapse. This isn't to say they should not be enjoying the growing freedom of feeling better, however if, as Cassie's mum believes, her daughter does not continue to be sensible as far as getting enough sleep and not pushing herself physically she may undo all of the time and care that has gone into the recovery process thus far.

Something else that strikes me about Cassie's story is the long term impact that caring for a sick child may have on a parent's life. Cassie's mum has had to devote a great deal of time and energy, at the expense of her own freedom, in order that Cassie not only receive proper care and advice but also starts to recover. When a

care-giver's lifestyle has become so consumed with concentrating on an individual it may be a struggle to learn to adjust their lifestyle when they are no longer in such great demand. This process is complicated by the fact that these are teenagers whom need caring for – usually as your child reaches adolescence they require their parents less as they learn to manage a new found independence and autonomy, when this situation is reversed and the young person requires more of their parent's time and concentration due to ill-health, and then having consumed the time and begun on the road to recovery begin requiring their parents less again, it is a complicated mix of emotions for parents.

6.12 Cassie's Mum 'Deborah'

Deborah was trained as a healthcare worker, she was hoping to return to work but due to Cassie's ill-health had to abandon that plan, her husband, Cassie's father works full-time, they have no other children apart from Cassie.

Deborah told me that she had a friend with Fibromyalgia, abbreviated to FM, (a condition which is considered to be a close relative of CFS), who suggested to Deborah that Cassie's ill-health could be CFS, so even prior to receiving an official diagnosis Deborah began researching CFS online and implementing the management advice with her daughter. Deborah describes achieving a diagnosis as being “a very long hard route”. She relayed the process which she believes was severely hampered by an unsupportive GP who refused to believe there was anything wrong with Cassie. Eventually, due to Cassie's limited school attendance, they were visited by an Education Welfare Officer who referred Cassie to the school doctor and for an assessment by an educational psychologist. The assessment did not uncover any school-related issues, such as bullying, which could be responsible for Cassie's sporadic attendance, and finally they received a CFS diagnosis through a referral to a hospital consultant. Deborah told me how she felt relief when they finally felt believed;

We had already been looking at ME as the cause to Cassie's poor health for probably six months before we saw the GP who was totally useless, unhelpful and unsympathetic. It was a further nine months before we got a diagnosis...the actual diagnosis came as a relief because it meant someone

was finally listening and taking us seriously, and that the way we were managing it was actually the right way – so a relief! (DEBORAH).

Deborah believes that the family doctor's negative attitude towards them resulted in a prolonged and unnecessary period of suffering for Cassie, and confusion and stress for them as a family. Alongside the GP's reluctance to believe or diagnose a problem in Cassie, Deborah described another situation where she struggled to get assistance in transporting Cassie to and from school following an operation which rendered her unable to drive for many weeks. Also, she feels she has had to convince and justify to others Cassie's condition, for example when renewing benefits claims. All of these factors have contributed to a stressful period of time being exacerbated.

Deborah has felt encouraged by the positive attitude of the Occupational Therapist at the CFS Service who has been helpful and reassuring, however she said that other team members have struggled to understand or integrate Cassie's ADHD into a CFS management plan.

Deborah has felt a continued struggle in convincing family members that her daughter is genuinely ill, and has felt isolated in her battle to be believed;

Trying to make people believe and understand about ME/CFS and the effects it has on the sufferer and that they are not just being lazy or putting it on. It has taken my family about 5 years to actually accept that when Cassie is tired and she is totally drained of colour, that she will want to sit quietly in a room and not play with the nieces or have the mickey taken out of her, and that it is because of the ME and is genuine. The bigger problems are definitely trying to get other family members to understand, (DEBORAH).

This ongoing fight to be believed and accepted as genuine by her family members has taken its toll on Deborah, leaving her feeling frustrated and isolated. She made a comment when she accompanied her daughter to interview that she had hoped for more support from her family – that she accepts that outsiders can be ignorant and dismissive but she had hoped for more from her own blood relations.

Deborah has felt generally supported by her close friends who have been understanding. Cassie's private dance teachers, however, have, at times, struggled to comprehend the nature of CFS;

I think when she started class lessons she was often overlooked and it seems to take a long long time for teachers to realise that just because she may not be smiling all the time and sometimes she looks totally exhausted that it doesn't mean she is not trying. When she gets too tired she occasionally loses time or makes mistakes - this is still affecting dance teachers opinions now I feel, no matter how hard she tries or how much we tell them that the ME, (DEBORAH).

Cassie really enjoys dancing and is hoping to pursue a career in the arts, so these lessons are very important to her and she is determined to continue with them even when doing so is not easy physically.

Deborah has felt exhausted by the constant uphill struggle to feel believed and understood by others;

As a mother I often feel very drained at what seems like a constant fight to get any help or advice, and I think because of the ME it seems that life treats my daughter very unfairly at times...I feel like she is being overlooked in preference to those that have more stamina, but she has a massive amount of determination, behaves well and doesn't let people down whereas others often do. Life for me feels a struggle at times, although the ME is certainly much much better than in the early days it definitely impacts on her life still and I worry that this is going to cause more problems when she starts applying to universities/ theatre schools etc as she will either need to live away from home or travel daily. I think and feel for her that just getting through auditions alone will be hard work because of the energy levels combined with the anxiety - it's more of a struggle than many others will have and I guess I worry. I think we are generally so close I actually now feel her hurt and disappointment at the unfairness of life, (DEBORAH).

Deborah is obviously anxious about her daughter's health and how this may impact on her future aspirations and ambitions. Whereas many mums of children in their late teens feel some sadness when their children leave for university, not many are in a position where they actively worry about whether their son/daughter will cope with the physical demands of life away from home pursuing a course.

Deborah feels that her relationship with Cassie has become deeper as a result of the difficulties they have had to overcome regarding her health issues, they have acted as a team and this has often meant feeling isolated from other people which in turn has strengthened their mother-daughter bond.

Overall we have grown extremely close now, she went through a very bad patch of behaviour last summer but came through really well. However she is terrified of losing me and if I am honest I am of her. I think she is very vulnerable and although I try to give her freedom to grow and mature it is very difficult as I don't want to offload too much responsibility onto her as she has so much going on in life anyway and suffers anxiety also, I would rather do it bit by bit when we feel she is ready. She understands this as do I, (DEBORAH).

As a mum Deborah feels torn as to the amount of freedom and responsibility she should grant her daughter, which is perhaps unsurprising considering the amount of barriers that Cassie has had to overcome. She feels more protective towards her than she maybe would have done if Cassie had not had so many health issues to contend with.

Deborah's story demonstrates the pressure that constantly feeling disbelieved and needing to justify oneself can put on to sufferers and their care-givers. She has felt the need to campaign for assistance over the years and this unrelenting battle has led to her feeling isolated and drained.

6.13 'Andy'

6.13.1 Pen Portrait

Andy is a 17 year old white British male who started with CFS 19 months ago. He was diagnosed by a specialist at the time, but now feels he has recovered and attributes that to doing the Lightning Process course, on which topic he is almost fanatical. He also suffers with hay fever for which he takes allergy tablets. His sister is asthmatic, and his mother had cancer last year for which she is now in remission. He lost touch with school friends which he seems slightly bitter about.

Andy is living at home with his parents and one sister. I am unclear whether his mother has returned to part-time work or still remains at home, but his father works

full-time. He is older than school age and currently working at a firm of architects for 30 hours a week and studying for a maths A'Level at night school. Pre-CFS Andy was doing well at school, and was almost a year ahead of his peers in GCSE coursework prior to becoming ill.

His condition started after surgery and came on rapidly, over 24 hours. When asked whether he has problems with fatigue in the past one month he says 'no', but his mum says 'yes'. He describes his fatigue as getting better over time. According to the AYME Functional Ability Scale Andy rates himself as fully recovered 100 percent – 'no symptoms even following physical or mental activity'. He is able to study and work full-time without difficulty, plus enjoy a social life.

True to form for his age Andy enjoys parties and socialising. He has been socially confident before and after CFS, but became withdrawn and isolated when ill. His major issues when ill were nausea and associated weight loss, insomnia, exhaustion and sensory overload. I also felt that he had perhaps experienced some level of anxiety and depression although he did not say this explicitly.

Andy is part of a close-knit family. His mum was diagnosed with cancer when he was ill – the family pulled together to look after her as she was very ill for several months. Andy has particular respect for his dad who held the family together and cared for his mum, she has now recovered. When she was seriously ill Andy had to overcome his own feelings and ill-health to care for her.

Andy believes he is fully recovered from CFS, and as such rates himself on the AYME Functional Ability Scale as 100%.

6.13.2 Adolescent CFS is...*Now in My Past*

When Andy attended for interview he felt he had recovered from CFS, however I was still keen to hear his story and learn about the journey his health had taken him on. He told me that he had suffered with CFS for 20 months, but a few weeks before our interview he had been on a residential course called the 'Lightening Process' and now feels he has regained his health fully.

The initial trigger for becoming ill Andy believes was a general anaesthetic he was given for a surgical procedure. He relayed to me;

I had an operation; had a general anaesthetic and that was that – I was just tired all the time, I couldn't eat anything, I couldn't sleep. Got pretty isolated, wasn't feeling too great and that was that. About six months later I saw a doctor at the hospital who said "I think you've got Chronic Fatigue Syndrome", after she'd cancelled out quite a lot of other things, (ANDY).

Andy attempted to play down his emotions as he spoke but despite this it was obvious that he had felt concerned and possibly depressed during the time his health started to deteriorate. He explained to me how he felt in the period prior to receiving a conclusive diagnosis;

I was just waiting to get better and get back into school really. I remember I had been ill for about two months and my birthday party was coming up. I thought "yeah, I'll bet better" – as you do when you get ill, you think just a couple of weeks in advance and that will be that. It came to my birthday, I had a party but I was just lying on the floor the whole time, trying to have fun but I just couldn't do anything – quite literally lying on the floor. Ummm, I thought "I'll have another party when I am better", waited another month, still wasn't recovered...carried on like that 'til the next year; couldn't have a party again. Now my 18th is coming up in two months and it's gonna be absolutely massive! (ANDY).

Andy spent many months anticipating a recovery but the weeks passed and he remained ill. This must have been a period filled with repeated disappointments as he appeared to be setting mini goals such as "in a couple of months..." but could not adhere to them. Also he made repeated trips to the GP surgery during this time for further tests to eliminate other possible causes of his ill health, which again would have been an emotional roller-coaster repetitively believing at some point a discovery would be made which he could be treated for. During that time Andy missed almost an entire year of school, it would have been Year 11 for him and therefore busy as far as exam preparation and coursework, fortunately he had worked hard during the previous year and managed to complete a large proportion of the coursework ahead of schedule, which alleviated some of the pressure when he became ill. In the first year of his A' Levels Andy was forced to give up one subject as he was not well enough to cope with the workload, he also suffered from

infections around the time of his exams and achieved lower grades than he was hoping for. Andy is hoping to re-take those exams in the near future.

During the months that Andy felt particularly poorly he suffered with insomnia and a disturbed sleep pattern;

I didn't get to sleep and when I went to sleep it wasn't brilliant sleep. I used to wake up feeling tired and I just wouldn't be able to get out of bed. I used to sometimes go to sleep at 4 o'clock in the morning and wake up at 12 midday; go back to sleep at 4 o'clock. That's not much space to get out of the house and have some fun and see people, if you're awake all night and sleeping all day, (ANDY).

One of the most prolific problems in CFS is poor sleep and particularly un-refreshing sleep, so even if somebody manages six or seven hours in a block they can still wake feeling 'jet-lagged'. People struggle to understand why if you are tired you don't simply go to sleep and wake feeling better, but the insomnia and exhaustion are frustrating realities of CFS. One theory is that the body's circadian rhythms become disrupted and patients are unable to sleep and wake at the correct times. The knock-on effect of insomnia and poor quality sleep is that not only the night-time becomes disrupted, but individuals are exhausted and unable to function properly during the day-time too. Some patients are prescribed a low-dose tricyclic, not for its anti-depressant properties but because it is successful in promoting sleep in some individuals. Others try homeopathic remedies such as Melatonin tablets, which are effective in some sufferers at causing the 'sleepy' feeling necessary to go off to sleep at night. However, this is not available on prescription and is often sourced online which obviously carries some concerns regarding origin and safety for use.

Andy also struggled with other symptoms;

I had nausea all the way through my illness. I just couldn't eat. When I woke up I wouldn't be able to eat for about eight hours, I just felt awfully sick. When I did eat, I felt hungry and I ate a lot. I think on average I would eat about two meals a day, I lost quite a lot of weight. I lost about two stone and I'm not a big lad – there's not a lot of me! (ANDY).

Nausea and associated weight loss is not uncommon among CFS patients of all ages, but the effects of dramatic weight loss could have a psychological impact on the self-

esteem of young sufferers. Andy found wheat and dairy products particularly difficult to digest and therefore eliminated them from his diet, this may well have exacerbated the weight loss as they are two major food groups to cut out.

Andy struggled not only with physical effects of CFS, but also cognitive symptoms, primarily sensory overload. He found it impossible to remain in a confined place with a barrage of sound, temperature and moving stimuli. Andy felt so overwhelmed by these symptoms that when he went abroad on holiday his GP prescribed him Valium to help him cope with the flight. He described the way sensory overload made him feel, saying;

I always had to get out. I think they say 'fight or flight', and I just had to fly; get out of there. I was on a train once coming back from my Uncle's house, it was pretty full and there was nowhere for me to sit down. We were on it for about ten minutes and I was so bad – had this attack – and we had to get off. We were just stuck in Basingstoke two days before Christmas and there was no way I could get back on the train, (ANDY).

When someone has been confined to home for a significant period of time, within quiet familiar surroundings with only close family around them who are sympathetic to the sufferer's need for calm, and then they are flung into the hustle and bustle of a public place surrounded by strangers and unfamiliar noises, sights and smells it is unsurprising that they feel overwhelmed. However, it is not just due to unfamiliarity, many sufferers, particularly those more severely affected can experience sensory overload even at home – some cannot cope with having a television or stereo on, or even the glare of lights, and need to lay in a darkened room.

Andy continued to describe his frustration of being in a public place but people around him remaining unaware that he was ill and struggling;

When you've got CFS there's no disabled sticker on you and you're not in a wheelchair, people around you can't SEE it, it's hard... I looked tired, but who doesn't in winter? It's not a great time for anyone. I looked tired, but no- one knew what I was going through. No-one was aware anywhere except in your own house, not everyone's gonna know what you're feeling like, (ANDY).

Andy recognises that strangers are unable to see or understand how ill he was feeling when out – only his own family members had some insight into how much he was struggling. To try and make travelling easier Andy applied for a blue disabled badge for the car but his application was rejected – he was not given a reason why. Blue disabled badges cause some contention amongst CFS patients, as some applications are successful but not all. However, as previously mentioned, part of the criteria is the inability to walk a set distance – for many CFS sufferers it *is* possible to walk that distance even though it may be a struggle, or they may suffer extra fatigue afterwards due to the over-exertion.

During the time that Andy was ill his mother was diagnosed with cancer and was very seriously ill. He describes having to put his own feelings and health difficulties to one side during that time in order that her needs were met;

When I heard that my mum got cancer, what do you think? You think, “oh my god, she’s gonna die”. Umm, I think I did pick up – I rose to the occasion. I had to. I really worked hard and tried to do everything I could for her, but we went to a private hospital and got the operation almost straight away. She was in a bad way for a long time, and I was bad – I was what they call ‘disabled’ – but I had to do stuff, I had to help out. My mum was a lot worse than me at that time, she needed my help instead of the other way around for a change. I’m sure that sometimes there was nothing left in me. Umm, I just had to sort myself out at that time. My dad, my sister, they were only looking after mum, they had their own stuff to do, (ANDY).

Andy felt he had no choice but to shelve how bad he felt in order to support his mum, he admits to feeling completely depleted of all energy and yet pushing himself further in order to assist within the family. It is amazing the way in which human beings can find the extra reserves to overcome feeling ill when there is a higher priority to deal with. In this case, no matter how much Andy felt his own health was suffering he still found the strength to overcome his own feelings and fulfil a role as carer. It is interesting that he recognises the role-reversal that took place during that period – no longer was his mum in a position where she could care for him as her child, but he was required to display new levels of maturity and put her needs before his.

Andy makes the emphasis that he did not suffer from depression during the time his mum was particularly ill, and was eager to point out that he simply felt thoroughly exhausted. He does believe that depression and extreme fatigue are linked;

I think the two are definitely interlinked. If you're gonna be tired for a few months, you are gonna start feeling pretty rough. Not seeing people, that will lead to depression. I shouldn't expect there are many people with CFS that haven't been depressed at some time, (ANDY).

Andy is right, we are social animals with a strong need to interact with others, as well as the need to feel we are accomplishing new things in our lives. If individuals are isolated and unable to continue their lives as normal they will quite understandably feel demoralised. However, these feelings are not necessarily characteristic of *clinical* depression, but rather *situational* depression – a response to feeling exhausted, isolated and unable to function as one would like.

When speaking of how he felt when he was particularly ill Andy recalls feelings of fear and apprehension about the future, Andy had never heard of CFS prior to diagnosis (or Post-Viral Fatigue Syndrome - PVFS, which he was initially informed he had), and said that nobody around him - including his GP – knew anything about it either.

I spoke to people thinking “They've got to know about it”, but they really didn't. People at school didn't have a clue – teachers: not a clue, my GP – I could almost say he didn't have a clue. I didn't really know where to go, I looked on the internet and that helped me out – probably the best. Then I found out about support groups and stuff they can send you every month, (ANDY).

This period of searching for information appears to have been a stressful one, this is unsurprising, as if nobody can give you insight into what is happening to you – not even your family doctor, the supposed ‘expert’ – it is going to cause further anxiety. Andy joined AYME (Action for Youth With ME) and the local ME Support Group after approximately a year, although he didn't attend meetings he found reassurance in hearing other people's similar stories and knowing he wasn't alone in the symptoms he was experiencing. At one point during the time he was ill, Andy organised a presentation for his teachers in which he, his parents and a friend who was also a home-tutor and fellow CFS sufferer spoke about the nature of the

condition and how best to manage it, in an effort to educate those people who had contact with him. The decision to take the initiative and organise an information session for school staff members possibly reflects some frustration as to the lack of knowledge that Andy was dealing with at school, it also may show something of his strength of character.

Andy didn't feel he gained a great deal from attending the CFS Service in his area, he did not feel that the treatment plan suited him. He said;

I don't know – I worked at everything people told me to do but it was sort of exercise programmes, how often you should be trying to eat, how you should be getting to sleep, and stuff... I just think that approach didn't work for me, perhaps it works for other people. I tried doing that stuff for a long time but it didn't help, (ANDY).

As with any treatment plan or medical service different people will gain different measures of success from them dependant on attitude, lifestyle and personality. Not everyone will find they fit comfortably into a pattern of doing things, especially something such as a treatment programme which requires commitment to its routines and advice.

Andy relays feelings of loneliness and isolation, and I think felt a little let down by his friends when he was unable to go out;

*No-one really took the time to come out and see me, sort of at the weekend and stuff, which was a bit... *Trails off* ... My parents helped, but after a while it's just not quite what you need, is it? (ANDY).*

It could be suggested that this petering off of friendships could be a gender difference or simply an age-characteristic, that they are so engrossed in their own lives that adolescents tend not to think about people that slip away from the social group. Despite having the support of a close-knit family Andy still craved the company of his peers, this is understandable, as social ties are very important mechanisms of feeling accepted and significant at this age. After approximately a year Andy started a new college and made new friends;

it I pretty much missed out on all the social life of about a year, after that time was about when everyone was leaving school and I just lost out. I didn't have a clue and everyone had changed quite a lot. I just carried on going – I started a new college and I met a new bunch of people which was great and I think they probably did care more than the last bunch of friends I had, (ANDY).

Andy's recounting of his feelings when he was ill I felt omitted a lot of emotion concerning just how upset he was that he had been 'left behind' by his peers – that everyone had moved on with their lives and he had remained static as his academic and social lives had been put on hold, he seemed to underplay the true extent of his disappointment. The final year of secondary school is a significant milestone in a young person's life – having to make decisions as to what direction they are going to follow in the future as they leave the safe confines of school which has dictated the path of their life thus far. Now they have to begin the journey towards independence, learning to make autonomous decisions, whether it be applying to university and moving away from home or getting a job.

Andy has recently been on a three-day residential course called the 'Lightening Process', which he attributes the major improvement in his health to;

*me I heard about this thing called the Lightening Process, it was sort of put to as a miracle cure, of course at first I was very sceptical thinking there's not worth a try". I rang this guy who does it in Wales, had a good chat with him and my hopes started to pick up, and I heard that he'd had a 95% success rate curing people with CFS. Two weeks after that I went to Wales. I was in a pretty bad place at this time, it was before my exams – I'd probably been in bed for about 20 hours every day, very stressed, no social life. I went away at Easter for three days and I picked right up. After two weeks hard work on the Lightening Process I was doing amazingly well. Didn't miss any lessons at school, bit of a social life, things looked great. 'Bit of a social life' is not quite right – I had a hell of a good social life *laughs* All the time I had a good time, I was loving it! (ANDY).*

Andy obviously feels vastly improved since going on the course, in fact he believes he is now cured of CFS. The thing I found slightly uncomfortable as he spoke about it was his belligerence about other CFS sufferers not doing it. He raves about the Lightening Process as the miracle cure he believes it to be but so fervently that it

feels like he has become a self-appointed ‘crusader’ for the course. For example, he says;

It's a completely new look on life and I put my name to it. I completely believe in it and I've talked to a lot of people about it and persuaded them to go on the course... It's a miracle cure I think... there's quite a lot of people with CFS who are very single-minded and need a lot of persuading to do this. The way I looked at it at the time was – I was feeling awful, I was quite depressed and anything was worth a try. So I did it. I did it full-heartedly and it worked. I don't think there is anyone who shouldn't do it, it just seems stupid to me. (ANDY).

Andy has gone out of his way to try and persuade individuals he knows of with CFS to attend the course, he has advocated it on the Lightning Process official website and has even volunteered to speak on local radio to promote it;

I don't spend a lot of time thinking about CFS any more, but I do want to help people to get better. If they wanna talk to me, I'll talk to them about the Lightning Process, (ANDY).

He has left his phone number with an acupuncturist, a chiropractor, staff members at his school and anyone else he comes into contact with who has CFS. He is ardent in his belief that the course is a cure for CFS and dismisses anyone who feels sceptical about the origins or theory behind it. It is not particularly surprising that if an individual has been ill for several months, has become depressed, isolated and unable to see a positive future and then stumbles upon something that turns that entire situation on its head s/he will recommend it to others. What concerned me a little was the almost arrogant way that Andy did this calling people with CFS ‘idiots’ if they did not consider trying the course. This attitude towards people who are unwell and generally worried and confused could be very damaging. What also made me uncomfortable is that this is being presented as a ‘miracle cure’ to people who are desperate to get well and yet has not been given any medical credence and has not undergone any medical scrutiny. The founders of the Lightning Process have created a shroud of mystery about it, they discourage people who have been on the course from explaining it in detail to other people, they also say that anyone with any sense of scepticism about it need not apply for a place. The tutors hand-pick who they accept onto the courses and it is almost prohibitively expensive. Surely if

something is discovered to be a ‘cure’ for a condition where no cure has as yet been found there is a moral obligation to make it readily accessible to all who may benefit, and to publicise information about it. I am sceptical as the limited medical information displayed about the course online has a ‘cult mentality’ feel about it – the secrecy, the careful selection of candidates, the reluctance to invite independent medical research, and so on.

It could be suggested that Andy’s extreme positivity towards the Lightning Process and the “*re-mapping of the way you think*” (p. 5) as Andy described the course to be is linked to the point Andy had been in his life when he attended. At the time that Andy discovered the course and applied to go on it, he was – by his own admission – at a very low ebb, he felt depressed. His family situation was complicated by his mother being critically ill and his whole family, and father especially, having to pour their attention and compassion into caring for her. The focus was not on Andy or how disrupted his life had become due to his ill-health as his mum’s situation took priority because of it’s life-threatening severity. I wonder whether Andy was so desperate for an escape from the bleakness of what was happening at home that he had lost the ability to see a way out of the negativity. It is only a suggestion on my part but it is not outside the realms of possibility that Andy had reached a point where he had recovered from the CFS enough to start living his life again but needed some direction as to how to do that. The success of the Lightning Process for him may have been more about good timing than presenting a true miracle cure. This does not make it any less successful in one sense and may well have a part to play in some people’s recovery in the same way as psychotherapy has.

6.13.3 Andy’s Story - In Summary...

The thing that dominates Andy’s story is his praise of the Lightning Process. There are many different alternative therapies that people with CFS try from homeopathic remedies such as Melatonin to aid sleep, to those things which require a larger financial and time commitment such as the residential Lightning Process course. Some things work for some people, not everything works for everyone and if there was one thing which was resoundingly successful it would become highly publicised as sufferers and their families are so intent on finding an answer. Although there has

been no ‘miracle cure’ which has been medically endorsed, even those things which show some alleviation of symptoms – whether this be true or placebo – have genuine benefit for some individuals and so are worth the effort.

Andy’s story reiterates how disruptive CFS symptoms can be on a young person’s life. The physical symptoms he suffered – nausea and associated weight loss; insomnia and disturbed sleep pattern all significantly impacted on Andy’s lifestyle, making normal functioning impossible. Cognitive symptoms such as sensory overload can be equally as difficult to contend with, in fact Andy’s experiences demonstrate just how terrifying this part of CFS can be.

Many people with CFS relay just how frustrating it is that they can be inwardly really struggling with symptoms and yet those around them are totally unaware of how much they are suffering – as Andy said, there is no disabled sticker to wear. This can be a very isolating experience for individuals who have to either choose to explain how they are feeling or try to continue regardless.

6.14 Concluding Thoughts about Participants’ Stories

The participants’ stories paint a picture of what life is like when living with CFS, either as an adolescent or a mother of a young person with the condition. The stories have been distilled from the interview data to ‘hold onto’ their coherence, whilst removing information that may identify them to others. The narratives present an overview of what the participants *said* and in the sections which follows an attempt to draw out what this all *means* is made.

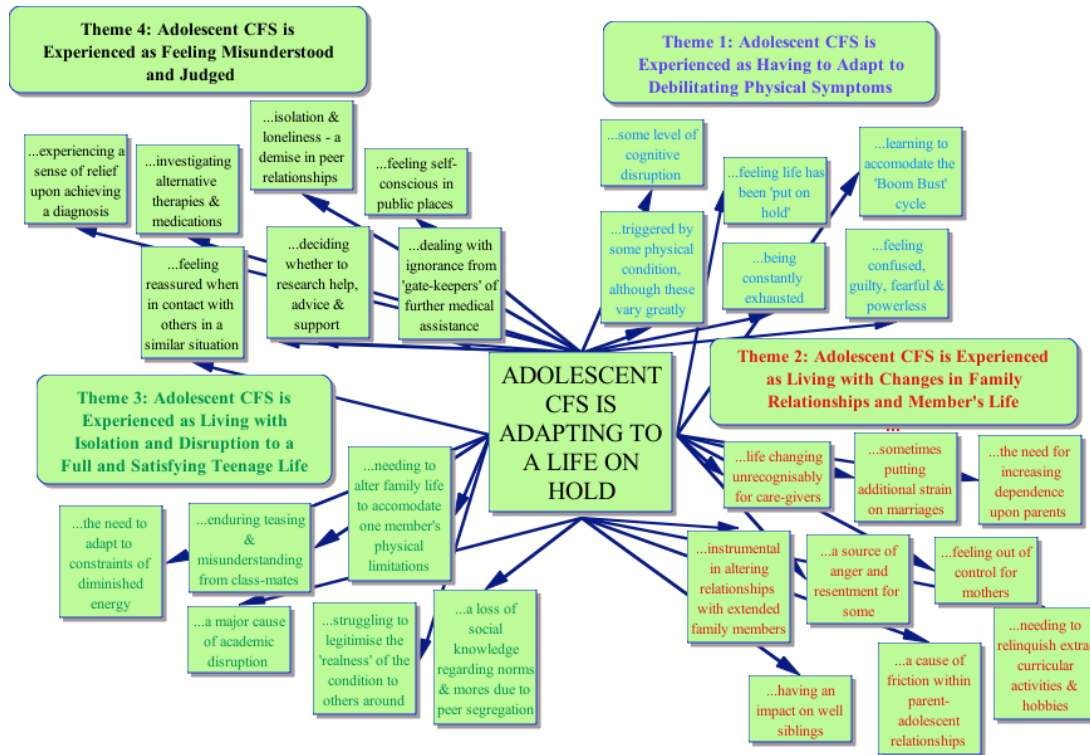
6.15 Adapting to a Life Put On Hold

The diagram of findings, (Figure 4), illustrates a number of themes and sub-themes that have emerged from the interviews with young people and their care-givers. The overarching theme to emerge from the stories was that the young people are having to adapt to a life put on hold by a confusing and debilitating condition, their families too have to adapt to the changes that effect their child/sibling. The four major themes I have identified are listed in Box 13. I will consider each of the sub-

themes in relation to these areas in turn and then consider what this means for practice.

Figure 4: Diagram of Findings

Box 13: The Major Themes



1. Adolescent CFS experienced as having to adapt to debilitating physical symptoms
2. Adolescent CFS experienced as living with changes in family relationships and member's life experiences
3. Adolescent CFS experienced as living with isolation and a disruption to a full and satisfying teenage life
4. Adolescent CFS experienced as feeling misunderstood and judged



Adapting to a Life Put On Hold

6.15.1 Adolescent CFS is ...experienced as having to adapt to debilitating physical symptoms

Chronic Fatigue Syndrome incorporates a number of incapacitating features which make daily life for individuals suffering from it, and for those sharing a household with them, difficult to always understand. The acceptance of certain physical symptoms into daily life means adapting lifestyles to accommodate a novel and often depressing situation which must be allowed for by all the family members, not just those individuals suffering from the condition.

➤ **Being constantly exhausted**

The most widely reported and debilitating characteristic of CFS is unprecedented exhaustion, fatigue that is out of the ordinary and crippling in nature. Some level of occasional fatigue is normal in the daily cycle of healthy adults and adolescents, however it is the overwhelming nature of the tiredness and the fact that it is unaltered by normal amounts of rest that sets it apart in CFS. This constant exhaustion makes functioning on a day-to-day basis difficult, it interferes with activities and responsibilities that individuals once took for granted. In adolescence it impacts abilities to continue schooling as normal and interferes with social life, it can lead to individuals becoming isolated and largely confined to home as they juggle life with restricted energy.

Some participants reported use of a wheelchair to aid mobility outside the home, but in CFS it is not simply about disability restricted to one set of limbs. An individual unable to use their legs but otherwise healthy can still maintain a certain level of freedom through the use of a wheelchair, however it is also the lack of energy to provide impetus to *want* to go out that is present in CFS. Exhaustion can be physical, mental and/or emotional, in CFS it is often all three simultaneously.

A major contributor to the physical exhaustion experienced by people with CFS is difficulty with sleep; either being unable to fall asleep despite being totally exhausted, or sleeping at the wrong times. One of the most prominent symptoms is waking in the mornings unrefreshed. Many of the ‘triggers’ leading to CFS in the participants of this study were widely varying, however, poor sleep hygiene is a prominent theme in all of the stories and vastly interferes with the participant’s daily lives, leaving them feeling ‘out of synch’ with the rest of the world, tired and lethargic.

➤ **Feeling life has been put on hold**

Liz for example, expressed her frustration that although her friends have matured and changed through the normal teenage experiences they have been through, she has been unable to do that, it's as though someone has hit the 'Pause' button on her life and she has remained motionless whilst her peers have moved on;

Umm, I think that people have sort of moved on...changed...and I haven't, 'cos I wasn't able to be out and about seeing people...(LIZ)

Much of adolescent life is conducted through school life, this is where the majority of peer relationships (both same sex and opposite sex) play out and where the social framework of norms and morès is learnt, those who are absent from a school environment for lengthy periods of time miss out on this important social education.

The participants in this study demonstrated that it is not just the fact that they are ill but also the fact that CFS is a condition of 'unknown quantity' – without clear understanding of origin or cause and with still so much unknown about the nature of the illness and no set time by which they can expect to be better, young people with CFS have an unknown present and future state to deal with. However, even with this indefinite and unspecified illness they still appear to quickly adjust to a positive and level-headed way of thinking about things, refusing to panic about academic qualifications being put on hold or social opportunities being missed. It could be suggested that teenagers have the freedom of pragmatism because they are without the responsibilities of jobs, families or households and therefore they do not need to worry about anything other than getting well, but I feel it cuts deeper than this, that the young people I have spoken to have a rationality that isn't simply due to lack of duties to perform but is an acceptance of the situation despite the boundaries they are faced with.

A poem which reflects this sub-theme;

I AM ALL AGES

I am all ages,

*I am the child who disappeared,
Passing like a shadow from your lives.
I am the one who gained knowledge,
Understanding beyond my years.
I am in body what time made me,
Yet in spirit I do not match.
I am a youth kept captive from society,
Now underage for my circle.
I am someone who is old,
Having learnt the true values of living.
I am myself and now alien to you.*

(Tymes Trust 2004, p. 17).

This poem describes the experience of having to mature quickly in order to deal with the difficult and trying experiences of living with CFS as an adolescent, and yet the writer recognises that she is out of synch with her peers now. The true sentiment of feeling robbed of her youth is expressed as she faces up to the reality of being denied normal, teenage experiences. Many participants in my study reflected these feelings in their stories, the sense that they had been ‘left behind’ by their school friends.

➤ **Feeling confused, guilty, fearful and powerless**

Many sufferers and their family members experience confusion when faced with the myriad of unexplained and novel symptoms which fluctuate on a daily basis, add to this the lack of diagnostic test to conclusively confirm or rule out CFS and individuals are left with many ‘unknowns’ to deal with. Sufferers struggle to understand the overwhelming symptoms which restrict their daily functioning, parents are confused by the lack of medical certainties, siblings are baffled by the inconsistent nature of the condition, and extended family members find it difficult to comprehend the major changes they witness in the nuclear family.

The young people interviewed in this study commented upon feelings of guilt about their condition, especially at the extra burden them having CFS has meant for their mothers, Jack for example is conscious that his mum’s life is made more difficult as

a result of him being ill, and Vicky commented that she felt her having CFS was in some way her fault. Similar findings were made in Brotherston's study of adolescents;

The participants felt at fault for their mothers' distress. As well, they experienced shame and a sense of failure due to their dependence on their families, (Brotherston 2001, p. 50).

Guilt is a difficult emotion to bear, especially when one feels unable to alter the situation. These adolescents not only have their own feelings and emotions to deal with linked to coping with the impact of CFS, but also feel responsible for the impact it is having on the rest of their family.

Parents often struggle with feelings of powerlessness and being unable to alter their child's struggle or alleviate their symptoms, for example Claire commented upon her frustration that she cannot repair the situation – cannot make it right;

I want to fix it (as mums are meant to) and I cannot...(CLAIRE)

There is a cultural and social belief held by mothers that it is their role as protector of their children to mend a situation which causes their offspring pain or struggle, when they are unable to do so it causes emotional upheaval and a sense of helplessness.

➤ **Some level of cognitive disruption**

Apart from the physical difficulties are cognitive symptoms also. Music in a department store, or a combination of dozens of chattering strangers' voices in a café can feel like a wall of noise to somebody accustomed to the quiet confines of the family home. Having to cope with bright or flashing lights, or negotiate a number of shoppers in a crowded aisle in the supermarket can seem very intimidating, especially if an individual is sat in a wheelchair and therefore on a lower level physically to the people around them. Sensory overload isn't experienced by everyone with CFS, but those who do report it in varying degrees from simply frustrating to incredibly frightening, as both Liz and Andy described in their narratives.

➤ **Triggered by some physical condition, although these vary greatly**

Whilst the cause of CFS remains unknown there are widely accepted triggers of the condition, these can include infectious agents, environmental toxins and emotional distress. The participants in this study cited an array of triggers which they or their diagnosing physician suggest to be the activating agent, these include a general anaesthetic, infectious disease, an ongoing emotional state, and so on.

➤ **Learning to accommodate the boom bust cycle**

Learning to understand and accommodate the unusual and sometimes baffling elements of the condition make CFS a particularly difficult illness to live with on a daily basis, sufferers and their families must come to terms with their new limited energy levels and build their daily activities around it. Ascertaining how to continue life whilst simultaneously pacing activity is not easy for anyone, let alone a young person or child. Sufferers and their families must learn to recognise and accommodate the ‘Boom and Bust’ cycle which often accompanies this condition, the former in not over-doing it but at the same time trying to work within the bounds of their energy levels, the latter in acknowledging that this isn’t always an easy balance for the sufferer to get right. Claire commented upon her frustration that her daughter felt it acceptable to go out on a weekend evening with her friend but then suffer the consequences afterwards and be unable to do anything that her mother asked of her, and yet the adolescents made reference to the ‘need’ to push themselves a little harder than they knew they ought to at times, in order that they could have some fun. This situation is bound to cause friction within any household and as much as understanding the peaks and troughs it is about understanding the other family members needs and desires.

Adolescent CFS is Experienced as Having to Adapt to Debilitating Physical Symptoms... In Summary

The overriding symptom which CFS sufferers must learn to come to terms with is that of unrelenting fatigue, exhaustion that is overwhelming and unresolved by rest. This makes functioning on a daily basis difficult and frustrating for those young people who feel that their lives have put on hold; that they are ‘stagnating’ and unable to move on or do the things they want to do because they are captive to their

bodies' unwillingness. Alongside the tiredness are the other symptoms of CFS, and also those effects of whatever the trigger illness may have been, for some this is sore throats, for others headaches, as well as the effects of cognitive disruption for many, these are daily struggles they need to contend with. In an effort to come to terms with these changes to health status and functionality adolescents with CFS often have to learn to accommodate the Boom and Bust cycle, which can cause friction within families when the teen is determined to push themselves beyond what they know their energy levels can withstand in order that they have some fun, and parents misunderstand this as foolishness or selfishness. The emotional impact of these physical symptoms is the experiencing of feelings such as guilt, confusion, fear and powerlessness for both sufferers and those closest to them as all of the family members struggle to adapt to the newfound situation.

6.15.2 Adolescent CFS is experienced as... living with changes in family relationships and member's life experiences

As previously mentioned, the effects of CFS are not restricted just to the individual suffering from it, but also to those who live in close proximity to them. In the case of young people, parents, siblings and extended family members all experience some level of disruption to the family relationships and experiences by individual members – everybody in the household has to adjust to a new way of living, accepting disappointments, trying to comprehend new-found restrictions and coming to terms with future aspirations.

➤ Needing to alter family life to accommodate one member's physical limitations

According to one study, (Canam 1993), there are a number of adaptive tasks which face parents of chronically ill children, listed in Box 14. The family unit then has to adapt to a new lifestyle, having to adapt to the new routines, responsibilities and burdens that come with learning to accommodate changes in one member. Family activities are disrupted; as Jack and Amy's stories demonstrated the families could no longer plan outings or holidays without having to consider the extra needs of the person with CFS, (Jackson 1999). Parental leisure activities are curtailed if not abandoned due to being unable to leave their adolescent unattended at home, or simply no longer having the time or energy left having first prioritised their child's

needs. One study investigating quality of life for adolescent-onset CFS sufferers and their families found that 71% of mothers and 51% of fathers had to take time off work, and 17% of mothers and 3% of fathers were forced to give up their jobs entirely, (Newnham et al. 2007). In this study several of the mothers had to either stop working altogether or tailor their jobs to fit in with their child's requirements.

Box 14: Adaptive Tasks Facing Parents of Chronically Ill Children

1. Accept the child's condition
2. Manage the child's condition on a day-to-day basis
3. Meet the child's normal developmental needs
4. Meet the developmental needs of other family members
5. Cope with ongoing stress and periodic crises
6. Assist family members to manage their feelings
7. Educate others about the child's condition
8. Establish a support system

The typical process of a child becoming ill includes different stages; the child becomes sick; parents approach healthcare professionals whom then diagnose a cause and treat the symptoms, and if the suggested treatments or therapies are followed through to completion the child is expected to become well again, (Jerrett 1994, p. 30). In the case of chronic conditions this 'typical process' does not always occur, or at least does not occur in as short a time period and this is a huge thing for the sufferer and their family to come to terms with. It is within the home and family unit that the majority of caring for a chronically ill child/young person is done, (Hentinen and Kyngas 1998; Jerrett 1994). In order that this can be achieved effectively requires a process of *adaptation* by family members – sufferer, parents and siblings – in order that some sense of harmony and *normalisation* may be accomplished. 'Adaptation' within the household is defined as the extent of coping - psychologically, socially and physically - which is achieved by family members, (Hentinen and Kyngas 1998). Similarly, 'Normalisation' refers to the individual and corporate reaction of the family to one member's illness, (Peck and Lillibridge 2005). This learning to cope is the family's way of coming to terms with a novel situation and learning to incorporate it into their lives; corporately and as individuals. Sufferers, parents and siblings must learn to accommodate the changes that occur. In

dealing with the condition on a daily basis the family in which there is a child with CFS must make major changes to the lifestyle they once regarded as familiar;

ME/CFS dramatically alters every part of a family's functioning. Family members struggle to adjust to daily uncertainty, to sharp dichotomies in what the medical professions, media, and community tell them is reality and what they see as a different reality unfolding in their own and their child's lives, (Brotherston 2001, p. 1).

Parents with chronically ill children are faced with added burdens alongside the everyday responsibilities of family life;

In addition to fulfilling the usual duties and obligations of being parents, they are now expected to meet the new needs arising from the illness. This constitutes a severe disruption to the ordinary continuity of family life as previously understood, (Jerrett 1994, p. 1051).

Ray and Ritchie make the comment that parents who care for chronically ill children within the home need to acquire the skills necessary for decision-making and clinical assessment, (Ray and Ritchie 1993). New CFS-related tasks arising within the stories of the participants in this study include for example having to drive children to school at times outside of normal school hours, attending GP and hospital appointments, adapting family life to allow for the energy-restrictions experienced by youngsters, maintaining harmony between the child with CFS and their siblings, explaining the characteristics of the illness to those outside the family home, and so on. All of these things constitute a change in lifestyle and a need for parents to adapt to a different way of living. Family centred care for a child, according to Meleski (2002), involves that which is listed in Box 15. This new system for working requires much effort on the part of the family, and in particular the primary care-giver, it also requires adaptation by other family members, and a significant part of this is the response by the healthcare provider to assist the family through its day-to-day functioning in caring for the child with a chronic condition.

In our culture mothers are, generally speaking, the ones who carry the emotional and physical burdens within the family unit (Bristol 1987; Gibson 1995), keeping the entire household functioning on a day-to-day basis as well as becoming the primary care-givers when children become ill, this is so even in cases where mothers are in paid employment outside of the home also.

Box 15: Elements of Family Centred Care

1. Collaboration between parent and healthcare provider
2. Communication concerning the child's needs
3. Recognition of a family's strengths
4. Comprehensive support of families
5. Acknowledgement of family developmental needs (e.g. during times of transition such as adolescence)
6. A responsive healthcare delivery system

According to research mothers' mental health is affected by perception of impact upon the entire family, (Ireys and Silver 1996), as mums feel responsible for all family members they are aware of the impact of one child's condition upon the collective family unit. For example, Charlotte felt that her daughter having CFS and all of the extra responsibilities that went along with caring for her caused a rift to appear in the relationship she had with her son, she felt that she was missing out on experiences with him and that a distance had formed between them.

➤ Life changing unrecognisably for care-givers

In our culture mothers are, generally speaking, the ones who carry the emotional and physical burdens within the family unit (Bristol 1987; Gibson 1995), keeping the entire household functioning on a day-to-day basis as well as becoming the primary care-givers when children become ill, this is so even in cases where mothers are in paid employment outside of the home also. According to research mothers' mental health is affected by perception of impact upon the entire family, (Ireys and Silver 1996), as mums feel responsible for all family members they are aware of the impact of one child's condition upon the collective family unit.

Despite mothers being the primary care-givers and typically the person within the household who oversees the emotional and practical needs of all of the family members, the women themselves have their own social, emotional, practical and occupational requests and desires and they often struggle to accommodate those needs, finding that they become lower down the priority list as the ill child and other member's requirements are met first. Research into care-giving burdens isolated mothers' primary and secondary care-giving demands, the former including physical

demands linked directly to the child's illness and the child's psychological and social development, the latter category included mother's own needs; family relationships and mother's activities outside the home, (Stewart et al. 1994).

According to one study an integral part of the normalisation process is acceptance by parents that their chronically ill child is unable to attain the same level of achievements as their healthy counterparts, (Peck and Lillibridge 2005). The lowering of expectations leads to an increased feeling of achievement which in turn enhances the sense of self-fulfilment. Amy's need to reduce the academic expectations she placed upon herself and instead learn to enjoy more simple pleasures in life could be related to this re-evaluation of what is important, as her mum explained;

It's become about enjoying the things that she could do, although it was very little. If it was sitting curled up on the sofa drinking hot chocolate watching a really weak movie – that was good; she got some enjoyment, it was about taking pleasure in little things...(CHARLOTTE)

➤ **Feeling out of control experienced by mothers and a learning to live with the situation**

All of the mothers included in this study relayed feelings of being out of control of their child's ill-health, however they did say that despite this, with time they have learnt how to 'read' their child better and anticipate what activities/level of activity may negatively effect them, in essence they have become skilled at recognising signs which may predict an exacerbation in symptoms. Jerrett attributes this process to increased confidence on the part of parents, she comments upon this issue with regard to parents of children with juvenile arthritis;

With the growth of self-confidence they become more involved and, in turn, felt able to impose some meaning on their ability to affect change, (Jerrett 1994, p. 1054).

This learnt ability by mums to read their child's symptoms is however a significant part of the normalisation process, despite still feeling that they are lacking in control they have attained a depth of understanding that allows them a semblance of empowerment.

A definition of 'empowerment' given within one study is outlined as;

A social process of reorganising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives, (Gibson 1995, p. 1201).

According to Gibson's study of empowerment in mothers of chronically ill children, this process involves a period of critical reflection in order that women can familiarise themselves with their own strengths and abilities and in turn learn to utilise these to take charge of the situation. In the research by Cheryl Gibson 'Taking charge' involves: (a) advocating for the child, (b) learning the ropes to interact efficiently with the health care system, (c) learning to persist to get the attention they needed for the child, (d) negotiating with healthcare professionals so that opinions and requests were heard, and (e) establishing a partnership in which there was mutual respect and open communication between the professionals and the mothers as well as commitment to a common goal, (Gibson 1995, p. 1206). In situations where these elements are not achievable it is more difficult for parents to feel they are taking any control and leaves them feeling frustrated, disappointed and dismissed.

The feeling of lack of control has been linked to maternal distress and self-esteem, particularly when children's functional limitations are high and maternal efficacy is low, (Silver et al. 1995). With the added stresses and strains that mothers caring for a chronically ill child experience it is unsurprising that many suffer from depression, one study comparing mothers of healthy, diabetic and asthmatic children found depression rates of 16%, 30% and 27% respectively demonstrating almost double the rate of depressive symptoms in mums with chronically ill children, (Kheirabadi et al. 2007). Individuals identified as sources of maternal support are spouses, professionals and immediate family members, (Pelletier et al. 1994), however, generally speaking mothers feel in need of more support than they actually receive. A piece of research looking at mothers of children with cystic fibrosis (Hodgkinson and Lester 2002) highlighted some of the challenges facing healthcare workers associated with this group of care-givers, the paper reported the three main roles that professionals could play as: (a) holders of hope; (b) bridge builders and (c) providers

of continuity of care for families, healthcare workers surrounding the child and family need to be mindful of the effects of the condition, not just on the child, but also upon parents – particularly primary care-givers.

➤ **The CFS as a source of anger and resentment for some**

Claire in particular spoke candidly about her frustration and resentment towards her daughter's condition and described feeling angry that not only did she feel robbed of the child she once knew, but also that her own freedom and decisions have been dictated by Chloe's CFS, however her feelings are compounded by guilt that she is resentful of an illness when it is not even her directly experiencing it;

I have felt I have not been a complete success in coping with Chloe or the illness so I feel I have failed as a mother to some degree. I am not very tolerant of the illness and very, very angry because of all the things I wanted for her, the lack of freedom for me, an adjustment to all the things I had planned for my life. This sounds dreadful as Chloe is the one suffering, but I want to fix it (as mums are meant to) and I cannot... (CLAIRE).

Many primary care-givers have to abandon or at least limit their social and recreational activities when caring for a chronically ill child, as one study into carers of adolescents with diabetes, intellectual or physical disabilities found, (Taanila et al. 1999), this can be a frustrating situation as parents feel socially restricted and unable to socialise with their peers.

➤ **Sometimes putting additional strain on marriages**

Despite there being a wealth of literature concerning marital relationships in families containing a child with a terminal disease, less has been written about ongoing strains on a marriage where a child has a long-term chronic illness, requiring additional time and attention and therefore incurring extra burdens upon parents. This was an issue touched upon by Deborah when she attended interview with her daughter and spontaneously mentioned the relationship with her husband;

*I think generally the whole package has put strains on us – it puts a strain on our relationship and it's very *pause* no, it's not volatile at the moment – it's 'fragile', it's very fragile right now... (DEBORAH)*

Caring for a chronically ill child puts added strains on a marriage in practical terms of time and finances, the requirement for a mother to give up her job or take on part-time hours will result in a drop in family income, money may be needed for additional car journeys to and from school outside of school transportation times, even trips to and from the hospital for check-ups can be expensive, (Clulow 1991). The additional changes to routine and the amount of attention needed by the child means little time is left for parents to spend alone with each other, sometimes partners blame each other for the child's condition which compounds the stress further, (Klossner and Hatfield 2005, p. 743). 'Iatrogenic effects' or unintended negative consequences – emotional and physical - of medical treatment can, according to Clulow (1991), lead to unprecedented weight being put on the marital relationship as one family members needs are met at the expense of others. A combination of all of these extra stressors can put even the strongest relationship under intense pressure, resulting in marital discord and difficulties.

Part of the mother's role as care-giver and overseer of the family unit is not only to juggle her own emotions and feelings, but also those of her sick child, other well children and her husband, as is illustrated in Claire's situation with Chloe's father working abroad.

➤ **Feeling 'sidelined': the impact on well siblings**

Well siblings of children with chronic condition can often feel sidelined or excluded as their parents struggle to deal with their brother or sister's health needs. This can lead to jealousy or rivalry between the children, resentment in the child-parent relationship and a breakdown in communication and harmony within the family unit.

Siblings of children with chronic illness also have their lives disrupted in many ways, Jackson (1999) writes;

Sick children become the focal point of family life. Their needs and limitations colour the decisions taken on a daily basis for the whole family. Teachers, friends and members of the extended family repeatedly enquire about their health. Healthy siblings are expected to accept all this and to act as messengers to the outside world, (Jackson 1999, p. 27).

A paper concentrating specifically on well siblings of children with CFS (Jackson 1999) listed significant stressors for well brothers and sisters, Box 16. Siblings have to make major adjustments to their lifestyle, a paper focusing on the adaptation process experienced by siblings of chronically ill children reported a wide variety of reactions including anger, guilt, resentment and shame, (Seligman 1987). As Brotherston writes;

Healthy siblings struggle with the changes in their own roles within the family unit. Their legitimate needs and wants are often subsumed by the prevailing challenge of care management for the child with ME/CFS. Healthy siblings often harbour feelings of resentment and anger, intermingled with guilt and worry about their ill sibling, (Brotherston 2001, p. 1).

No longer do they have a ‘sparring partner’ or a play-mate, instead they find someone too lethargic to compete or socialise, as Tom, Jack’s younger brother has found, his previous equal and mate has become someone isolated and withdrawn, no longer willing or able to mess about in the family pool in the summertime. Someone who has undergone a personality change as well as now demanding more time and attention from their parents.

Box 16: Stressors for Well Siblings (Jackson 1999)

- The apparent dilution of parental concern or care
- The loss of a previously healthy companion or rival
- The restrictions imposed on family activities
- Deterioration in peer relationships
- The often unhelpful and contradictory medical advice and the uncertainty over how much, and indeed whether, the sick child will recover

The sibling relationship which may previously have been harmonious or competitive can change unrecognisably. When they have previously shared a school with their now unwell sibling children may feel abandoned that they no longer have that social support during the school day, they may experience misunderstanding or even teasing from their peers, and if their sibling does return to school may feel the need to take on role of ‘protector’ against other people’s unhelpful or ignorant remarks. People outside of the family unit may appear more concerned with hearing how their

sick brother/sister is progressing, which may make the well sibling feel a loss of identity. Their parents' time and focus will be on the needs of the ill child and hence they may no longer feel they are getting equal attention, this difficulty in relationships can lead to problems in adaptation for the healthy sibling, (Clulow 1991; Hentinen and Kyngas 1998). Family outings may be cancelled at the last minute causing resentment and disappointment, as in the case of Amy's younger brother. They may have to take on additional chores and responsibilities in order that the care-giver can concentrate on the sick sibling and to alleviate their brother/sister of his/her errands. Age-spacing has been found to be a factor linked to increased risk for sibling adjustment issues, (Lobato et al. 1988). Older siblings may feel they should take on some caring role, as in the case of Chloe's brother, and this may lead to frustration and a lack of equilibrium within the family unit, younger siblings may be confused or scared by snippets of medical information they have heard, or feel sidelined if parents choose not to explain adequately the situation. It is not all negative though, not all studies report negative psychological impact on well siblings, for example, (Lobato et al. 1988), researchers have found that some siblings of children with chronic illness have remarked upon a new closeness within the household and the development of compassion in response to the new situation, (Jackson 1999; Kramer 1984). As children grow in maturity and understanding of the new family set-up, responsibilities and changes many learn to appreciate their sibling's and their parents' struggles, as relayed by Charlotte in her story of how her son has come to terms with his sister's condition and the impact it has upon them all. It has also been reported that in families with a chronically ill child the sibling is positively impacted by the change in circumstances, feeling there is more scope for personal independence and the strengthening of family ties, (Gallo and Szychliński 2003).

➤ **The need for increasing dependence upon parents**

Having a chronic health condition and especially one as misunderstood as CFS can lead to an increased physical and emotional dependence upon parents for young people, one perhaps inconsistent with that which is ordinarily accepted as 'normal' for this age group of children, for instance taking an example from Sue's story;

I suppose in some ways I am closer to Jack - I don't think there are many mothers that have their 15 year old son saying 'can you lay with me please for a while?!' (SUE).

The physical dependencies include, for example, the access to freedom that can only be obtained outside the home by having mum push a wheelchair or drive their child to school and social activities where they would normally catch a bus or walk. Increased emotional dependence is due to the need for additional emotional support when a child feels constantly unwell, disappointed and misunderstood.

In coming to understand the change in situation some parents feel they identify with a new view of their son or daughter, in one study;

Each parent saw their 'past' child from an individual unique perspective that, in turn, informed their coming to a different, new view of the child, (Jerrett 1994, p. 1053).

This was a notion reflected in Charlotte's story when she spoke about the changes she had witnessed in Amy;

*I just want Amy back, I want the old Amy back *long sigh*. It's coming gradually, but it's not the old Amy, it's a new Amy. (CHARLOTTE).*

The strength in relationship between Charlotte and Amy was evident and in many ways makes this process of renegotiation even more difficult, but requires adaptation on behalf of both the mothers and daughters in order that a new relationship and a new sense of self can be found for each of them. Brotherston found;

The mother-daughter relationship, which is considered foundational by self- in-relation theorists, evolved for each of these participants from dependency through a sometimes intensively conflictive renegotiation to a more egalitarian, more balanced relationship. The renegotiation, as described by the participants, is a reciprocal one in which both mother and daughter struggle to grow to a deeper understanding of each other and themselves, (Brotherston 2001, p. 117).

Charlotte and her daughter both spoke about the journey on which they had come together, during which time they both experienced a myriad of emotions but through

communicating candidly about how they felt have forged a bond between them which may never have occurred had Amy not become ill.

This renegotiation process though, is difficult, especially for a mother, and it incorporates a sense of grieving for the child they once had, despite recognising and appreciating the changes that have occurred. In the case of Claire, she resents the condition that has robbed her of her daughter;

It is very frustrating understanding the condition and not seeing her flourish and enjoy a 'normal' young person's life, she is a very intelligent, beautiful girl who turns into an angry depressed person. (CLAIRE).

A piece of poetry penned by one mother of an adolescent child with CFS reflects these feelings of frustration and being unable to improve the situation;

HEATHER

Locked

In a dark silent world

An eerie tomb

This was once

My daughter's room.

Dead

To the world

And all its joys

Dead to the music

And teenage toys

Dead to friends

Laughter and fun

Dead to family

...poor little one.

And yet...

*There is life
A little thread
One that lets her
Lie in bed
She goes to the toilet
And eats her food
She would do much more
If only she could.*

*Yes.
There's a pulse
Dull thud of a heart
Beating in hope
Yet so torn apart
How do you live
Through a death such as this?
Do butterflies come
From such chrysalis?*

(Tymes Trust 2004, p. 28).

This mother feels that CFS has so very nearly robbed her daughter of her life altogether, she can only just manage the bare essentials of functioning. All of the things that teenagers typically do and enjoy are non-existent for this girl, in her mother's eyes she is not living, merely existing. This mum, as with the mothers in my study, would do anything to improve the situation for their children, they feel useless and desperate that they cannot change the situation.

In meeting their child's developmental needs parents are faced with the dilemma of balancing their son/daughter's emotional and social needs against the physical ones imposed by their ill-health, Canam writes;

...If parents focus on the illness or disability to the exclusion of the child's developmental needs the child's development is likely to be thwarted, (Canam 1993, p. 48).

Both Sue and Deborah touch on this issue with reference to their respective children, commenting upon the uneasy truce that must be made between allowing their children freedom to be teenagers, without burdening them with more responsibility than they can easily cope with. In overcoming this problem successfully parents must learn how to avoid cosseting their child on the one hand, or expecting too little of them on the other, it is not a simple task to attain equilibrium, however it is only in pursuing normalisation that parents can aid children in diminishing the effects of a chronic condition. Certain things may assist this transition, including the pursuit of discipline, avoiding 'preferential treatment', emphasising what is achievable and de-emphasising what is less achievable, (Knafl and Deatrck 1986). Despite these things though it must be made explicit that adaptation is neither easy nor quick to achieve, it is a difficult learning curve that all members of the family have to deal with.

➤ **A cause of friction within parent-adolescent relationships**

When parents 'read' their child and attempt to alter the way they behave in order to prevent them from 'crashing', it may well cause friction within the relationship. The adolescents in this sample have generally commented on this situation saying that their mums can often predict a 'dip' in energy/health better than they can themselves, and although they recognise this to be true they still at times challenge it...despite having to apologise later!

Returning to the topic of adaptation, Hentinen and Kyngäs (1998 p. 321) define 'good adaptation' and 'poor adaptation' within families (as listed in Box 17).

Box 17: Stages of Family Adaptation

Good Adaptation:

- Acceptance of the situation
- All children within the household are treated equally, with the same chores and rights

- Parents are confident that their ill child will cope as well as any healthy siblings in the future
 - Open, honest relationships prevail
 - There is freedom to express emotions and feelings between members
- Poor Adaptation:**
- There is conflict between family members
 - The chronic condition negatively affects the marital relationship
 - Parents experience guilt for having an ill child
 - The ill child is treated differently to his/her healthy siblings
 - There are problems in caring for the chronically ill child

It is possible to see some of these elements reflected within the narratives in this study. According to these definitions it could be argued that Sue's anxieties about her ill son's future well-being and her well son's reluctance to discuss his feelings; Deborah's reference to a 'fragile' marital relationship and Vicky's mum's burden of guilt that she had somehow 'caused' her daughter to have CFS (a similar finding is made in Brotherston's book, (Brotherston 2001), that parents feel they are somehow responsible for their child's CFS), could be regarded as examples of poor adaptation within these families, and Charlotte's determination to pursue open, frank lines of communication in the form of 'family chats' is an example of good adaptation. Hentinen and Kyngas do not refer to any kind of time bracket within which this adaptation process should be completed, therefore it could be suggested that the families within this study who have had a relatively short amount of time since diagnosis within which to come to terms with their situation are still in a transitional stage and have not reached a point wherein they can be referred to as having achieved 'good' or 'poor' adaptation. As previously mentioned, the process of adaptation is a 'hard won' process for all the household members and certain elements of the life that they all once were familiar with is lost in the process of acclimatising to a new way of life, with new challenges and new ways of functioning.

Adolescent CFS is Experienced as Living with Changes in Family Relationships and Member's Life Experiences... In Summary

Having one young member of the family with CFS impacts all the other members too, parents have extra responsibilities aside from their normal parenting duties to learn to make time for as well as trying to adequately meet everybody's attention needs, and siblings must learn to deal with the loss of an equal and the presentation of someone whose condition disrupts family plans and incites a need to compete for attention. Primary care-givers especially experience a dramatic and unforeseen alteration to their lives, often having to juggle a career, the household, the harmony within the family, their spouse's and other children's needs alongside the worry and daily burden of having a chronically ill child, many experience feelings of loss of control and it is only through demanding journeys of learning to cope with varying situations that they achieve a sense of empowerment and newly discovered ability. Additional strains on marriage include challenges of finding time for each other, financial pressures, and fulfilling their spouse's practical and emotional needs. Many mothers feel robbed not only of the child they once knew, but also of the aspirations and desires they had for their child's life and their own, feeling that their own freedom has been curtailed by the negative turn of events. Siblings often feel sidelined, this can be as a result of perceived or actual lessening of parental attention and disappointing changes to routines and family activities, this can oftentimes lead to feelings of jealousy or rivalry. Young people with CFS frequently become more dependant – physically and emotionally upon their parents, a dependency which is out of character for this age of child, and this can lead to feelings of claustrophobia for all involved. Some parents comment upon their child's difference in maturity compared to their peers, as a result of living in a cocooned world. CFS can be a cause of friction in the adolescent-parent relationship when parents try to enforce boundaries upon activity when they feel it is in their child's best interest, but the child feels this is unfair or suffocating. Finally, CFS often impacts relationships with extended family members – either positively for example grandparents assisting in the care of family members, or negatively such as demonstrating a lack of understanding towards the situation which can leave young sufferers and their parents feeling isolated and frustrated.

6.15.3 Adolescent CFS is experienced as living with isolation and a disruption to a full and satisfying teenage life

The normal components of adolescent life include it being a time of experimentation with new beliefs, ideas and social groups. It is a time of increasing independence away from family and towards freedom of individuality. Simultaneously it is a time of increased affinity with peers and exploration of different social relationships. When a young person is struck down with a chronic illness, which is only limitedly understood and of no known prognosis many of the ‘normal’ socially acceptable adolescent explorations and freedoms are curtailed. Rather than being a time of increased social confidence and independence away from the household, teenagers with CFS are often denied this opportunity and may become isolated either due to prolonged school absence or insufficient energy to allow involvement in out of school social events and hobbies.

➤ **The forced-need to adapt to constraints of diminished energy**

For many young people with CFS working within the boundaries of restricted energy levels means foregoing hobbies and other activities which they have previously taken great pleasure in, this can be not only disappointing but feel like a robbery of their sense of self and identity. The person who most markedly spoke about this aspect of loss is Amy’s mum with reference to her daughter;

*Before, everything she loved and held dear, like her school-work, her dancing, her social life, (‘cos she was very very popular), was all being chipped away at...so everything she loved had gone and it had just left ..*pause*..well, it had left nothing. She had no social life as such, she had no outlet because she couldn’t dance. The main subjects she wanted to do at school being dance GCSE, she couldn’t do. Everything was just being chipped away and she didn’t seem to be getting anything back and all she said was: “I had to give up so much”, and that was really, really difficult – very difficult. In fact it was quite devastating for Amy. (CHARLOTTE).*

All of the elements of her life that Amy had used to define who she was and what she enjoyed were gradually picked off until she felt there was nothing of any worth left, this was a difficult time for both Amy and her mum as she watched her daughter deal with extreme disappointment.

➤ **Isolation & loneliness - a demise in peer relationships**

As mentioned previously the adolescent period is a time when social relationships and a sense of belonging are very powerful and desirable, young people yearn for

friends and peers to feel accepted and to promote self esteem. The loss of friendship groups can be devastating for teenagers and all of the participants in this study made reference to the importance of their peers, either commenting on the loneliness of not seeing other young people, mourning the loss of friends from school or in appreciating those people who had made the effort to remain in contact and supportive. Similarly, Brotherston's book states;

All participants experienced the loss of most or all of their peer relationships during the early years of their illness. These relational losses were mourned more deeply than any others, (Brotherston 2001, p. 117).

The loss of friendships and feelings of abandonment and isolation during adolescence is a crucial blow, it can leave individuals feeling cut-off from the rest of the world.

The piece of writing below explains the frustration and isolation that having CFS as a young person can cause;

HANGING OUT IN BED

*Hanging out in bed, staring at the ceiling
A pain in my head, numbs all the feeling
Minutes merge with hours, the clock ticks away
Trying to remember the name of the day.*

*Some thought me lucky, staying home all day
Thought I was a yuppie, lots of time to play
But would they wear my shoes if they could really see
The bars on my window, my cry to be free?*

*Hanging out in bed, sick of lying still
I went to the doc, he had no wonder pill
What did I do to deserve this crushing fall?
The sounds of my cry echoes on the wall.*

*Some thought me lucky, lots of time to spend
But would they feel so lucky praying for a friend?
A soul to share the pain, of years trod in dirt
Would they wear the shoes, filled with thorns of hurt?*

*Hanging out in bed, longing for a cure
Body feels like lead, stomach is a sewer
My instinct is to fight, I push myself to crawl
Again I feel the bite as I hit the brick wall.*

*Some thought me strange, I rarely was around
They just didn't see me writhing on the ground
Some didn't care, just went on their way
They had their own lives, had no time to stay.*

*Hanging out in bed, chained by fatigue
Battery has gone dead, strength just a dream*

*Mountains I have climbed to fall in a pit
But the spirit borne within me says "I never quit".*

(Tymes Trust 2004, p. 82).

The lack of understanding from others leaves young people feeling isolated and lonely, people around him thought him 'lucky' that he didn't have to do the things that others his age have to do and yet he yearns for the opportunity to be the same as everyone else. This boy's desperation for a friend to share the burden that he feels is tangible, he feels inaccessible and abandoned. He is unable to be the person that he wants to be, the person he once was and yet refuses to give up hope. All of these sentiments are present in the themes that emerged from my participants' stories, and are articulately summed up by this young man; the desperate loneliness and yet perseverance that they refuse to give up hope of things improving.

Wallander and Varni investigated social adjustment in children with chronic conditions and discovered that those with a strong family *and* peer support networks demonstrated much better adjustment than those children with only one of these support systems, (Wallander and Varni 1989). This was true for Andy who made reference to being grateful for his parent's backing and encouragement and yet still missing his friends;

*No-one really took the time to come out and see me, sort of at the weekend and stuff, which was a bit... *Trails off*... My parents helped, but after a while it's just not quite what you need, is it? (ANDY).*

As much as Andy appreciated his parent's support he still felt a need for peers and friends, he missed adolescent conversation and activity.

➤ **A loss of social knowledge regarding norms & mores due to peer segregation**

All of the participants have experienced disruption to their academic life, whether this be relatively minor in simply having to re-negotiate their school timetable, or fairly major in some being absent from school for long periods of time and having to be home-tutored. The proposition of returning to school having been absent for a lengthy spell of time has caused anxiety and trepidation for some, feeling that their friends have 'moved on' with their lives whilst they have remained stagnant and that they are now out of touch with what their peers' topics of conversation, activities and belief systems are, this can be an added source of anxiety. Vicky described her experience of returning to school for a temporary period mid-way through her illness;

I missed my friends and I wasn't very good at talking to people. I wasn't up with all the things that people talk about, like fashion, I was like "What? What's that about? I don't know anything about that". So it was quite hard, but I got better over time. (VICKY).

This was an adjustment that she had to make, learning the 'rules of engagement' for fitting in with her peers again, having been out of contact and isolated for a long time at home.

➤ **Struggling to legitimise the ‘realness’ of the condition to others around**

Generally speaking, unless we make a conscious effort to educate ourselves about an issue, our knowledge can be largely influenced by the mass media, which acts as a drip-feed colouring our opinions and emotions, perhaps more than we are actively aware of. In the case of Chronic Fatigue Syndrome, the negative articles in newspapers in the 1980s and ‘90s did much to sway public opinion and unfortunately stigmatising labels such as ‘yuppie flu’ have stuck, even all these years on. A comment made by one author addresses the derogatory connotations of the label;

The disease is often reputed in the media to be the outcome of some members of a self-indulgent, materialistically driven society ‘opting out’ or ‘burning out’. This metaphor of malaise encourages negative stereotypes of a self-generated condition driven by over-reaching ambition and greed, (Brotherston 2001, p. 99).

This lack of understanding within the public domain impacts the generic attitude towards CFS and is, in part, responsible for the ongoing need for sufferers and their families to have to explain the character of the illness to friends and family. This is evident in the stories of several of the participants but perhaps most succinctly summed up by Claire’s belief that had her daughter been suffering from a more widely-understood illness, such as cancer, some emotional and social aspects of coping may have been easier. The far-reaching effects of widely attributed misconceptions impacts the individual sufferers and their families on a number of levels, and the battle to feel, not only believed and empathised with, but at times even vindicated in their experiences with others is of great importance to those affected by CFS. Brotherston extends her earlier description of the impact the media has had in this area and the extensive consequences for individuals with CFS and their families;

The media, with their formidable power to shape perceptions and opinions, have addressed the issue of ME/CFS in a way that encourages a stigmatising perception of the disease, its ‘realness,’ and its aetiology. This stigma is influential in perpetuating an uncertain and unsupportive approach toward individuals with ME/CFS, from persons in their school and work environments, in their community network, in their extended families, in their

nuclear families, and even within the individuals themselves, (Brotherston 2001, p. 100).

A study by Horner and colleagues reiterated the need for the general public to be educated about paediatric chronic health conditions, especially when that education rectifies stereotypical myths which are detrimental to sufferers, (Horner et al. 1987).

➤ **Instrumental in altering relationships with extended family members**

There is often a need with chronic conditions for sufferers to have to educate those around them, in the case of young people this means the child's siblings, extended family members, peers and school staff, this is not always an easy task as Claire's story demonstrates – she feels a burden in having to repeatedly explain and even justify her daughter's condition to her mother when she comes to stay. Also Deborah has found it has taken almost five years to convince her extended family that Cassie's illness is real and the true nature of it, this extended period in which she has felt the need to constantly battle to be believed has left her feeling isolated. The longevity of a chronic illness can also cause people outside of the immediate situation to struggle to understand the stress it causes, as Kralik and colleagues writes;

Because living with a chronic illness was a long-term proposition, the problems associated with it were often discounted by other people, (Kralik et al. 2000, p. 910).

People who do not have a day-to-day understanding of CFS, witnessing the ups and downs and experiencing the struggles first-hand often forget that it is ongoing and cannot fully appreciate the difference between normal coughs and colds and the persistent stresses of a chronic illness.

➤ **Enduring teasing & misunderstanding from classmates**

Those participants who experienced the most misunderstanding from their peers are those for whom the condition was more 'visible', for example Vicky's reliance upon a wheelchair at one point meant that there was no escape from her peers seeing that she was 'different', and this led to displays of ignorance and bullying;

It was so difficult to explain to them, partly because I didn't know myself quite what was going on, all I knew was sometimes I could walk and sometimes I couldn't. I didn't know what was causing it, no-one could find any reason except for the ME, and explaining that to them was just too hard, as it's quite complicated...some people didn't believe me and would say "Get out of the chair" and I would say that I couldn't...it was hard. (VICKY).

The situation was exacerbated for Vicky because she felt a certain level of confusion about CFS herself which made it difficult for her to understand herself, let alone explain to other people.

➤ **Needing to relinquish extra-curricular activities & hobbies**

When a young person is forced to relinquish freedoms and aspirations it can be a devastating time for them, as Amy found initially when she had to give up all of the things she enjoyed and excelled at. Other findings concerning adolescent CFS reflect this;

Areas of achievement in the past (academic, peer popularity, community recognition and competence, reputation as reliable and rational) seemed to be eroded, then eradicated, one by one. Embedded in these areas of loss were the very elements that participants had always accepted to be the external markers of a maturing self moving toward adulthood: school attendance, move from home to peer influence, graduation, first boyfriend, first job, entrance to university, leaving home, marriage. The feelings of bitterness, betrayal, loss, anger, failure, and grief, combined with the uncertainty of the reality and aetiology of the disease, pushed participants towards depression and a sense of immobility and total loss of control in their lives, (Brotherston 2001, p. 38).

The overwhelming sense of loss and even failure at having to forego all of those things that were once integral to one's life is incredibly demoralising and upsetting to a young person with CFS.

➤ **A major cause of academic disruption**

All of the participants have experienced some level of interference with their school lives, from relatively minor effects such as having to slightly amend the timetable to being absent and home tutored for significant periods of time, some for many years. For some this represented a devastating set-back to their ideals and aspirations as their school life was a top priority and they always strived to achieve high grades.

Amy, for example, had to re-evaluate her attitude towards school in order that her health was given the chance to improve, as her mum explained this was exceptionally difficult for her daughter;

She was an 'A' grade student and when she was poorly she would really sort of force herself into school knowing that it was going to make her feel even worse but school was everything to Amy, because she was very intelligent and very bright and knew exactly what she wanted to do. At the first interview we had at the (CFS) Clinic the OT actually said: "What's more important – your health or school?" and Amy answered "School". So we had to kinda change that...(CHARLOTTE).

Similarly, Chloe struggled with the fear of falling behind in her school-work;

It was quite scary 'cos I hadn't got a clue what was happening and because I was so into school my priority was "Oh my god, I'm missing another day of school", which sounds really stupid as you health comes before education, but I'd be "Oh, I'm going to fail my GCSEs" and that would be a really big worry for me. (CHLOE).

For conscientious pupils who have always worked diligently to achieve the highest standard of work they can, having to ease back or re-assess their priorities, with schoolwork no longer being at the top of the list, can lead to feelings not only of disappointment and panic but also of having failed. This can effect self-esteem and motivation and is a big adjustment to have to make.

Adolescent CFS is Experienced as Living with Isolation and Disruption to a Full and Satisfying Teenage Life... In Summary

The forced need to adapt to constraints of lessened energy can lead to a sense of being robbed of identity, those activities that young people with CFS once held dear may now be unattainable which can be devastating to self esteem. Major academic disruption for a conscientious student can result in them feeling a sense of failure and disappointment in themselves. Isolation as a result of prolonged school absence or only attending on a part-time basis can lead to a demise in social relationships at a stage of life when friendships are vital as a method of building self confidence and feelings of belonging. Prolonged isolation can make individuals feel out of touch with the norms and mores of their cultural group and leave a sense of feeling left behind and unable to communicate on the same level as their peers. Stigmatising labels such as 'Yuppie Flu' can leave sufferers and those closest to them with an

added burden of feeling they need to legitimise themselves and the limitations on their daily lives, and dealing with negative comments and attitudes can make families feel isolated and upset.

6.15.4 Adolescent CFS is experienced as feeling misunderstood and judged

Not only do sufferers of CFS and their families have the debilitating symptoms and disruption to their lives to contend with but also many have to endure the added pressure of feeling misunderstood and not believed, this can lead to an even deeper sense of isolation and segregation. This sense of not feeling understood or 'met' began early in the CFS journey; through the awaiting a diagnosis period and a search for answers, including feelings of relief on receiving a diagnosis. However feeling misunderstood and judged permeated many aspects of life in an ongoing way. Sometimes this was tempered by opportunities to be with peers in the same situation.

➤ Dealing with ignorance from 'gate-keepers' of further medical assistance

The lack of understanding within the general public is somewhat comprehensible considering the negative effects that the mass media has had over the past two decades, however participants' experiences of negative attitudes from GPs or healthcare professionals as highlighted in several of the narratives is more alarming. In 1998, then Chief Medical Officer Sir Kenneth Calman said to a meeting of the Royal College of Physicians;

I recognise Chronic Fatigue Syndrome is a real entity. It is distressing, debilitating, and affects a very large number of people. It poses a significant challenge to the medical profession, (Hutchinson 2002).

The first point of contact in the medical profession is the general practitioner and so it is his/her job to take on the challenge posed by the condition of CFS. Recent research in the UK shows that only 72% of GPs accept CFS as a recognisable clinical entity; only 48% felt confident about making a diagnosis of CFS and 41% did not feel confident about treating it. CFS obviously therefore remains a controversial issue, (Bowen J et al. 2005). As William Cullen (1710 – 1790) says;

A Physician who does not admit to the reality of the disease cannot be supposed to cure it, (Hutchinson 2002).

As old as this quote is the sentiment is true today, without understanding from a physician the patient is subjected to a difficult journey to find help and support. Generally all of the participants' stories reflected some aspect of feeling ignored, dismissed or unsupported by family doctors, which left the young people and their families feeling alone, abandoned and at a loss as to where to access advice and assistance. Lisa, for example struggled with a dismissive attitude from her GP surgery. The refusal of a general practitioner to take an individual seriously can be very destructive for people who are already feeling at a low ebb, and can cause a strong sense of frustration, (Gibson 1995). Not only are family doctors the 'gate-keepers' for other medical services – the ones who hold the key to further help and treatment, but also the act of visiting a GP for confirmation or expert advice as a young person can be intimidating. If they are then dismissed as “making it up” or malingering it can have a damaging effect, not only on the person's health (which is being left untreated) but also on their self-esteem and their confidence in healthcare professionals. This could cause problems within the family as parents may feel that either the doctor is correct and therefore force the child back to school, thus further alienating him/her, or where parents disagree with the GP's opinion leave them too feeling powerless to access further help for their child, or have the credibility of a physician's diagnosis to access support from other agencies such as academic or social services. In Hummelinck and Pollock's study into the information needs of families with chronically ill children they found that parents were not satisfied with the nature of information given by physicians and felt it did not meet their present or anticipated future needs, (Hummelinck and Pollock 2006).

It is shocking that despite the recognition by Sir Kenneth Calman, over a decade ago, still today people with CFS are battling with people's prejudiced opinions that it is not a real illness. Not only do sufferers have their symptoms, isolation and debilitation to contend with, but also other people not believing that they are even genuinely ill. This is major pressure for an adult, but is compounded further for a child or adolescent as younger people lack the emotional and cognitive maturity to know how to process such experiences.

According to one study, (Hentinen and Kyngas 1998), parent's lack of coping is linked to feeling unsupported by physicians and health care staff. Canam comments that the lack of a clear and concise understanding as to what is required of healthcare professionals to aid families in the adaptation process is partly responsible for their failing in this area;

The difficulty experienced by health care staff in supporting the parents of chronically ill children is due to the fact that these adaptive tasks have not been clearly defined. It is therefore difficult to have any guidelines or framework for assessing the family's coping tasks, (Hentinen and Kyngas 1998, p. 323).

This may go some distance in explaining the lack of support offered to families, not as an act of neglect, but more as misunderstanding or innocent ignorance, however it still does not justify those practitioners who ardently refuse to accept the existence of CFS and refuse to listen to requests for support or advice made by sufferers and their families.

A major player in assisting families in achieving normalisation is the main healthcare provider associated with caring for their needs, this support may be given in the form of providing information or referring families on to other professionals who may be able to address their needs more specifically. The lead Occupational Therapist at the specialised CFS service from which I recruited participants has been successful in providing this kind of support to many of the families within the study by addressing their needs including direct communication with schools, referral to other healthcare providers, and providing information and encouragement. One author comments upon the issues that healthcare providers working with families containing a chronically ill child needs to address;

Professionals who deal with children with chronic disabilities or illnesses, and with their families, must empathise with the experience of parents in the foreign world of medicine and disability, respect the immediacy and gravity of their concern, and tolerate their occasional confusion and irrational behaviour, (Cherry 1989, p. 11).

More often than not, when children are diagnosed with a chronic condition parents are thrust into an alien world, which contains foreign terminology, unfamiliar

protocol and strange and unknown therapies, this constitutes a dramatic change in the life of the family. A sympathetic and empathetic healthcare professional can significantly aid this process, easing the passage as the family learn to navigate new territory, as much as a dismissive and unsupportive physician can cause the process to be a more taxing one.

A cause of stress to parents is the consistent presence of illness-related demands, as well as anxieties such as present and future vulnerability (Canam 1987) which was spoken about by Sue with relation to her fears about her son's future, and the unpredictability of the condition, (Ferrari et al. 1983). One way of combating this ongoing stress is to foster supportive environments, (Canam 1993), in which parents are encouraged to isolate and work through specific anxieties. Possibly one of the most crucial things for parents is the need for supportive healthcare professionals who provide emotional assurance and understanding, this is necessary to help them not only cope with their own emotions but also deal with the feelings and concerns of their children, (Canam 1993). This support has certainly been showed to be lacking in many of the participant's stories (young people and adults) in this study, some families such as Charlotte's have dealt with the situation relatively successfully without the backing of their GPs, however other families have found it more difficult to do so.

➤ **Feeling self-conscious in public places**

A point of developmental importance is that, during adolescence especially, young people do not want to be seen as different from their peers or to draw attention to themselves, therefore markedly different symbols such as a wheelchair can be intimidating things for a young person to incorporate into their life, but is something that Lisa and Vicky had to come to terms with. Both believed that people had misconceptions about them and that strangers were commenting negatively about their use of a wheelchair, Liz described the situation;

...people just assume things and are wrong about them. I can feel people watching me and assuming things about me and sort of saying "Oh, what's she doing? What is she thinking? Why is she in a wheelchair?" (LIZ).

Whether Liz's assumptions about other people's negative opinions are true or not, what is important is that she felt awkward and embarrassed, this is an additional pressure on top of all of the other things she has to deal with. These participants' feelings may also be linked to a loss of agency, that is; experiencing a sense of having to become more passive than others around them and indeed than they themselves would like, when in a public place.

➤ **Experiencing a sense of relief upon achieving a diagnosis**

Many participants and care-givers commented upon their confusion and feelings of being at a loss prior to being given a firm diagnosis of CFS, however even when a diagnosis is presented this can be an emotional time. Upon diagnosis parents of children who are chronically ill are presented with a name for a condition which may or may not be familiar to them, they have to then process that information in order to make sense of it and to incorporate it into their family lifestyle. This is an emotional process and not only signals a change to present functioning, but also the need to modify future outlook, it is in accepting and facing up to emotional changes that parents learn to manage the new expectations placed upon them, (Jerrett 1994). Point of diagnosis is a particularly emotional experience for many parents coming to understand their child's condition, as the mothers who participated in this study explained their feelings, specifically of relief when a diagnosis was made, in all cases after a lengthy time period of feeling bewildered as to what was happening to their son or daughter; Charlotte for example;

It was a bit of a relief to know that what she was suffering was a recognised condition and that help was available, not knowing what she was suffering from was really difficult, as all sorts run through your mind. At one stage I even thought that she was suffering from a terminal illness, knowing that it was CFS (although difficult) made it easier to deal with. (CHARLOTTE).

Brotherston discovered a similar sense of relief was experienced by participants in her study of adolescent CFS;

...the participants greeted the initial labelling of their disparate symptoms as a real disease with a sense of relief, (Brotherston 2001, p. 29).

Meleski believes that this sense of relief is linked to the new-found ability to assign meaning to the illness (Meleski 2002), it also allows parents to begin planning realistically for the future, (Gibson 1988), which allows a sense of control over the situation having been in a state of confusion up to this point.

The process of acceptance and making sense of a new diagnosis requires a clear and concise explanation from the person delivering it, (McCubbin et al. 1980; Venters 1981), this was not so in the case of Jack and his family as his mum Sue explained her thoughts on the walk home from the GP surgery having been lulled into a false sense of security by the doctor;

I remember when we walked home we said, "oh, it's a good job that it's not glandular fever 'cos he would have been really tired for six weeks if he'd had that!"...of course I'd heard about it but didn't really know that much and then we found out that ME lasts a lot longer...(SUE).

Without a clear and lucid explanation of a diagnosis and its prognosis sufferers and their families cannot predict what the future may hold and so cannot begin the journey towards acceptance and adjustment. In order to manage a child's condition on a daily basis parents require the full facts about what they may be facing, it has been demonstrated that inaccurate information from healthcare professionals can lead to a sense of helplessness within families, (Power 1985). It has been found that the major psychosocial stressor for families of chronically ill children is chronic uncertainty; regarding the illness, its treatments, other family members and healthcare professionals, (Sharkey 1995), and parent's top three priorities in information needs are; treatment, prognosis and caring for the child, (Pyke-Grimm et al. 1999). The reasons for parents requiring this information is;

A wish to be able to understand the background to treatment decisions, reassurance, to feel involved in the child's care and to enable them to confidently answer their child's questions, (Hummelinck and Pollock 2006, p. 232).

In situations where parents feel that their healthcare provider is supportive and a potential source of ongoing advice and support they feel better equipped to cope with the tasks ahead, (Barbarin et al. 1985).

However, as one author highlights diagnosis is simply one of the initial steps in learning to cope with the condition;

The diagnosis of a chronic illness or disability in a child represents a major stressful event for all the family members, yet the diagnosis is but one point in the family's ongoing experience with the ill child, (Canam 1993, p. 46).

The family must all then learn to adapt their lifestyle to make room for a new situation with new demands and expectations upon them.

The admittance, by parents especially, that their prior knowledge of CFS was very limited and largely linked to information which had been presented in the popular press was done so with a sense of apology and feeling somewhat foolish, for example Claire comments;

My knowledge was very limited and I am afraid I put it down to people having 'yuppie flu'. (CLAIRE).

Having now learnt the full and devastating effects that the condition can have has unsurprisingly altered their outlook.

➤ **Deciding whether to research help, advice & support**

Families; individuals and parents are diverse and the way that they approach and adjust to a novel situation can differ also, however there are similarities within the experience despite the variety of reactions to it;

The care of a chronically ill child is a particular experience and each parent is an individual with a unique perspective; yet there are patterns that can be determined from each person's account and meanings that are common to all, (Jerrett 1994, p. 1051).

For example, Charlotte, Sue, Deborah and Claire all chose to research CFS independently; finding out as much information as they possibly could regarding diagnosis, prognosis and support, this need to comprehend the condition is reflected in a study of parental coping in childhood cancer, (Clarke-Steffen 1997). Vicky on the other hand decided that 'ignorance was bliss', she didn't want to know anything about the condition and preferred to remain uninformed. According to some studies

the decision to *not* seek information can be attributed to an attempt at normalisation and seen as a positive coping strategy, (Coyne 1997; Hummelinck and Pollock 2006). Similarly, Peck and Lillibridge found in their study focussing on fathers of chronically ill children;

The fathers in the study were reluctant to seek information pertaining to their children's illnesses, believing that negative knowledge of the illness could generate greater stress for the family, (Peck and Lillibridge 2005, p. 42).

Some, as Vicky did, believe that knowledge will lead to greater pressure and therefore choose not to know what is possibly in store, but rather take each day as it comes.

➤ **Investigating alternative therapies & medications**

As a response to the debilitating symptoms experienced by the participants in this study many spoke about researching alternative therapies and treatments. With a condition such as CFS where still so little is universally understood about its origins and characteristics, and the lack of medically-recognised cure people become desperate for an answer to their suffering, or in the case of children their parents are anxious to end their child's struggles and therefore willing to try anything which may alleviate the condition. This often means attempting diets, homeopathic treatments, and alternative therapies that have not been approved of or even recognised by healthcare professionals, and have not undergone any rigorous medical testing in an effort to find something – anything – to help. Unfortunately this can mean large financial and emotional disappointments when it does not have the desired effect, as Chloe referred to when she spoke about a friend she knew who had paid out a lot of money on the Lightning Process courses, just to become worse as a result. Some people however, have found success with this alternative treatment, as both Vicky and more explicitly Andy spoke about in their stories. On a personal note, I struggle with the whole concept of the course, of course I could be being unnecessarily negative and suspicious and the Lightning Process may well be all that it is presented to be by its founders, in which case I welcome the day that it gains medical approval and can be made available to the many thousands of CFS sufferers in this country and abroad. My primary concern is for those individuals who have been on the course at a financial cost that they cannot easily afford and suffered not only the

disappointment of not regaining their health, but also the damaging psychological and emotional criticism of the course's onus being on the individual and therefore being his/her responsibility to get well and the inability to do so being blamed on them for not doing the process correctly or not having a strong enough desire to recover.

➤ **Feeling reassured when in contact with others in a similar situation**

The very nature of CFS makes it a difficult condition to understand even by those with first-hand experience of it, so educating others who are completely unaware of its character is challenging. Jackson recognises this;

Today, society does not recognise invalid status, rather it looks toward enabling people with disabilities to participate fully in normal life. CFS/ME does not allow its victims to do this however much they want to, (Jackson 1999, p. 30).

The vagueness in characteristics of the condition, the fact that there is no origin or cause upon which everyone agrees, the unpredictability and fluctuation of symptoms and the fact that not all symptoms are experienced by all sufferers makes it a difficult illness to comprehend. Typically those diagnosed with a health-condition are given a diagnosis as well as advice and some sort of treatment plan, this is not so in the case of CFS, neither does it allow individuals to push themselves beyond what their bodies can cope with. All of these aspects make CFS a contentious condition which is difficult to fully appreciate unless you are a sufferer or somebody very close to one.

Many of the participants in the study have found solace in utilising the website and resources of AYME (Action for Youth with ME), having lost their previous social relationships and friendships they have felt great relief and a sense of legitimisation in making contact with other young people with CFS. This has been labelled a 'life-line' by a couple of the young people who believe this affiliation has lessened their feelings of isolation and loneliness. For example, Liz said;

It stops me feeling isolated. It gives...it's nice to have people going through the same thing as you. It's nice to be able to say "I'm feeling really bad today" and have one of your friends say "Oh, me too!" They think about me too and...it's nice. (LIZ).

Finding other people in the same situation as you, with the same struggles and daily trials makes one feel less alone and different from the rest of the world, it provides a sense of affinity and justification and helps alleviate feelings of isolation and loneliness. This is an important part of securing a support network and helps sufferers come to terms with their limitations and difficulties.

Adolescent CFS is Experienced as Feeling Misunderstood and Judged...In Summary

The lack of universal acceptance by physicians that CFS even exists is both alarming and the cause of much anxiety and unnecessary stress to sufferers and their families, without GP acknowledgement of the condition families can be left unable to access further care, financial assistance or the support necessary to legitimise poor school attendance. Many individuals describe a sense of relief upon receiving a diagnosis, it allows them a sense of empowerment that knowing the cause can now be responded to with a management plan of action, it also stops confusion and anxiety about what the cause may or may not be, and can help people stop feeling 'in limbo' without the knowledge they need to move forwards with their lives. Once diagnosis is given sufferers and their families can make the decision about whether they wish to research the condition which for many enables a feeling of liberty as they can once again retain a locus of control over their lives, others prefer to remain ignorant to the facts in an attempt to remain blinkered to symptoms and outcomes which may or may not ever be relevant to their own experiences. In the absence of a medication which can cure and as a sense of 'doing *something*' many choose to pursue alternative therapies, this can help some but has the danger of leading desperate people into unmonitored arenas where the therapies have not received medical acknowledgement and may result in more harm than good. There is a generalised sense of reassurance that individuals report upon making contact with others in a similar situation and support groups such as AYME (Action for Youth with ME) can restore a sense of validation and legitimisation, as well as lessen the feelings of isolation. Adolescents try to avoid standing out from the crowd, but for those who require the use of a wheelchair or other assistance it is impossible to not look different and this can cause distress for some, who feel they are being criticised and misunderstood.

6.16 Adolescent CFS is Adapting to a Life Put On Hold

It is possible to see the far-reaching and destructive physical, emotional and social effects that CFS can have on individuals and their families. The disruption to normal teenage activities, harmonious family interactions, social relationships, educational attainment and parental aspirations and wellbeing can be extensive and damaging. The controversy that still surrounds the condition means negative, stigmatising labels which stick fast and make life all the more difficult. The loss of a sense of identity and feelings of validity, as well as damage to self esteem can make sufferers feel alone and like they have failed. Having CFS, or having a child or sibling with it, is not an easy situation to be in, there are burdens and pressures that those outside the home are unaware of. The lack of knowledge in the general domain is reflective of the paltry amount of knowledge in the medical literature concerning such issues as raised above.

Apart from Naida Edgar Brotherston's study which she compiled into a book *Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Journeys with the Dragon*, (Brotherston 2001), there is very little narrative information specifically pertaining to adolescent CFS and the social, psychological and emotional issues affecting this particular sub-set of the CFS population. Through this present study my aim has been to help plug that literary gap and generally raise the profile of this specific area, which will, I hope, assist not only the sufferers and their families who have expressed relief that they could take part in a research project which may increase understanding, but also healthcare professionals who come into contact with young people and their families affected by this condition.

Narratives, as spoken word or poetry, present something precious and unique – an insight into a lived world - a peek into the everyday lives of individuals. They capture something which cannot be achieved in other forms of research and should be treated with reverence and respect. Illness narratives provide a window through which to gain understanding of the thoughts, feelings, struggles and disappointments of individuals in a particular situation which may otherwise go unnoticed.

6.16.1 Issues Applicable to Healthcare Workers

The top priority of physicians, especially those on the frontline of medical care, such as family doctors, is to show compassion and sensitivity when interacting with a potential CFS patient, in order that they feel legitimised and at ease with the medical world. It is also important that the recommended tests and screenings are conducted as quickly and efficiently as possible to rule out other possible causes of ill health, and to reassure the patient the reasoning behind the course of investigation. The issue of trust between doctor and patients and their parents and the establishing of a baseline of activity are significant ones which needs to be established early in order that an honest record of progress can be kept. Doctors need to remain mindful of the social inhibitions that young people may feel and that attending an appointment may be an intimidating experience, in this vein they need to speak to the young person directly whilst including parents, as opposed to speaking *over* or *at* them. It is crucial that healthcare workers are not only aware of the individual sufferer and treat them with the respect and intelligence they deserve, but also that the plight of parents and siblings are addressed; if the majority of chronic health care is provided for within the family home then this must become the centre of focus to ensure as little stress and as much harmony as possible during a difficult time. Links with schools and continuing education must be a priority in an attempt to keep young sufferers with some semblance of normality amidst a sea of change, as well as help them to retain a sense of achievement and self esteem. Alternatives to physical activities could be suggested that are quiet and less energy consuming in nature but still allow teenagers hobbies and pastimes outside of just schoolwork and dealing with feeling ill. Healthcare specialists need to work in unison to provide strong links to other services such as psychologists, occupational therapists and physiotherapists, in an effort to address young sufferers as holistic beings and attend to their different physical and psychological needs accordingly. The recommendation of patient support groups and organisations such as AYME (Action for Youth with ME) are beneficial ways of preventing feelings of isolation.

Having CFS as a young person or being a parent of a child who has it can be frightening and lonely roles to play, roles which individuals did not expect to have to undertake. It is essential that these individuals gain the support and reassurance they require in order that they can learn how to move forward with their lives in a

meaningful way and that issues of segregation, confusion, frustration and stress are minimised as far as possible by sensitive and informed healthcare professionals.

CFS is a complex condition, shrouded in controversy and misunderstanding but this situation will only be altered by raising awareness within the medical world and public domain to increase empathy for sufferers and their families. Nobody knows when they or one of their loved ones will become ill and it is only through living the experience of being in the situation that people can fully appreciate the impact a chronic condition can have, however through uncovering some of the facts about the condition and its effects, and by publicising personal experiences empathy can be learnt and accurate comprehension taught. Within this present study I aim to do those things, by giving young people a voice and reiterating their individual and collective experiences the profile of CFS can be raised and hopefully better understanding achieved.

6.17 My Contribution to this Field

There is a growing bank of robust research into CFS, although many researchers are apprehensive about investigating young people due to the inherent ethical difficulties surrounding access to this group of the population. In recent years the focus has turned towards the genetic breakthroughs that have been made and much medical funding and research writings have been drawn towards this critical turning point in CFS history, as well as the ongoing work linked to treatment of symptoms and rehabilitation. I wanted to do something which is scarce in the literature on adolescent CFS, I wanted to give young people and their families a ‘voice’, allow them to tell their story in their own words without fear of recrimination or judgement, in an effort to illuminate the plight of so many which goes unheard. I hope I have achieved that.

6.18 Being ‘Part insider’

I have perhaps more understanding than some regarding these issues as I myself have personal knowledge and experience of CFS and the extensive impact it can have on the lives of young people and families, as a service user myself I can fully appreciate the difficulties experienced and it is this background knowledge that has fuelled my interest in researching this area.

In recent years, since the early 1990s, there has been an increase in the amount of participation, or what has come to be known as, *user involvement*, in policy and decision making and this shift is linked to the recognition that *users/survivors* of these services are significant in giving more democratic insight into the needs of particular groups and the outcomes which they need and desire, based on first-hand experience. This is an effort to allow users to define areas of importance and to move away from existing models of practice, which Mike Oliver, a Professor of Disability Studies, states are *discriminatory and oppressive*, (Oliver 1996). The National Health Service (NHS) is regarded generally as being for public good, individuals within society are prepared to pay for it regardless of the amount to which they utilise it, despite this, historically it has been dominated by professionals and service users have assumed a role of subservience (Bradshaw 2008). In 1993 the then Minister of Health, Brian Mawhinney in his address to the Federation of NHS Trusts stated;

The health service now has to learn to listen better to the public and be more guided by its wishes. It has to learn to trust them, to respect their opinions and respond to what they say. The people we serve should not be treated as mere passive recipients of care, (Heyman 1995, p. 1).

The development of websites such as '*healthtalkonline*', formerly known as Dipex, '*Involve*' set up by the National Institute for Health Research (NIHR), and the work of influential individuals such as Professor Peter Beresford, tutor in Social Policy of Brunel University, have contributed to the area of service users being actively involved in healthcare, social care, social policy and social work research;

There has been a demand by service-user movements (and those sympathetic to them) that service-users should pose the questions for inquiry about their own condition and treatment, and should be active in undertaking the research. Otherwise, it is argued, service provision will lack a crucial dimension of understanding which only service-users can make available, (Winter and Munn-Giddings 2001, p. 28).

The personal and intimate knowledge and understanding that service users have of a particular area of care holds deep meaning and can provide professionals and decision-makers with a window of insight into a world they would otherwise have little empathy with. In research where investigators themselves are service users the gap between professionals and patients can be bridged and insight into an area

provided. There are advantages and disadvantages of this mode of investigation, as with any research. Any individual who undertakes a study brings to the table a set of biases, they have integral pros and cons, shaped by personality, individual areas of interest, prejudices and desires for the research outcome. Some would argue that user-led inquiry is laden with prejudice and self-seeking, preconceived notions, that it cannot be objective, however others might say that it is precisely this subjectivity which provides the research with a level of perceptiveness difficult to ascertain by those outside the immediate vicinity.

6.19 My Stance on the Usefulness of this Study

No researcher is totally bias-free, every human being is shaped by their own background and experience, and as an ‘insider researcher’ I recognise that I have perhaps more personal predispositions and preconceived notions than someone without a personal experience of CFS. One of these partialities is contained in my aim to ‘allow individuals to speak openly without fear of prejudice’, in this I recognise my own desire to promote the often ignored and dismissed opinions and feelings that the young people and their family members have, and to protect those that have been ridiculed in their CFS experience. My choice to focus largely on the family context and the way in which, not only individual sufferers, but also their parents and siblings, suffer as a result of CFS has, I am sure, been influenced by my own experience as a sibling and an observer of my parent’s struggle to feel legitimised and heard over the years. I am disappointed about the focus of the current literature, recognising that yes, the scientific/medical research projects are crucial to further our understanding of this condition, however without the personal accounts of individual experience how can healthcare workers be expected to understand the social, psychological and emotional needs that are not uncovered in the search for new rehabilitation techniques or more accurate diagnostic criteria? The highlighting of stigmatisation that goes on not only in the media and general public, but also (perhaps more worryingly) amongst healthcare professionals themselves, is reflective of my own personal history of feeling the need to ‘prove’ the genuine existence of the condition and the effects it has on everyday life, hopes, aspirations and ambitions, fighting to feel not only heard but also legitimised adds pressure to an already stressful experience.

Having said all of this I again counter-balance what could be perceived as ‘negative biases’ which could be regarded as potentially swaying the focus of this project by reiterating that without an insider perspective this study would not have been able to access some of the depths of experiences and understandings that have been achieved. I have worked hard to recognise my own partialities and to keep these at the forefront of my mind allowing them to be a tool to aid me as a researcher and not to hinder the overall impact of the research itself. Returning to a point made by Riessman;

A narrative representation required that I place myself in dialogic situations and include my emotions, typically stripped from the social scientist’s account. Making the backstage visible challenges the rules of much scholarly writing, including the ‘monologism’ that characterises some narrative accounts. (Riessman 2005, p. 486).

I have recognised and even ‘embraced’ my own perspective in this study as it is something that I cannot escape, nor would I want to, and has enabled me a recognition of elements of individual stories which comes from the basis of shared experiences we have in common, and has enabled me insight throughout the course of the research – from data collection, through to analysis.

I have been reassured to hear feedback from primary care-givers post-data collection, in which they have expressed, both for themselves and on behalf of their children, that the act of speaking about their experiences has been a cathartic one. As Seale writes;

Telling narratives is a major way that individuals makes sense of disruptive events in their lives, (Seale 2004, p. 375).

Whilst I do not necessarily subscribe to the ‘therapy culture’ which exists in some countries today I do believe that narrative accounts have an important role to play in the healing process and that this type of qualitative research opens up a whole new dimension on human experience that cannot be ignored if we are to recognise the most effective ways to treat patients in clinical practise settings.

Many qualitative researchers in the area of medicine have argued that the present-day need for target-reaching and national standard-meeting have pushed out the crucial element of healthcare provision, that is, the compassionate caring of human beings, in psychiatry it is referred to as ‘empathic failure’, (Divinsky 2007). Many have commented upon the damage that this incurs.

Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illnesses. Despite medicine’s recent dazzling technological progress in diagnosing and treating illnesses, physicians sometimes lack the capacities to recognise the plights of their patients, to extend empathy toward those who suffer, and to join honestly and courageously with patients in their illnesses, (Charon 2001, p. 1897).

Holloway and Freshwater, state:

Narrative research emphasises intimate alliances, working closely with the personal truths and core values of both the researcher and participant...narrative research attempts to rehabilitate the person, restoring the experiencing person to the centre of inquiry, and is akin to a humanistic and holistic approach to patient-care; that is to say that narrative research can be described as person-centred, (Holloway and Freshwater 2007, p. 24).

This is in direct opposition to the way medical professionals have been trained to respond to patients. It appears that a distant relationship is encouraged in order to preserve the power credentials of patient and professional. Narrative study returns the power differential in favour of the patient and not the healthcare worker, which is surely what is needed to fully appreciate the needs of patient groups.

This is often regarded as a dispassionate stance that doctors (and other health-care professionals) take in their relationships with patients, in recent years as a response to this there has been an increasing amount of medical establishments teaching the valuable role of narrative medicine; whereby doctors become emotionally involved with their patients, whereby a relationship including elements of compassion, understanding and trust is taught and promoted. In the same way that Charon centres upon the need for more reflective and less detached doctors, researchers too have a vital role to play in continuing this trend.

The highly regarded evidence-based research and practise is important in its own right however it does not always present the best or most effective experience for the individual. The Evidence-Based model of medicine (EBM) is regarded by some as taking the caring out of healthcare by making medical environments austere and target-driven, disregarding the healthcare professional's understanding of individual situations and disallowing particularised modes of care. The long established medical model of course has value but if it is considered to be the be-all and end-all of patient care to the total exclusion of a more holistic, person-centred approach it may well restrict understanding of patient-experience and in doing so have a detrimental effect on the provision of care.

In an effort to respond to this favouring of RCT-type knowledge some researchers have chosen to utilise quality of life measures in the field of healthcare, however such data collection predominantly relies upon quantitative methods which is essentially removing the depth of holistic understanding once again. Some of the unique strengths of qualitative research are: the depth of information obtained; the shift of power in the interest of the participant; and the glimpses into lives of individual human beings; which can provide insight and empathy for the researcher, and in turn can be transferred to the healthcare provider. If we do not fully understand and listen to those we are caring for how will we know the best way to care?

It seems counter-intuitive that healthcare professionals and policy-makers reject a source of information collection which gets straight to the very heart of that which they are attempting to provide benefit for, (Fairbairn and Carson 2002). It is through the encompassing of different research approaches that a wide knowledge-base can be explored and gathered, qualitative research methods plays an imperative and valid role here. Rather than treating the concentration on one sole case as a negative, Rita Charon highlights the way that it should be perceived as advantageous to aid understanding and clarity. Charon in *Narrative Medicine* goes on to comment on the benefits related to an increase in narrative discourse in medicine;

This growing narrative sophistication has provided medicine with new and useful ways in which to consider patient-physician relationships, diagnostic

reasoning, medical ethics, and professional training. Medicine can, as a result, better understand the experiences of sick people, the journeys of individual physicians, and the duties incurred by physicians toward individual patients and by the profession of medicine toward its wider culture, (Charon 2001, p. 1897-902).

Without better understanding of personal experiences, no matter how many sophisticated RCT-based research we have, we are ignoring a crucial element of patient care and understanding. Narrative study bridges the gap between patients feeling isolated and misunderstood (especially in a condition such as CFS) and doctors continuing their efforts to find medical solutions to the problems in hand, it provides ‘on the ground’ information about how best to relate to patients and treat them as holistic beings as opposed to distinct body parts which require healing.

6.20 What This All Means

The findings which have emerged from the data analysis demonstrate the far-reaching consequences that having a chronic debilitating condition can have on a young person’s life. The experience was characterised as having to adapt to a life on hold for both the young person themselves and their family. These struggles are compounded by the lack of knowledge and empathy within the public domain and the stigmatising labels that have been applied over the years which still influence attitudes today. In order that this section of the CFS population can be assisted to deal with their illness experience not only does the knowledge base within the literature need to be extended, but also the level of awareness as to the individual plight of this group of patients needs to be made explicit so that healthcare workers, academic staff, and all of those in a position to support this group of sufferers and their families know how best to advise, comfort and encourage them.

Chapter 7

Conclusion

7.1 Introduction

This final chapter concerns a concluding discussion of the findings, a reflection upon the overall process of the research – how well it worked and its major strengths and weaknesses. The chapter concludes with my reflections on the potential contribution of the study, including suggestions for future research.

7.2 What are the Personal Experiences of Young People with CFS and How Does It Impact Family Life?

The four key themes describe the personal experiences of young people and an overarching theme apparent throughout the narratives can be articulated as: Adolescent CFS is Experienced as ‘Having to Put Life on Hold’. What emerged from the findings describes how this having to put life on hold illuminates the far-reaching consequences of CFS, not only for the individual sufferer, but also for those in immediate contact with them; parents – particularly primary care-givers, siblings and extended family members.

7.2.1 Theme 1: Adolescent CFS Experienced as Having to Adapt to Debilitating Physical Symptoms

The most widely reported and one of the most disruptive symptoms is that of exhaustion, young CFS patients are forced to come to terms with a daily lifestyle that is far removed from the one they once knew, in which energy management is a key player and normal activities such as school, hobbies and a social life are lost. Many feel isolated and lonely as they are aware of friends and peers fulfilling the activities they are no longer able to partake in, sufferers report feeling ‘left behind’ as they are unable to function in a way that their counterparts do. Sufferers have to cope with ongoing physical symptoms associated with the ‘triggers’ which precipitated the onset of CFS, as well as new symptoms such as cognitive disruption which can be, at best frustrating, and at worst, terrifying. The ‘Boom and Bust’ cycle so frequently

observed and reported by CFS sufferers can be particularly difficult for adolescents to learn to accommodate and can be a cause of friction within the household when a young person decides they 'need' to push their energy boundaries in order to have some fun and 'feel normal', but the parents see this as an act of selfishness or irresponsibility. All members of the family are faced with feelings of guilt, confusion, powerlessness and fear as they try to adjust to the situation they find themselves in. Although papers written on CFS make reference to the physical symptoms associated with the condition few, if any, describe just how disruptive these symptoms are on everyday functioning and how devastating these physical changes can be not only to the individual, but also the impact they have on others within the household such as parents and siblings, who also have to learn to accommodate the effects of the condition and adjust their own lifestyles accordingly. Theme 2 encompasses some of these effects on all family members.

7.2.2 Theme 2: Adolescent CFS is Experienced as Living with Changes in Family Relationships and Member's Life Experiences

Parents of chronically ill adolescents have to learn to accommodate a new role requiring more input and hands-on caring at a time when they expect their children to become more independent and needing less attention. This is particularly difficult in families with younger children and a juggling act ensues in which parents have to try to meet all the individual needs of their family members, including their spouse's and their own. The lives of primary care-givers are significantly disrupted and often their own career, social and emotional needs are placed on a back-burner as they learn to prioritise the needs of their children, many report experiencing a loss of control and feelings of powerlessness as they adjust to a new lifestyle with extra responsibilities and pressures. Some struggle with feelings of loss of the child they once knew and the hopes and dreams they had for them, as well as the ambitions they had for their own lives. Additional strains on marriage include financial pressures if one wage is lost or cut due to one parent needing to care for a child at home, as well as the additional emotional pressures and fatigue which accompany extra responsibility and less time spent as a couple or family unit. Siblings are also impacted, often feeling secondary to their ill brother or sister's needs, jealousy can erupt from both sides – the ill child due to lack of freedom and health and the sibling envying the amount of attention the CFS child receives. An increase in dependency can lead to a stifling

situation for all concerned. It has been recognised by parents and adolescents alike that there is a change in maturity levels, many displaying traits and attitudes more mature than their years in response to the adaptation to a lifestyle living within the confines of having a chronic health condition, others have recognised that isolation and ongoing ill-health has hampered their own/their child's ability to communicate on a par with their peers as they have missed many of the socialisation processes. Outside of the immediate family unit CFS also impacts relationships within the extended family, either positively – causing more reliance and hence more closeness within relationships, or negatively when there is a lack of understanding and empathy for the nuclear unit.

7.2.3 Theme 3: Adolescent CFS is Experienced as Living with Isolation and Disruption to a Full and Satisfying Teenage Life

A major impact of CFS in young people's lives is the need to forego activities that were once part of a normal lifestyle, in some cases this can be devastating, for example for those adolescents who consider school-work and academic achievement a high priority having to drop subjects or only attaining grades which are lower than they know they are capable of is not just frustrating, but can effect individuals' self-esteem and sense of personal achievement. The loss of friendships as a result of social isolation or prolonged absence from school can significantly impact teenagers' self confidence and sense of belonging, at a time when the negotiation of social relationships is of prime importance. The effects of negative and ignorant labels such as 'Yuppie Flu' and a constant barrage of scepticism from others can cause an added burden on individuals and families, leaving them feeling isolated and struggling for legitimisation.

7.2.4 Theme 4: Adolescent CFS is Experienced as Feeling Misunderstood and Judged

An unsympathetic or even disbelieving GP can leave patients and their families feeling abandoned and hopeless, unable to access the resources and care they require. A universal experience of relief upon receiving a diagnosis is linked to feeling believed, legitimated and with a sense of hope and purpose that now, after – for some – many weeks or months of confusion they can start to be pro-active in their response to the condition and how best to manage it. Many, but not all, decide to

research the condition for themselves, searching for treatments and therapies which may help, this can sometimes be of benefit but also may contain a potential danger as the internet is a main source of information and this is an uncensored domain. Alternative therapies may give the psychological boost required by some, but for others can result in a relapse and accompanying disappointment. Those that have pursued support groups have reported a sense of relief and legitimisation that they are not alone in how they feel and no longer have to fight to be believed. Finally, those teens who have been left with no alternative but to utilise wheelchairs in order to have some freedom outside the home often feel self-conscious and embarrassed that they 'stand out from the crowd'. Overall the effects of having CFS as a young person can have major negative impact on self-esteem and social confidence at a time when these are developmentally important issues. Isolation and frustration are common in adolescents' stories, as they struggle to resolve the imbalance between wanting to fulfil a normal life that they see their peers living, but lack the energy capabilities to do so.

7.2.5 CFS Experienced by Adolescents as Having to Adapt to a Life Put On Hold

The narrative findings demonstrate the extensive impact that CFS can have on young people and their families, influencing physical, social, emotional, academic and occupational spheres of daily life. All of these areas of life 'were on hold' to some degree. Not only do those affected have these issues to contend with, but it is often done so in isolation from others due to the disbelief which still exists surrounding the condition. By raising awareness of the plight of young CFS sufferers and their families, not only can their journeys be made easier by increasing the empathy of others towards them, but also care-givers can implement best codes of practise into their interaction with them.

7.3 Reflections on Process and Implications

7.3.1 Practicalities

At the outset of this PhD study the proposal was much larger incorporating both quantitative and qualitative research methods to define, characterise and assess CFS in adolescents. However I spent the best part of my first year writing and submitting

funding applications which were very time consuming. Also, as I started exploring the data obtained from the eight qualitative interviews that I had conducted I realised that in order to do the project justice I needed to focus primarily on the qualitative aspects as the amount of information I was gathering was extensive. I therefore decided to forego the more statistical elements of the original proposal and concentrate on a solely qualitative approach. As I proceeded through the interviews I realised that the occasions where mothers accompanied their children to the meeting opened up a whole new realm of narratives, those encompassing family life, not simply experiences limited to the individual. I then returned to the Ethics Board to request permission to conduct email interviews with the primary care-givers in order to explore this wider picture of impact in care-givers and families. The email interviews worked well, participants responded fully and frankly, I asked them to ‘type as if they were speaking’ and they did so, which maximised the data gathered.

7.3.2 Remaining True to the Stories

I was very keen to remain as true to the participants’ stories as possible, so as to convey the most meaning to the reader. When transcribing the interviews I ensured that extra non-verbal cues such as pauses, giggles, sighs and so on were included to help indicate emotional responses. Through inclusion of these extra communicative signs it is easier to build up a picture of the true meaning behind the teller’s words. As previously quoted in Chapter 5, page 126, but is worth revisiting, Riessman and Quinney point out;

Analysis in narrative studies interrogates language – how and why events are storied, not simply the content to which language refers, (Riessman and Quinney 2005, p. 394).

During face-to-face communication many non-verbal cues exist which aid the passage of information from teller to listener, such as amount of eye contact, voice intonation and body language, these are lost to some extent when the verbal account becomes written. Through the inclusion of additional ‘clues’ such as pauses and laughter in written format readers gain more insight into meaning implied by the narrator.

7.3.3 Stories Recounted for the First Time

For many of the participants (both adolescents and care-givers), this project was the first time they had been allowed the opportunity to speak about their experiences. Not only did being asked give them a sense of their narratives being important and valid, but for many, if not all, it contained a cathartic element whereby the act of oration helped them to assess their situation and process the past, present and future. The feedback that I received from mothers who took part was positive and reflected feelings of benefit due to participation. My hope was that someone, such as myself, who is not a doctor, occupational therapist or psychiatrist conducting loosely structured interviews in which young people can feel at liberty to discuss their thoughts and feelings due to the impact of CFS on their lives will get to the crux of what CFS *feels like* for a young person, without there being any danger of ‘having to say the right thing’ in case of offending a healthcare professional. However, I cannot be certain whether this was achieved as I still played a role of being a researcher and this meant I may have been perceived to retain a sense of authority in the situation and therefore participants could have held back. To a certain extent I can never fully know what was going on inside the heads of those who took part, however emails I received after meeting with young people and post-email interviews were positive and included a real friendliness which indicated that a relationship of some equality had been forged.

Participants were also keen to share their experiences ‘for the common good’, all recognised the amount of misunderstanding and stigma related to CFS and felt that if they could in some way alter the existing image and benefit other people in the same position as they, their participation was worthwhile and necessary.

7.3.4 Myself as an ‘Insider-Researcher’

As someone with intimate experience of CFS the project has to some degree been an emotional roller-coaster. I felt personally affected by the stories I heard, both from adolescents and adults, and although this could be regarded as a negative I have tried my utmost to harness those emotions and use them for the benefit of the research. My own background has allowed me a sensitivity and insight right from the very beginning that equipped me with additional ‘tools’ such as recognising fatigue in the faces of participants who attended for interview, and wording questions in such a way as to project my own familiarity with the condition and ensure that participants felt that no detail was too small or insignificant to be included. My personal

experience of CFS has aided the relationship of trust between participants and myself as they have commented that speaking to someone they felt was already ‘on their side’ was easier than speaking to a sceptic or somebody who was a detached medical professional. I have felt a real affinity with those I have spoken to and in many ways I am sad to end the relationships because of reaching the end of the research, the mothers especially have commented (both from their own perspective, and on behalf of their children) that they felt that my empathy with their situations has been an important asset in assisting them to open up a window into their lives.

7.3.5 Implications for ‘Insider Research’

Two of the major benefits of ‘insider research’ which I experienced are; (1) having a prior knowledge which the outsider researcher is not privy to, and (2) gaining the trust of the participants due to my personal background making them feel more at ease and giving them the freedom to talk openly about their experiences. In research where the participants have a history of experiencing negative or stigmatising attitudes from others, such as with a condition like CFS which is still so largely misunderstood, having an investigator with prior personal knowledge of the situation allows an insight that outsiders may miss. I was aware, for example, of the physical symptoms and able to spot the signs of a participant tiring, also I could ‘meet them on their level’, thus removing the need to further explain or expand upon a point. ‘insider researchers’ can provide a richness and depth to the research process, allowing a specific authenticity that many outside of the situation may be unable to achieve. All of these added insights gives ‘insider researchers’ the ability to bypass much of the ground-work necessary in establishing a rapport. I believe that investigators with personal experience of a situation give an additional, positive dimension to the data collection and analysis process.

Having a personal background of CFS in my own life alongside an academic agenda has shaped the research, it has helped me to recognise those areas which are largely lacking in the literature and allowed me to focus in on those issues which I know are important to sufferers. For example, growing up in a family with a child with CFS alerted me to the plight not only of patients, but also of parents and siblings. Having witnessed the difficulties friends with personal experience of CFS have had, I knew how damaging stigmatising labels and negative media images can be. Also, from a

personal perspective of feeling a need to legitimise the ‘realness’ of the condition I can empathise with the lack of understanding in the public domain and this has been a focus in raising the profile of the condition.

I acknowledge that being an ‘insider’ has influenced this study, my own personal experiences of the medical world as a CFS patient have, no doubt, coloured that which I have heard during the course of this research. My background has influenced those aspects of the data which I have regarded as significant and has narrowed my vision in cases where I have felt personally affronted by negative perspectives, for example within the literature. I found the interviews emotionally challenging, I often felt drained by what I had heard because I wasn’t only receiving the information as a researcher, but also recognising it – as a sufferer. I do not believe these correspond to being major weaknesses of the study, however I do recognise that I have had a personal agenda to a certain extent. I still believe that it is this personal agenda which has provided me with the motivation to, not only, choose this research path in the first place, but also see the entire study through to completion.

7.3.6 Concluding Thoughts on Process Reflections

This PhD has been a journey, as many are I’m sure, but I have been surprised at the way in which I and the study have evolved over the months. The initial application was somewhat different to that which has been produced, however I am pleased that I decided to concentrate whole-heartedly on qualitative methods and I feel it has done the research the justice it deserves. Practical issues have had an influence, finances, time and my own health have all played their part in shaping the route that the project has taken.

I have attempted to remain true to the participants’ stories, by sticking closely to what the young people told me. This was an important priority to me as I felt that only in doing so could I represent the narrators’ true meaning. Many, if not all, the participants were telling their stories for the first time, there was a sense of this being a cathartic process for many, and they felt appreciated and legitimised that they were even being asked to recount their own experiences.

Finally, my knowledge as an ‘insider researcher’ has been imperative to producing the type of thesis I intended to write, something personal and insightful, something which incorporated untold tales and opened up a window into people’s private worlds. Yes, I did pursue this study with an agenda, to tell young peoples’ stories of CFS, but believe the findings can make a contribution to the literature.

7.4 The Methodological Approach

7.4.1 How Well the Approach Worked

I believe that applying a narrative approach to this research was the most appropriate method for achieving the aims of the project. The sample size was manageable to explore the stories offered fully, and by keeping them as a whole, and identifying common and variant themes within them, I could build up a picture of the way in which CFS affects adolescents and their families. The life narratives gave accounts of how daily life has been disrupted and the emotional, academic and physical effects of the changes that have occurred. Participants were open and candid about their experiences, they spoke easily regarding their disappointments, anxieties and achievements, and emotions were expressed in the form of humour, laughter and tears. All of those that took part were keen to do so in order to raise the public profile of CFS and allow others into their own private world which many felt has been largely misunderstood. I believe that this methodology was the most effective to achieve the aims of the research (see below) and if I was to repeat the project I would choose a narrative approach again.

Box 18: Original Research Questions

Original Research Questions

- ❖ What are the personal experiences of young people with CFS – how does the condition affect their daily lives – including the educational, social and psychological issues?
- ❖ How does CFS impact family life – how does the condition influence not only the lives of sufferers but also those closest to them?

❖ Through open-ended interviews with this largely under-researched population, can the knowledge base be extended to help guide practise for those caring for the needs of adolescent CFS sufferers and their families?

7.4.2 Major Strengths and Weaknesses

Firstly the **strengths** - narrative methods gather information-rich, descriptive data that provides insight into a private world, a world which is often unseen and that is something which is not only sacred, but also valuable to aid understanding and empathy, and in turn inform practise and policy-making. In the case of this study, it has allowed collection of data related to a largely misunderstood condition, and has gained insights into personal experiences that have been seldom accessed previously. Narrative interviews allow freedom for participants to speak openly, the power differential is weighted in favour of the respondent who can decide what to include in their narrative, what to omit and in which way to present the information. This has been evident in the topics that participants chose to focus upon and the way in which they expressed deep emotions.

There are inherent **weaknesses** though, for example there are uncontrollable expectations of the participants as to what is expected of them, and this casts doubt over the claims of this method being non-directive. This may be more of an issue in narrators who aren't adults and lack the social and personal confidence to speak without fear of 'getting it wrong'. If the adolescents who participated in my research felt that I was 'digging' for particular answers or opinions, or that I may be offended by certain subjects they may have chosen to dilute or even leave out specific issues, this is something that I can only hope did not occur, I will never fully know. There can also be difficulties within the narrator/researcher relationship in narrative interviewing, for example those who have a specific agenda, such as one of the male participants in this study who believed he had discovered a 'miracle cure'. This interview was not as easy as others, as it was difficult to keep him 'on track' in recounting his experiences as he constantly reverted to telling me how convinced he was of the therapy he had undergone. The other boy who took part was particularly shy and his timidity threatened to jeopardise some of the information that he could have provided had he felt more at ease within the situation, for example he may have

felt more at liberty to express his feelings had it not been in a face-to-face setting, a written questionnaire with open-ended questions may have achieved more.

Despite the weaknesses though, I still hold to the belief that the narrative approach was effective in achieving the aims and rationale laid down at the beginning of the study. My choice of pursuing a narrative research approach was for three main reasons;

- (1) To present narratives in their entirety, as *whole* stories, in order that a holistic approach to the participants' experiences could be achieved and insight into 'real worlds' could be made;
- (2) To capture *subjective experiences* – not simply an overview of a general idea, but real, tangible elements of intimate, personal experience; and
- (3) I have remained focused upon the individuals' accounts of their own stories, how they chose to tell the stories that they did, how specific issues in their illness narrative has impacted their thinking, emotions and expectations.

In this way a picture of real and profound experiences could be portrayed to a wider audience of how CFS affects young people and their families, and how best those involved in caring for them can be empathetic in their assistance of daily life.

7.5 Future Research

I believe that this present research project could be further extended in a number of ways. Firstly, implementing narrative interviews with other members of the household, for example fathers and siblings, to gain a deeper understanding of how their lives have been affected by having a family member with CFS. Conducting a further interview with the original participants, (adolescents and mothers), in a year's time to establish how the passage of time has altered their outlook, or if it has remained the same, in this way further knowledge could be gained as to the impact of CFS and whether current thinking on prognosis is accurate or not. Replicating the same study design in a different part of the country, with participants from different ethnic or socioeconomic backgrounds, or using a different route of access, for example primary care, to see if any of these factors have influenced the data collected. Finally, if time, finances and logistics were not an issue, a larger scale

project with more participants may reveal whether the themes extracted from this current research are replicable across a wider population.

7.6 Can the Knowledge Base be Extended to Help Guide Practice?

Listening to the narratives of young people and their families affected by CFS can provide us with insight into their experiences and help educate those responsible for caring for their needs. The findings demonstrate the widespread effects that CFS has on young sufferers and those closest to them, struggles with frustration, disappointment and anxiety are often battled with behind closed doors and people outside the household are oblivious to the major impact the condition has on families. These findings can assist healthcare providers in their interactions with young people, and the crucial issue appears to be that patients require a holistic approach to their well-being not just an addressing of their immediate medical needs, but also recognition and assistance with the emotional burdens that are being carried. Parents and siblings too require support to deal with the changes that they experience.

Aiding adaptation to a new lifestyle where debilitating physical symptoms are a part of life needs to be sensitive to 'a life on hold'. Psychological support that is informed by young peoples' perspectives may assist patients, (and in turn, other members of the family), by helping young people come to terms with changes which are outside of their control, helping them reassess their priorities and cope with disappointments.

All family members may be affected by CFS, not just the patient, therefore support needs to be offered to parents and siblings also. Some of which may be available via the specialised CFS centres which are dotted around the country, however failing this, encouragement to join a support network of some support may lessen the feelings of confusion and isolation. Information needs to be provided about financial support which is available through government schemes such as Carer's Allowance, in situations where one parent has had to give up work or become part-time due to the care needs of their child, this could ease some of the stress caused by a lack of earnings. Supply of written literature to give to extended family members and friends

may help raise awareness of the condition without affected families feeling the need to constantly explain about CFS and its effects.

Steps could be taken to decrease the impact of isolation and disruption to a full teenage lifestyle. Counselling may provide answers to patients' questions as to why they feel the way they do and whether or not it is 'normal'. Having an outlet other than parents may allow opportunities for young people to express their emotions, hopes, fears and so on, without fearing they may be an added burden on their family members. Suggestions of alternative hobbies to replace those lost may provide creative opportunities which require less energy expenditure but still help adolescents feel a sense of achievement. Liaison between medical and school staff can marry the gap between healthcare and social and academic provision to make any period of school absence as un-disruptive as possible. The encouragement of peers to remain in contact with the young sufferer may lessen feelings of isolation, and providing an explanation to class members and staff about the effects of the illness could improve understanding and increase empathy prior to the individual's return to school. Education to raise the profile of the condition is the only way of banishing the stigmatising myths which continue to exist in the public domain.

To assist patients and families who feel misunderstood encouragement by medical staff towards legitimate, well reputed support networks could prevent people straying into unchartered territory as far as alternative therapies which are costly and often without benefit. Such networks can provide help lines for patients and parents to telephone to gain advice on schooling matters and government financial aid, as well as providing regional contacts for support meetings in the local area and pen pals. Such measures provide people with a sense of legitimacy and lessen feelings of isolation.

7.7 My Contribution

Adding to the Existing Literature

The only similar study to this one that I could identify in the current literature which takes a qualitative approach to the individual and corporate experiences of young CFS sufferers (and to a certain extent their families too), is that of the book

Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Journeys With The Dragon, by Naida Brotherston (2001). There are many similarities between this project and the findings in Brotherston's book including the experience of dramatic changes to physical capabilities, academic aspirations and social interaction. Participants in the book also struggled with long periods of diagnostic uncertainty and experienced a major sense of relief upon achieving a diagnosis, as did the young people in this study. A sense of solace being found in the interaction with others experiencing the same condition was also a similar feature. Feelings of isolation and trepidation at what the future holds, appears universal, as does an increase in introspection during illness and a subsequent maturation of outlook and perspective. Similar to the narratives I heard, stories in the book recounted feelings of guilt and responsibility and a sense of pushing themselves to recover or appear recovered, which contradicted the way they actually felt in an effort to relieve burdens on other family members. The destructive impact of stigmatising media coverage and ignorance within the public and medical domains affected the participants Brotherston interviewed in America, in the same way as it did for those I spoke to here in England.

The major difference between my present study and Brotherston's research is the age of participants studied, this project concentrated on younger adolescents, between the ages of 11 and 18, Brotherston's book focused on four young girls in their late teens and early twenties as they approached adulthood. Subsequently there are some major differences linked to stage of life and personal expectations between the two groups, the older girls were concerned about college educations, romantic relationships and the transition to an adult lifestyle, many characteristics of which would not be recognisable, or indeed worrisome for younger adolescents. Despite these differences many similarities remain. The comparison between this research project and Brotherston's work can be seen as complimentary in the effort to increase the existing knowledge base within the literature. Any publications derived from this current study can be viewed alongside Brotherston's as supporting many of the similarities in findings that were achieved in the two pieces of research

The main conclusions that can be drawn from my findings which add to the current knowledge base is the full extent to which CFS affects the lives of patients and their

families, and the common experience of having to adapt to a life put on hold that clearly runs through all of the stories which have been gathered. Care providers need to be mindful of all of the consequences of the condition and treat people affected as holistic beings attending to their emotional and psychological health, as well as medical issues. It is only by listening to and coming to understand the condition and its impact that people outside of the situation can empathise with those affected and support them during the rehabilitation process, however long that may be.

References

- Acheson, E. D., 1959. The clinical syndrome variously called benign myalgic encephalomyelitis, iceland disease and epidemic neuromyasthenia. *American Journal of Medicine*, 26 (4), 569-595.
- Ackard, D. M., Neumark-Sztainer, D., Story, M., and Perry, C., 2006. Parent-child connectedness and behavioural and emotional health among adolescents. *American Journal of Preventative Medicine*, 30 (1), 59-66.
- Afari, N., and Buchwald, D., 2003. Chronic fatigue syndrome: A review. *American Journal of Psychiatry*, 160 (2), 221-236.
- Akagi, H., Klimes, I., and Bass, C., 2001. Cognitive behavioural therapy for chronic fatigue syndrome in a general hospital--feasible and effective. *General Hospital Psychiatry*, 23 (5), 254-260.
- Archakis, A., and Tzanne, A., 2005. Narrative positioning and the construction of situated identities. *Narrative Inquiry*, 15 (2), 267-291.
- Aro, H., Paronen, O., and Aro, S., 1987. Psychosomatic symptoms among 14-16 year old finnish adolescents. *Social Psychiatry*, 22 (3), 171-176.
- Asbring, P., and Narvanen, A. L., 2002. Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, 12 (2), 148-160.
- Atkinson, R., 1998. *The life story interview*. California: Sage Publications.

- Bagnall, A. M., Whiting, P., Richardson, R., and Sowden, A. J., 2002. Interventions for the treatment and management of chronic fatigue syndrome/myalgic encephalomyelitis. *Quality and Safety in Health Care*, 11 (3), 284-288.
- Baldwin, C., 2004. Narrative analysis and contested allegations of munchausen syndrome by proxy. *In*: Hurwitz, B., Greenhalgh, T., and Skultans, V. eds. *Narrative research in health and illness*. Oxford: Blackwell Publishing.
- Barbarin, O., Hughes, D., and Chesler, M., 1985. Stress, coping, and marital functioning among parents of children with cancer. *Journal of Marriage and the Family*, 48, 473-480.
- Barsky, A. J., and Borus, J. F., 1999. Functional somatic syndromes. *Annals of Internal Medicine*, 130 (11), 910-921.
- Beard, G., 1869. Neurasthenia, or nervous exhaustion. *Boston Medical and Surgery Journal*, 1869 (3), 217-221.
- Behan, P. O., Behan, W. M., and Bell, E. J., 1985. The postviral fatigue syndrome-- an analysis of the findings in 50 cases. *The Journal of Infectious Diseases*, 10 (3), 211-222.
- Behan, W. M., More, I. A., and Behan, P. O., 1991. Mitochondrial abnormalities in the postviral fatigue syndrome. *Acta Neuropathologica*, 83 (1), 61-65.
- Belknap, M., 2002. The CNN Effect: Strategic Enabler or Operational Risk?, *Parameters*, 32.
- Bell, D. S., Bell, K. M., and Cheney, P. R., 1994. Primary juvenile fibromyalgia syndrome and chronic fatigue syndrome in adolescents. *Clinical Infectious Diseases*, 18 Suppl 1, S21-23.
- Bell, D. S., Jordan, K., and Robinson, M., 2001. Thirteen-year follow-up of children and adolescents with chronic fatigue syndrome. *Pediatrics*, 107 (5), 994-998.
- Bell, D., 1997. Illness onset characteristics in children with chronic fatigue syndrome and idiopathic chronic fatigue. *Journal of Chronic Fatigue Syndrome*, 3 (2), 43-51.
- Bell, K. M., Cookfair, D., Bell, D. S., Reese, P., and Cooper, L., 1991. Risk factors associated with chronic fatigue syndrome in a cluster of pediatric cases. *Review Infectious Diseases*, 13 Suppl 1, S32-38.
- Bersamin, M. M., Walker, S., Waiters, E. D., Fisher, D. A., and Grube, J. W., 2005. Promising to wait: Virginity pledges and adolescent sexual behavior. *Journal of Adolescent Health*, 36 (5), 428-436.

- Blakely, A. A., Howard, R. C., Sosich, R. M., Murdoch, J. C., Menkes, D. B., and Spears, G. F. 1991. *Psychological Medicine*, 21(2):347-62.
- Boeing, L., Murray, V., Pelosi, A., McCabe, R., Blackwood, D., and Wrate, R., 2007. Adolescent-onset psychosis: Prevalence, needs and service provision. *British Journal of Psychiatry*, 190, 18-26.
- Bombardier, C. H., and Buchwald, D., 1995. Outcome and prognosis of patients with chronic fatigue vs chronic fatigue syndrome. *Archives of Internal Medicine*, 155 (19), 2105-2110.
- Bou-Holaigah, I., Rowe, P. C., Kan, J., and Calkins, H., 1995. The relationship between neurally mediated hypotension and the chronic fatigue syndrome. *Jama*, 274 (12), 961-967.
- Brace, M. J., Scott Smith, M., Mccauley, E., and Sherry, D. D., 2000. Family reinforcement of illness behavior: A comparison of adolescents with chronic fatigue syndrome, juvenile arthritis, and healthy controls. *Journal of Developmental Behaviour in Pediatrics*, 21 (5), 332-339.
- Bradley, L.A., McKendree-Smith, N.L., and Alarcón, G.S. 2000. Pain Complaints in Patients with Fibromyalgia Versus Chronic Fatigue Syndrome. *Current Review of Pain*. 4:148–157.
- Bradshaw, P. L., 2008. Service user involvement in the NHS in England: Genuine user participation or a dogma-driven folly? *Journal of Nursing Management*, 16 (6), 673-681.
- Braun, V., and Clarke, V., 2006. Using thematic analysis in Psychology. *Qualitative Research in Psychology*, 3, 77-101
- Breau, L. M., Mcgrath, P. J., and Ju, L. H., 1999. Review of juvenile primary fibromyalgia and chronic fatigue syndrome. *Journal of Developmental Behaviour in Pediatrics*, 20 (4), 278-288.
- Bristol, M. M., 1987. Mothers of children with autism or communication disorders: Successful adaptation and the double abcx model. *Journal of Autism Developmental Disorder*, 17 (4), 469-486.
- Brotherston, N., 2001. *Adolescence and myalgic encephalomyelitis/chronic fatigue syndrome: Journeys With The Dragon*, New York: Haworth Medical Press.
- Bruner, J., 1991. The narrative construction of reality. *Critical Inquiry*, 18 (1), 1-21.

- Buchanan, C. M., Maccoby, E. E., and Dornbusch, S. M., 1996. *Adolescents After Divorce*, Cambridge, Massachusetts London, England: Harvard University Press.
- Buchwald, D., Herrell, R., Ashton, S., Belcourt, M., Schmaling, K., Sullivan, P., Neale, M., and Goldberg, J., 2001. A twin study of chronic fatigue. *Psychosomatic Medicine*, 63 (6), 936-943.
- Bulow, P., 2004. Sharing experiences of contested illness by storytelling. *Discourse and Society*, 15 (1), 33-53.
- Bunting, S., Russell, C., and Gregory, D., 1998. Use of electronic mail (email) for concept synthesis: An international collaborative project. *Qualitative Health Research*, 8 (1), 128-135.
- Bury, M. 2001. Illness narratives: Fact or fiction? *Sociology of Health and Illness*, 23 (3), 263-285.
- Butler, S., Chalder, T., Ron, M., and Wessely, S., 1991. Cognitive behaviour therapy in chronic fatigue syndrome. *Journal of Neurological Neurosurgery and Psychiatry*, 54 (2), 153-158.
- Byrne, E., and Trounce, I., 1987. Chronic fatigue and myalgia syndrome: Mitochondrial and glycolytic studies in skeletal muscle. *Journal of Neurological Neurosurgery and Psychiatry*, 50 (6), 743-746.
- Byrne, E., Trounce, I., and Dennett, X., 1985. Chronic relapsing myalgia (? Post viral): Clinical, histological, and biochemical studies. *Australian and New Zealand Journal of Medicine*, 15 (3), 305-308.
- Canam, C., 1987. Coping with feelings chronically ill children and their families. *Nursing Papers*, 19 (3), 9-21.
- Canam, C., 1993. Common adaptive tasks facing parents of children with chronic conditions. *Journal of Advanced Nursing*, 18 (1), 46-53.
- Canetti, L., Bachar, E., Galili-Weisstub, E., De-Nour, A. K., and Shalev, A. Y., 1997. Parental bonding and mental health in adolescence. *Adolescence*, 32 (126), 381-394.
- Cantor, J., 2000. Media violence. *Journal of Adolescent Health*, 27 (2), 30-34.
- Carruthers, B., Jain, K., De Meirleir, K., Peterson, D., Klimas, N., Lerner, A., Bested, A., Flor-Henry, P., Joshi, P., Powles, A., Sherkey, J., and Van De

- Sande, M., 2003. Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical working case definition, diagnostic and treatment protocols. *Journal of Chronic Fatigue Syndrome*, 11 (1), 7-116.
- Carter, B. D., Edwards, J. F., Kronenberger, W. G., Michalczyk, L., and Marshall, G. S., 1995. Case control study of chronic fatigue in pediatric patients. *Pediatrics*, 95 (2), 179-186.
- Carter, B. D., Kronenberger, W. G., Edwards, J. F., Marshall, G. S., Schikler, K. N., and Causey, D. L., 1999. Psychological symptoms in chronic fatigue and juvenile rheumatoid arthritis. *Pediatrics*, 103 (5 Pt 1), 975-979.
- Carter, B. D., Kronenberger, W. G., Edwards, J. F., Michalczyk, L., and Marshall, G. S., 1996. Differential diagnosis of chronic fatigue in children: Behavioral and emotional dimensions. *Journal of Developmental & Behavioral Pediatrics*, 17 (1), 16-21.
- CDC (Centres for Disease Control and prevention), 2006. *Chronic Fatigue Syndrome Basic Facts*. Available from: <http://www.cdc.gov/cfs/cfsbasicfacts.htm>. [Accessed: 2008-02-07].
- Chalder, T., Deale, A., Wessely, S., and Marks, I., 1995. Cognitive behavior therapy for chronic fatigue syndrome. *American Journal of Medicine*, 98 (4), 419-420; author reply 421-412.
- Chalder, T., Goodman, R., Wessely, S., Hotopf, M., and Meltzer, H., 2003. Epidemiology of chronic fatigue syndrome and self reported myalgic encephalomyelitis in 5-15 year olds: Cross sectional study. *BMJ*, 327 (7416), 654-655.
- Chalder, T., Tong, J., and Deary, V., 2002. Family cognitive behaviour therapy for chronic fatigue syndrome: An uncontrolled study. *Archive of Disease in Childhood*, 86 (2), 95-97.
- Charon, R., 2001. The patient-physician relationship. Narrative medicine: A model for empathy, reflection, profession, and trust. *Jama*, 286 (15), 1897-1902.
- Chaudhuri, A., and Behan, P. O., 2004. In vivo magnetic resonance spectroscopy in chronic fatigue syndrome. *Prostaglandins Leukot Essent Fatty Acids Journal*, 71 (3), 181-183.
- Cherry, D. B., 1989. Stress and coping in families with ill or disabled children: Application of a model to pediatric therapy. *Physical and Occupational Therapy in Pediatrics*, 9 (2), 11-32.

- Chia, J. K., 2005. The role of enterovirus in chronic fatigue syndrome. *J Clin Pathol*, 58 (11), 1126-1132.
- Ciccone, D. S., and Natelson, B. H. 2003. Comorbid Illness in Women With Chronic Fatigue Syndrome: A Test of the Single Syndrome Hypothesis. *Psychosomatic Medicine*, 65:268–275.
- Clarke-Steffen, L., 1997. Reconstructing reality: Family strategies for managing childhood cancer. *Journal of Pediatric Nursing*, 12 (5), 278-287.
- Clements, A., Sharpe, M., Simkins, S., Borrill, J., and Hawton, K. 1997. Chronic fatigue syndrome : A qualitative investigation of patients' beliefs about the illness. *Journal of Psychosomatic Research*. 42(6), 615-624.
- Clulow, C., 1991. The chronically ill child and the parents' marriage: Interactive effects. *British Journal of Psychotherapy*, 7 (4), 331-340.
- Cobley, P., 2004. *Narrative*. London: Routledge.
- Compan, E., Moreno, J., Ruiz, M. T., and Pascual, E., 2002. Doing things together: Adolescent health and family rituals. *Journal of Epidemiology and Community Health*, 56 (2), 89-94.
- Connolly, S., Smith, D. G., Doyle, D., and Fowler, C. J., 1993. Chronic fatigue: Electromyographic and neuropathological evaluation. *Journal of Neurology*, 240 (7), 435-438.
- Cook, D. B., Lange, G., Deluca, J., and Natelson, B. H., 2001. Relationship of brain MRI abnormalities and physical functional status in chronic fatigue syndrome. *International Journal of Neuroscience*, 107 (1-2), 1-6.
- Cortazzi, M., 1993. *Narrative Analysis*. London: Falmer Press.
- Coulter, P., 1988. Chronic fatigue syndrome: An old virus with a new diagnosis. *Journal of Community Health Nursing*, 5 (2), 87-95.
- Cox, D., and Findley, J., 1999. Severe and very severe patients with chronic fatigue syndrome: Perceived outcome following an inpatient programme *Journal of Chronic Fatigue Syndrome*: , 7 (3), 33-47.
- Coyne, I. T., 1997. Chronic illness: The importance of support for families caring for a child with cystic fibrosis. *Journal of Clinical Nursing*, 6 (2), 121-129.
- Coyne, S. M., Archer, J., and Eslea, M., 2004. Cruel intentions on television and in real life: Can viewing indirect aggression increase viewers' subsequent indirect aggression? *Journal of Experimental Child Psychology*, 88 (3), 234-253.

- Crawley, E., 2006. Chronic fatigue syndrome in young people: The spectrum and the myths, *British Journal of Hospital Medicine*, 67 (9), 452-453.
- Crawley, E., and Davey Smith, G., 2007. Is chronic fatigue syndrome (CFS/ME) heritable in children, and if so, why does it matter? *Archives of Disease in Childhood*, 92 (12), 1058-1061.
- Daily Mail. 2001. *Health probe into Camelford poisoning*. Available from: <http://news.bbc.co.uk/1/hi/uk/1490142.stm>. [Accessed: 21/04/2009].
- Dale, J. K., and Straus, S. E., 1992. The chronic fatigue syndrome: Considerations relevant to children and adolescents. *Advanced Pediatric Infectious Diseases*, 7, 63-83.
- Davies, S., and Crawley, E., 2008. Chronic fatigue syndrome in children aged 11 years old and younger. *Archives of Disease in Childhood*, 93 (5), 419-421.
- Deale, A., Husain, K., Chalder, T., and Wessely, S., 2001. Long-term outcome of cognitive behavior therapy versus relaxation therapy for chronic fatigue syndrome: A 5-year follow-up study. *American Journal of Psychiatry*, 158 (12), 2038-2042.
- Deković, M., and Meeus, W. 1997. Peer relations in adolescence: effects of parenting and adolescents' self-concept. *Journal of Adolescence*, 20(2), 163-176.
- DeGruy, F., Columbia, L., and Dickinson, P., 1987. Somatization disorder in a family practice. *Journal of Family Practise*, 25 (1), 45-51.
- Dell'api, M., Rennick, J. E., and Rosmus, C., 2007. Childhood chronic pain and health care professional interactions: Shaping the chronic pain experiences of children. *Journal of Child Health Care*, 11 (4), 269-286.
- Dept of Health. 2002. *A report of the CFS/ME working group: Report to the chief medical officer of an independent working group*. London: Department of Health.
- Divinsky, M., 2007. Stories for life: Introduction to narrative medicine. *Canadian Family Physician*. 2007, 53(2): 203-205.
- Dobbins, J., Randall, B., Reyes, M., Steele, L., Livens, E., and Reeves, W., 1997. The prevalence of chronic fatiguing illnesses among adolescents in the United States. *Journal of Chronic Fatigue Syndrome*, 3 (2), 15-27.
- Douche-Aourik, F., Berlier, W., Feasson, L., Bourlet, T., Harrath, R., Omar, S., Grattard, F., Denis, C., and Pozzetto, B., 2003. Detection of enterovirus in

- human skeletal muscle from patients with chronic inflammatory muscle disease or fibromyalgia and healthy subjects. *Journal of Medical Virology*, 71 (4), 540-547.
- Dowd, M.D., Seidel, JS., Sheehan, K., Barlow, B., and Bradbard, S.L., 2000. Teenagers' perceptions of personal safety and the role of the emergency health care provider. *Annals of Emergency Medicine*, 36, 346-350.
- Dowsett, E. G., Ramsay, A. M., McCartney, R. A., and Bell, E. J., 1990. Myalgic encephalomyelitis--a persistent enteroviral infection? *Postgraduate Medical Journal*, 66 (777), 526-530.
- Dowsett, E., and Colby, J., 1997. Long term sickness absence due to ME/CFS in uk schools. *Journal of Chronic Fatigue Syndrome*, 3 (2), 29-42.
- Dowsett, E., Goudsmit, E., Macintyre, A., Shepherd, A., and Al, E., 1994. *Report from the national task force on chronic fatigue syndrome (CFS), postviral fatigue syndrome (pvfs), myalgic encephalomyelitis (me)*. . Bristol, England: Westcare.
- Eberhart, N. K., Shih, J. H., Hammen, C. L., and Brennan, P. A., 2006. Understanding the sex difference in vulnerability to adolescent depression: An examination of child and parent characteristics. *Journal of Abnormal Child Psychology*, 34 (4), 495-508.
- Elliott, J., 2005. *Using narrative in social research: qualitative & quantitative approaches*. London: Sage Publications.
- Estroff, S. E., 1981. *Making it crazy: An ethnography of psychiatric clients in an American community*. California: University of California Press.
- Estroff, S. E., 1995. Whose story is it anyway? . In: Toombs, S. K., Bernard, D., and Carson, R. A. Eds. *Chronic illness: From experience to policy*. Indiana: Indiana University Press.
- Evengard, B., and Klimas, N., 2002. Chronic fatigue syndrome: Probable pathogenesis and possible treatments. *Drugs*, 62 (17), 2433-2446.
- Fairbairn, G. J., and Carson, A. M., 2002. Writing about nursing research: A storytelling approach. *Nurse Research*, 10 (1), 7-14.
- Farmer, A., Fowler, T., Scourfield, J., and Thapar, A., 2004. Prevalence of chronic disabling fatigue in children and adolescents. *British Journal of Psychiatry*, 184, 477-481.

- Farmer, A., Scourfield, J., Martin, N., Cardno, A., and McGuffin, P., 1999. Is disabling fatigue in childhood influenced by genes? *Psychological Medicine*, 29 (2), 279-282.
- Feder, H. M., Jr., Dworkin, P. H., and Orkin, C., 1994. Outcome of 48 pediatric patients with chronic fatigue. A clinical experience. *Archives of Family Medicine*, 3 (12), 1049-1055.
- Ferrari, M., Matthews, W. S., and Barabas, G., 1983. The family and the child with epilepsy. *Family Process*, 22 (1), 53-59.
- Fiedler, N., Lange, G., Tiersky, L., DeLuca, J., Policastro, T., Kelly-McNeil, K., McWilliams, R., Korn, L., and Natelson, B., 2000. Stressors, personality traits, and coping of Gulf War veterans with chronic fatigue. *Journal of Psychosomatic Research*, 48(6):525-35.
- Fischler, B., Cluydts, R., De Gucht, Y., Kaufman, L., and De Meirleir, K., 1997. Generalized anxiety disorder in chronic fatigue syndrome. *Acta Psychiatrica Scandinavica*, 95 (5), 405-413.
- Frank, A., 1995. *The wounded storyteller: Body, illness and ethics*. Chicago: Chicago University Press.
- Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M. C., Dobbins, J. G., and Komaroff, A., 1994. The chronic fatigue syndrome: A comprehensive approach to its definition and study. International chronic fatigue syndrome study group. *Annals of Internal Medicine*, 121 (12), 953-959.
- Fulcher, K. Y., and White, P. D., 1997. Randomised controlled trial of graded exercise in patients with the chronic fatigue syndrome. *BMJ*, 314 (7095), 1647-1652.
- Gallagher, A. M., Thomas, J. M., Hamilton, W. T., and White, P. D., 2004. Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001. *Journal of Royal Society of Medicine*, 97 (12), 571-575.
- Galland, B. C., Jackson, P. M., Sayers, R. M., and Taylor, B. J., 2008. A matched case control study of orthostatic intolerance in children/adolescents with chronic fatigue syndrome. *Pediatric Research*, 63 (2), 196-202.
- Gallo, A., and Szychliński, C., 2003. Self-perception and family functioning in healthy school-age siblings of children with asthma and diabetes, and healthy children. *Journal of Family Nursing*, 9 (4), 414-434.

- Garralda, E., Rangel, L., Levin, M., Roberts, H., and Ukoumunne, O., 1999. Psychiatric adjustment in adolescents with a history of chronic fatigue syndrome. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38 (12), 1515-1521.
- Garralda, M. E., and Rangel, L., 2001. Childhood chronic fatigue syndrome. *American Journal of Psychiatry*, 158 (7), 1161.
- Garralda, M. E., and Rangel, L., 2002. Annotation: Chronic fatigue syndrome in children and adolescents. *Journal of Child Psychology and Psychiatry*, 43 (2), 169-176.
- Garralda, M. E., and Rangel, L., 2005. Chronic fatigue syndrome of childhood. Comparative study with emotional disorders. *European Child & Adolescent Psychiatry*, 14 (8), 424-430.
- Gazan, R., 2005. Imposing structures: Narrative analysis and the design of information systems. *Library & Information Science Research*, 27 (3), 346-362.
- Gibson, C. H., 1995. The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, 21 (6), 1201-1210.
- Gibson, C., 1988. Perspective in parental coping with a chronically ill child: The case of cystic fibrosis. *Issues in Comprehensive Pediatric Nursing*, 11 (1), 33-41.
- Giddens, A., 1989. *Sociology*. 1 ed. Cambridge: Polity Press.
- Gosling, S. D., Vazire, S., Srivastava, S., and John, O. P., 2004. Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *American Psychology*, 59 (2), 93-104.
- Goswami, U., (Ed), 2004. *Blackwell handbook of childhood cognitive development*, UK: Blackwell Publishing.
- Grafman, J., Schwartz, V., Dale, J. K., Scheffers, M., Houser, C., and Straus, S. E., 1993. Analysis of neuropsychological functioning in patients with chronic fatigue syndrome. *Journal of Neurology, Neurosurgery and Psychiatry*, 56 (6), 684-689.
- Grau, J. M., Casademont, J., Pedrol, E., Fernandez-Sola, J., Cardellach, F., Barros, N., and Urbano-Marquez, A., 1992. Chronic fatigue syndrome: Studies on skeletal muscle. *Clinical Neuropathology*, 11 (6), 329-332.

- Gray, D., Parker-Cohen, N. Y., White, T., Clark, S. T., Seiner, S. H., Achilles, J., and McMahon, W. M., 2001. A comparison of individual and family psychology of adolescents with chronic fatigue syndrome, rheumatoid arthritis, and mood disorders. *Journal of Developmental Behavioural Pediatrics*, 22 (4), 234-242.
- Gray, M. L., and Fossey, E. M., 2003. Illness experience and occupations of people with chronic fatigue syndrome. *Australian Occupational Therapy Journal*, 50, 127-136.
- Grinyer, A., 2007. The biographical impact of teenage and adolescent cancer. *Chronic Illness*, 3 (4), 265-277.
- Groesz, L. M., Levine, M. P., and Murnen, S. K., 2002. The effect of experimental presentation of thin media images on body satisfaction: A meta-analytic review. *International Journal of Eating Disorders*, 31 (1), 1-16.
- Guell, C., 2007. Painful childhood: Children living with juvenile arthritis. *Qualitative Health Research*, 17 (7), 884-892.
- Haggerty, R., Sherrod, L., Garmezny, N., and Rutter, M. E., 1996. *Stress, risk, and resilience in children and adolescents: Processes, mechanisms and interventions*. 2 ed. Cambridge: Cambridge University Press.
- Haines, L. C., Saidi, G., and Cooke, R. W., 2005. Prevalence of severe fatigue in primary care. *Archives of Disease in Childhood*, 90 (4), 367-368.
- Hamilos, D. L., Nutter, D., Gershtenson, J., Ikle, D., Hamilos, S. S., Redmond, D. P., Di Clementi, J. D., Schmaling, K. B., and Jones, J. F., 2001. Circadian rhythm of core body temperature in subjects with chronic fatigue syndrome. *Clinical Physiology*, 21 (2), 184-195.
- Hamilton, H. A., 2005. Extended families and adolescent well-being. *Journal of Adolescent Health*, 36 (3), 260-266.
- Hamilton, R. J., and Bowers, B. J., 2006. Internet recruitment and e-mail interviews in qualitative studies. *Qualitative Health Research*, 16 (6), 821-835.
- Hanninen, V., 2004. A model of narrative circulation. *Narrative Inquiry*, 14, 69-85.
- Hargreaves, D. A., and Tiggemann, M., 2004. Idealized media images and adolescent body image: "Comparing" Boys and girls. *Body Image*, 1 (4), 351-361.
- Hart, C. N., Palermo, T. M., and Rosen, C. L., 2005. Health-related quality of life among children presenting to a pediatric sleep disorders clinic. *Behav Sleep Med*, 3 (1), 4-17.

- Hawkins, J.D., Catalano, R. F., Kosterman, R., Abbott, R., and Hill, K. G., 1999. Preventing Adolescent Health-Risk Behaviors by Strengthening Protection During Childhood. *Archives of Pediatric Adolescent Medicine*, 153, 226-234.
- Hawton, K., Rodham, K., Evans, E., and Weatherall, R., 2002. Deliberate self harm in adolescents: Self report survey in schools in England. *BMJ*, 325 (7374), 1207-1211.
- Hay, I., and Ashman, A., 2003. The development of adolescents' emotional stability and general self-concept: The interplay of parents, peers and gender. *International Journal of Disability, Development and Education*, 50 (1), 77 - 91.
- Hendricks, C. S., Cesario, S. K., Murdaugh, C., Gibbons, M. E., Servonsky, E. J., Bobadilla, R. V., Hendricks, D. L., Spencer-Morgan, B., and Tavakoli, A., 2005. The influence of father absence on the self-esteem and self-reported sexual activity of rural southern adolescents. *ABNF Journal*, 16 (6), 124-131.
- Hentinen, M., and Kyngas, H., 1998. Factors associated with the adaptation of parents with a chronically ill child. *Journal of Clinical Nursing*, 7 (4), 316-324.
- Hershey, J. C., Niederdeppe, J., Evans, W. D., Nonnemaker, J., Blahut, S., Holden, D., Messeri, P., and Haviland, M. L., 2005. The theory of "Truth": How counterindustry campaigns affect smoking behavior among teens. *Health Psychology*, 24 (1), 22-31.
- Hetherington, E. M., 1991. The role of individual differences and family relationships in children's coping with divorce and remarriage. In P. A. Cowan and E. M. Hetherington (Eds), *Family Transitions*, (p. 165-194). Hillsdale, NJ: Erlbaum.
- Hetherington, E. M., and Clingempeel, W. G., 1992. Coping with marital transitions: A family systems perspective. *Monographs of the Society for Research in Child Development*. Chicago: University of Chicago Press, 57(2 & 3).
- Hetherington, E. M., and Parke, R., 1993. *Child psychology. A contemporary viewpoint*. Vol. 4. USA: McGraw-Hill Inc.
- Heyman, B., 1995. *Researching user perspectives on community health care*. London: Chapman and Hall.
- Heyman, I., Fombonne, E., Simmons, H., Ford, T., Meltzer, H., and Goodman, R., 2003. Prevalence of obsessive-compulsive disorder in the British nationwide

- survey of child mental health. *International Review of Psychiatry*, 15 (1-2), 178-184.
- Hickie, I., Davenport, T., Wakefield, D., Vollmer-Conna, U., Cameron, B., Vernon, S. D., Reeves, W. C., and Lloyd, A., 2006. Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: Prospective cohort study. *BMJ*, 333 (7568), 575.
- Himes, J. R. E., 1995. *Implementing the convention on the rights of the child: Resource mobilization in low income countries*. Florence, Italy: Martinus Nijhoff Publishers.
- Hodgkinson, R., and Lester, H., 2002. Stresses and coping strategies of mothers living with a child with cystic fibrosis: Implications for nursing professionals. *Journal of Advanced Nursing*, 39 (4), 377-383.
- Hokama, Y., Uto, G. A., Palafox, N. A., Enlander, D., Jordan, E., and Cocchetto, A., 2003. Chronic phase lipids in sera of chronic fatigue syndrome (CFS), chronic ciguatera fish poisoning (ccfp), hepatitis b, and cancer with antigenic epitope resembling ciguatoxin, as assessed with mab-ctx. *Journal of Clinical Laboratory Analysis*, 17 (4), 132-139.
- Holloway, I., and Freshwater, D., 2007. *Narrative research in nursing*. Blackwell.
- Holmbeck, G. N., and Hill, J. P., 1991. Conflictive engagement, positive affect, and menarche in families with seventh-grade girls. *Child Development*, 62 (5), 1030-1048.
- Holmes, G. P., Kaplan, J. E., Gantz, N. M., Komaroff, A. L., Schonberger, L. B., Straus, S. E., Jones, J. F., Dubois, R. E., Cunningham-Rundles, C., Pahwa, S., and Et Al., 1988. Chronic fatigue syndrome: A working case definition. *Annals of Internal Medicine*, 108 (3), 387-389.
- Home Office, 2006. *Identity Fraud puts £1.7bn Hole in Britain's Pocket*. Available from <http://press.homeoffice.gov.uk/press-releases/identity-fraud-puts-1.7bn-hole>. [Accessed on 18/06/2009].
- Horner, M. M., Rawlins, P., and Giles, K., 1987. How parents of children with chronic conditions perceive their own needs. *MCN The American Journal of Maternal Child Nursing*, 12 (1), 40-43.
- Horton-Salway, M., 2001. Narrative identities and the management of personal accountability in talk about me: A discursive psychology approach to illness narrative. *Journal of Health Psychology*, 6 (2), 247-259.

- Hotopf, M., David, A., Hull, L., Ismail, K., Unwin, C., and Wessely, S., 2000. Role of vaccinations as risk factors for ill health in veterans of the gulf war: Cross sectional study. *BMJ*, 320 (7246), 1363-1367.
- Hummelinck, A., and Pollock, K., 2006. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counselling*, 62 (2), 228-234.
- Hunt, N., and McHale, S., 2007. A practical guide to the e-mail interview. *Qualitative Health Research*, 17 (10), 1415-1421.
- Hutchinson, A. C., 2002. *A report of the CFS/ME working group: Report to the chief medical officer of an independent working group*. CFS/ME Working Group.
- Ireys, H. T., and Silver, E. J., 1996. Perception of the impact of a child's chronic illness: Does it predict maternal mental health? *Journal of Developmental Behavioural Pediatrics*, 17 (2), 77-83.
- Jaccard, J., Dittus, P. J., and Gordon, V. V., 1996. Maternal correlates of adolescent sexual and contraceptive behavior. *Family Planning Perspectives*, 28 (4), 159-165, 185.
- Jackson, E. L., 1999. The effects on siblings in families with a child with chronic fatigue syndrome. *Journal of Child Health Care*, 3 (2), 27-32.
- Jacobson, W., Saich, T., Borysiewicz, L. K., Behan, W. M., Behan, P. O., and Wreghitt, T. G., 1993. Serum folate and chronic fatigue syndrome. *Neurology*, 43 (12), 2645-2647.
- Jerrett, M. D., 1994. Parents' experience of coming to know the care of a chronically ill child. *Journal of Advanced Nursing*, 19 (6), 1050-1056.
- Jessor, R., Turbin, M.S., and Costa, F.M., 1998. Predictive factors in adolescent health behaviour. *Journal of Personality and Social Psychology*. 75(3), 788-800.
- Johnson, S. K., Deluca, J., and Natelson, B. H., 1996. Personality dimensions in the chronic fatigue syndrome: A comparison with multiple sclerosis and depression. *Journal of Psychiatric Research*, 30 (1), 9-20.
- Jones, J. F., Nisenbaum, R., Solomon, L., Reyes, M., and Reeves, W. C., 2004. Chronic fatigue syndrome and other fatiguing illnesses in adolescents: A population-based study. *Journal of Adolescent Health*, 35 (1), 34-40.
- Jones, J. F., Ray, C. G., Minnich, L. L., Hicks, M. J., Kibler, R., and Lucas, D. O., 1985. Evidence for active epstein-barr virus infection in patients with

- persistent, unexplained illnesses: Elevated anti-early antigen antibodies. *Annals of Internal Medicine*, 102 (1), 1-7.
- Jordan, K. M., Jason, L. A., Mears, C. J., Katz, B. Z., Rademaker, A., Huang, C., Richman, J., McCready, W., Ayers, P. M., and Taylor, K. K., 2006. Prevalence of pediatric chronic fatigue syndrome in a community-based sample. *Journal of Chronic Fatigue Syndrome*, 13 (2-3), 75-78.
- Jovchelovitch, S., and Bauer, M. W., 2000. Narrative interviewing. *In*: Bauer, M. W., and Gaskell, G. Eds. *Qualitative researching with text, image and sound*. London: Sage, 57–74.
- Joyce, J., Hotopf, M., and Wessely, S., 1997. The prognosis of chronic fatigue and chronic fatigue syndrome: A systematic review. *QJM*, 90 (3), 223-233.
- Kane, R., and Wellings, K. 1999. *Reducing the rate of teenage conceptions: data from Europe*, Health Education Authority, London.
- Karas, B., Grubb, B. P., Boehm, K., and Kip, K., 2000. The postural orthostatic tachycardia syndrome: A potentially treatable cause of chronic fatigue, exercise intolerance, and cognitive impairment in adolescents. *Pacing Clinical Electrophysiology*, 23 (3), 344-351.
- Kato, K., Sullivan, P. F., Evengard, B., and Pedersen, N. L., 2006. Chronic widespread pain and its comorbidities: A population-based study. *Archives of Internal Medicine*, 166 (15), 1649-1654.
- Katon, W. J., Buchwald, D. S., Simon, G. E., Russo, J. E., and Mease, P. J., 1991. Psychiatric illness in patients with chronic fatigue and those with rheumatoid arthritis. *Journal of General Internal Medicine*, 6 (4), 277-285.
- Kavelaars, A., Kuis, W., Knook, L., Sinnema, G., and Heijnen, C. J., 2000. Disturbed neuroendocrine-immune interactions in chronic fatigue syndrome. *Journal of Clinical Endocrinology & Metabolism*, 85 (2), 692-696.
- Kay, K., 2006. Are size zero models too thin for the catwalk? *The Daily Mail*, 18th Sept 2006.
- Kerr, J.R., 2005. Pathogenesis of Parvovirus B19 Infection: Host Gene Variability, and Possible Means and Effects of Virus Persistence. *Journal of Veterinary Medicine Series B*, 52 (7-8), 335 – 339.
- Kerr, J. R., Burke, B., Petty, R., Gough, J., Fear, D., Matthey, D. L., Axford, J. S., Dalgleish, A. G., and Nutt, D. J., 2008. Seven genomic subtypes of chronic fatigue syndrome/myalgic encephalomyelitis: A detailed analysis of gene

- networks and clinical phenotypes. *Journal of Clinical Pathology*, 61 (6), 730-739.
- Kheirabadi, G., Malekian, A., and Fakharzadeh, M., 2007. Comparative study on the prevalence of depression in mothers with asthmatic, type i diabetic and healthy children. *Journal of Research in Behavioural Sciences*, 5 (1).
- Kleinman, A., 1988. *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Klossner, N. J., and Hatfield, N. T., 2005. *Introductory maternity & pediatric nursing*. 4th ed.: Lippincott Williams & Wilkins.
- Knafli, K. A., and Deatrick, J. A., 1986. How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health*, 9 (3), 215-222.
- Knook, L., Kavelaars, A., Sinnema, G., Kuis, W., and Heijnen, C. J., 2000. High nocturnal melatonin in adolescents with chronic fatigue syndrome. *Journal of Clinical Endocrinology & Metabolism*, 85 (10), 3690-3692.
- Knoop, H., Stulemeijer, M., De Jong, L. W., Fiselier, T. J., and Bleijenberg, G., 2008. Efficacy of cognitive behavioral therapy for adolescents with chronic fatigue syndrome: Long-term follow-up of a randomized, controlled trial. *Pediatrics*, 121 (3), e619-625.
- Kralik, D., Koch, T., and Brady, B. M., 2000. Pen pals: Correspondence as a method for data generation in qualitative research. *Journal of Advanced Nursing*, 31 (4), 909-917.
- Kralik, D., Price, K., Warren, J., and Koch, T., 2006. Issues in data generation using email group conversations for nursing research. *Journal of Advanced Nursing*, 53 (2), 213-220.
- Kramer, R. F., 1984. Living with childhood cancer: Impact on the healthy siblings. *Oncology Nursing Forum*, 11 (1), 44-51.
- Krilov, L. R., Fisher, M., Friedman, S. B., Reitman, D., and Mandel, F. S., 1998. Course and outcome of chronic fatigue in children and adolescents. *Pediatrics*, 102 (2 Pt 1), 360-366.
- Kvale, S., 1996. *Interviews: An introduction to qualitative research interviewing*. California: Sage.

- Landay, A. L., Jessop, C., Lennette, E. T., and Levy, J. A., 1991. Chronic fatigue syndrome: Clinical condition associated with immune activation. *Lancet*, 338 (8769), 707-712.
- Lane, R. J., Barrett, M. C., Woodrow, D., Moss, J., Fletcher, R., and Archard, L. C., 1998. Muscle fibre characteristics and lactate responses to exercise in chronic fatigue syndrome. *Journal of Neurology, Neurosurgery & Psychiatry*, 64 (3), 362-367.
- Lane, R. J., Soteriou, B. A., Zhang, H., and Archard, L. C., 2003. Enterovirus related metabolic myopathy: A postviral fatigue syndrome. *Journal of Neurology, Neurosurgery and Psychiatry*, 74 (10), 1382-1386.
- Lapp, C., 2006. Recognizing pediatric CFS in the primary care practice: A practicing clinician's approach. *Journal of Chronic Fatigue Syndrome*, 13 (2&3), 89-96.
- Lasko, D. S., Field, T. M., Gonzalez, K. P., Harding, J., Yando, R., and Bendell, D., 1996. Adolescent depressed mood and parental unhappiness. *Adolescence*, 31 (121), 49-57.
- Ledina, D., Bradaric, N., Milas, I., Ivic, I., Brncic, N., and Kuzmicic, N., 2007. Chronic fatigue syndrome after q fever. *Medical Science Monitor*, 13 (7), CS88-92.
- Lerner, R., and Steinberg, L. 2004. *Handbook of adolescent psychology, 2nd edition*. 2 ed.: Wiley.
- Lichstein, P. R., 1986. Caring for the patient with multiple somatic complaints. *Southern Medical Journal*, 79 (3), 310-314.
- Lieberman, D., 1993. *Learning behaviour and cognition*. 2nd ed. California: Brooks/Cole.
- Lim, A., and Lubitz, L., 2002. Chronic fatigue syndrome: Successful outcome of an intensive inpatient programme. *Journal of Paediatric Child Health*, 38 (3), 295-299.
- Lin, K. K., Sandler, I. N., Ayers, T. S., Wolchik, S. A., and Luecken, L. J., 2004. Resilience in parentally bereaved children and adolescents seeking preventive services. *Journal of Clinical Child and Adolescent Psychology*, 33 (4), 673-683.
- Lloyd, A. R., Gandevia, S. C., and Hales, J. P., 1991. Muscle performance, voluntary activation, twitch properties and perceived effort in normal subjects and patients with the chronic fatigue syndrome. *Brain*, 114 (Pt 1A), 85-98.

- Lloyd, A. R., Hickie, I., Boughton, C. R., Spencer, O., and Wakefield, D., 1990. Prevalence of chronic fatigue syndrome in an Australian population. *Medical Journal of Australia*, 153 (9), 522-528.
- Lobato, D., Faust, D., and Spirito, A., 1988. Examining the effects of chronic disease and disability on children's sibling relationships. *Journal of Pediatric Psychology*, 13 (3), 389-407.
- Males, M., 2002. The new demons: Ordinary teens *Los Angeles Times*, 21st April 2002.
- Malt, U. F., Nerdrum, P., Oppedal, B., Gundersen, R., Holte, M., and Lone, J., 1997. Physical and mental problems attributed to dental amalgam fillings: A descriptive study of 99 self-referred patients compared with 272 controls. *Psychosomatic Medicine*, 59 (1), 32-41.
- Manu, P., Matthews, D. A., and Lane, T. J., 1991. Panic disorder among patients with chronic fatigue. *Southern Medical Journal*, 84 (4), 451-456.
- McBeth J, N. B., MacFarlane G.J., Jones G.T., Wynne-Jones, G., Silman A.J. 2006. Motor vehicle collisions predict the onset of axial skeleton pain but not widespread body pain. *In American College of Rheumatology 2006 Annual Scientific Meeting*, Washington, 10-15 November 2006, ACR.ARHP, pp 2108.
- McCann, S., 2006. *Children as young as 11 are victims of new mobile bullying phenomenon*. Available from: http://www.child-safe.net/2006/p_26.php [Accessed: 03/04/2008].
- McCubbin, H., Joy, C., Cauble, A., Comeau, J., Patterson, J., and Needle, R., 1980. Family stress and coping: A decade review. *Journal of Marriage and the Family*, 42 (4), 855-871.
- McKee, M.D., Karasz, A., and Weber, C.M., 2004. Health Care Seeking Among Urban Minority Adolescent Girls: The Crisis at Sexual Debut. *Annals of Family Medicine*, 2, 549-554.
- Mechanic, D., and Hansell, S., 1987. Adolescent Competence, Psychological Well-Being, and Self-Assessed Physical Health. *Journal of Health and Social Behaviour*, 28, 364-374.
- Meho, L., 2006. E-mail interviewing in qualitative research: A methodological discussion. *Journal of the American Society for Information Science and Technology*, 54 (6), 570-587.

- Meho, L., and Tibbo, H., 2003. Modelling the information-seeking behaviour of social scientists: Ellis's study revisited. *Journal of the American Society for Information Science and Technology*, 54 (6), 570-587.
- Meleski, D. D., 2002. Families with chronically ill children. *American Journal of Nursing*, 102 (5), 47-54.
- Miller, N. A., Carmichael, H. A., Calder, B. D., Behan, P. O., Bell, E. J., McCartney, R. A., and Hall, F. C., 1991. Antibody to coxsackie b virus in diagnosing postviral fatigue syndrome. *BMJ*, 302 (6769), 140-143.
- Miller, P. 1994 Narrative practices: Their role in socialisation and self-construction. In: U. Neisser and R. Fivush, Editors, *The remembering self*, Cambridge University Press, Cambridge (1994), pp. 158–179.
- Moore, S. M., and Rosenthal, D. A. 1992. Australian Adolescents' Perceptions of Health-Related Risks. *Journal of Adolescent Research*, 7(2), 177-191.
- Moss, J., 2005. Development of a functional ability scale for children and young people with myalgic encephalopathy (ME)/chronic fatigue syndrome (CFS). *Journal of Child Health Care*, 9 (1), 20-30.
- Moss-Morris, R., and Petrie, K., 2001. *Chronic Fatigue Syndrome*. London: Routledge.
- Moss-Morris, R., Sharon, C., Tobin, R., and Baldi, J. C., 2005. A randomized controlled graded exercise trial for chronic fatigue syndrome: Outcomes and mechanisms of change. *Journal of Health Psychology*, 10 (2), 245-259.
- MRC. 2003. *MRC CFS/ME research advisory group - CFS/ME research strategy*. London, UK: Medical Research Council. Newbury Park, California: Sage Publications, 709-710.
- National Institute for Health and Clinical Excellence, 2007. *NICE Clinical Guideline 53: Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy)*. London: National Collaborating Centre for Primary Care.
- National Statistics Omnibus Survey, 2008. *National Statistics Online*. Available from <http://www.statistics.gov.uk/CCI/nugget.asp?ID=8>. [Accessed: 18/06/2009].
- Newnham, T., Lubitz, L., Wilson, S., and Scheffer, I., 2007. Adolescent-onset chronic fatigue syndrome: Effect on quality of life for the patient and their family and the outcome of a multidisciplinary inpatient program. *Journal of Pediatrics and Child Health*, 43, A21.
- Newton, A. Z., 1995. *Narrative ethics*. USA: Harvard University Press.

- Nicoll, A., Catchpole, M., Cliffe, S., Hughes, G., Simms, I., and Thomas, D. 1999. Sexual health of teenagers in England and Wales: Analysis of national data, *British Medical Journal*, 318, 1321–1322.
- Nicholas, S., Kershaw, C., and Walker, A. E. 2007. Home office statistical bulletin: Crime in England and Wales 2006/07. *Home Office Statistical Bulletin* 4. Available from: <http://www.homeoffice.gov.uk/rds/pdfs07/hosb1107.pdf> [Accessed 03.04.2008].
- Nielsen, T., and Levin, R., 2005. Nightmare frequency by age; gender and 9/11: Findings from an internet questionnaire. *Sleep*, 28.
- Nijs, J., Van De Velde, B., and De Meirleir, K., 2005. Pain in patients with chronic fatigue syndrome: Does nitric oxide trigger central sensitisation? *Medical Hypotheses*, 64 (3), 558-562.
- Oakley, A., 1981. Interviewing women: A contradiction in terms. *In*: Roberts, H. ed. *Doing feminist research*. Boston: Routledge and Kegan Paul, 30-61.
- Ofcom. March 2008. The digital television progress report (1st quarter 2008). *The Digital Television Progress Report* Available from: http://www.ofcom.org.uk/media/news/2008/03/nr_20080327 [Accessed 03.04.2008].
- Oliver, M. (1996) *Understanding Disability: From Theory to Practice*. Basingstoke: Palgrave
- ONS (Office for National Statistics), 2008. Divorce Rate 2005. Available from <http://www.statistics.gov.uk>
- Ohashi, K., Yamamoto, Y., and Natelson, B. H., 2002. Activity rhythm degrades after strenuous exercise in chronic fatigue syndrome. *Physiological Behaviour*, 77 (1), 39-44.
- Oleske, J., Friedman, K., Kaufman, K., Palumbo, D., Sterling, J., and Evans, T., 2006. Review: Chronic fatigue syndrome in children and adolescents *Journal of Chronic Fatigue Syndrome*, 13 (2-3), 97-115.
- Pajevic, I., Hasanovic, M., and Delic, A., 2007. The influence of religious moral beliefs on adolescents' mental stability. *Psychiatr Danub*, 19 (3), 173-183.
- Patel, M. X., Smith, D. G., Chalder, T., and Wessely, S., 2003. Chronic fatigue syndrome in children: A cross sectional survey. *Archives of Disease in Childhood*, 88 (10), 894-898.

- Peck, B., and Lillibridge, J., 2005. Normalization behaviours of rural fathers living with chronically-ill children: An Australian experience. *Journal of Child Health Care*, 9 (1), 31-45.
- Pelcovitz, D., Septimus, A., Friedman, S. B., Krilov, L. R., Mandel, F., and Kaplan, S., 1995. Psychosocial correlates of chronic fatigue syndrome in adolescent girls. *Journal of Developmental Behavioural Pediatrics*, 16 (5), 333-338.
- Pelletier, L., Godin, G., Lepage, L., and Dussault, G., 1994. Social support received by mothers of chronically ill children. *Child Care Health Development*, 20 (2), 115-131.
- Pepper, C. M., Krupp, L. B., Friedberg, F., Doscher, C., and Coyle, P. K., 1993. A comparison of neuropsychiatric characteristics in chronic fatigue syndrome, multiple sclerosis, and major depression. *Journal of Neuropsychiatry and Clinical Neuroscience*, 5 (2), 200-205.
- Peters, S., Stanley, I., Rose, M., Kaney, S., and Salmon, P., 2002. A randomized controlled trial of group aerobic exercise in primary care patients with persistent, unexplained physical symptoms. *Fam Pract*, 19 (6), 665-674.
- Petersen, A. C., Sarigiani, P. A., and Kennedy, R. E., 1991. Adolescent depression: Why more girls? *Journal of Youth and Adolescence*, 20(2), 247-271.
- Pillay, A. L., and Descoins, S. E., 2006. Parental death and absence in children presenting for mental health care. *Psychological Reports*, 99 (1), 248-250.
- Pinto, K. C., 2004. Intersections of gender and age in health care: Adapting autonomy and confidentiality for the adolescent girl. *Qualitative Health Research*, 14 (1), 78-99.
- Powell, P., Bentall, R. P., Nye, F. J., and Edwards, R. H., 2004. Patient education to encourage graded exercise in chronic fatigue syndrome. 2-year follow-up of randomised controlled trial. *British Journal of Psychiatry*, 184, 142-146.
- Power, P. W., 1985. Family coping behaviors in chronic illness: A rehabilitation perspective. *Rehabilitation Literature*, 46 (3-4), 78-83.
- Price, J. R., and Couper, J., 2000. Cognitive behaviour therapy for adults with chronic fatigue syndrome. *Cochrane Database Systematic Reviews* (2), CD001027.
- Puri, B. K., Counsell, S. J., Zaman, R., Main, J., Collins, A. G., Hajnal, J. V., and Davey, N. J., 2002. Relative increase in choline in the occipital cortex in chronic fatigue syndrome. *Acta Psychiatrica Scandinavica*, 106 (3), 224-226.

- Pyke-Grimm, K. A., Degner, L., Small, A., and Mueller, B., 1999. Preferences for participation in treatment decision making and information needs of parents of children with cancer: A pilot study. *Journal of Pediatric Oncology Nursing*, 16 (1), 13-24.
- Racciatti, D., Guagnano, M. T., Vecchiet, J., De Remigis, P. L., Pizzigallo, E., Della Vecchia, R., Di Sciascio, T., Merlitti, D., and Sensi, S., 2001. Chronic fatigue syndrome: Circadian rhythm and hypothalamic-pituitary-adrenal (hpa) axis impairment. *International Journal of Immunopathological Pharmacology*, 14 (1), 11-15.
- Ramsay, M., 1986. *Postviral fatigue syndrome. The saga of royal free disease*. Gower Medical Publishing.
- Rangel, L., Garralda, E., Levin, M., and Roberts, H., 2000a. Personality in adolescents with chronic fatigue syndrome. *European Child and Adolescent Psychiatry*, 9 (1), 39-45.
- Rangel, L., Garralda, M. E., Hall, A., and Woodham, S., 2003. Psychiatric adjustment in chronic fatigue syndrome of childhood and in juvenile idiopathic arthritis. *Psychological Medicine*, 33 (2), 289-297.
- Rangel, L., Garralda, M. E., Levin, M., and Roberts, H., 2000b. The course of severe chronic fatigue syndrome in childhood. *Journal of the Royal Society of Medicine*, 93 (3), 129-134.
- Ransley, J., 1999. Eating disorders and adolescents: What are the issues for secondary schools? *Health Education*, 99 (1), 35-42.
- Ray, C., Jefferies, S., and Weir, W. R., 1997. Coping and other predictors of outcome in chronic fatigue syndrome: A 1-year follow-up. *Journal of Psychosomatic Research*, 43 (4), 405-415.
- Ray, C., Weir, W. R., Cullen, S., and Phillips, S., 1992. Illness perception and symptom components in chronic fatigue syndrome. *Journal of Psychosomatic Research*, 36 (3), 243-256.
- Ray, L. D., and Ritchie, J. A., 1993. Caring for chronically ill children at home: Factors that influence parents' coping. *Journal of Pediatric Nursing*, 8 (4), 217-225.
- RCPCH. 2004. *Evidence based guideline for the management of CFS/ME (chronic fatigue syndrome/myalgic encephalomyelitis) in children & young people*. Royal College of Paediatrics & Child Health.

- Reid, S., Chalder, T., Cleare, A., Hotopf, M., and Wessely, S., 2003. Chronic fatigue syndrome. *Clinical Evidence* (10), 1289-1303.
- Reis, E. C., Duggan, A. K., Adger, H., Jr., and Deangelis, C., 1994. The impact of anti-drug advertising. Perceptions of middle and high school students. *Archives of Pediatric Adolescent Medicine*, 148 (12), 1262-1268.
- Reeves, W.C., Lloyd, A., Vernon, S., Klimas, N., Jason, L.A., Bleijenberg, G., Evengard, B., White, P.D., Nisenbaum, R., Unger, E.R., and the International Chronic Fatigue Syndrome Study Group. 2003. Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution. *BMC Health Services Research*, 2003, **3**:25.
- Reynolds, K. J., Vernon, S. D., Bouchery, E., and Reeves, W. C., 2004. The economic impact of chronic fatigue syndrome. *Cost Effective Resource Allocation*, 2 (1), 4.
- Ridsdale, L., Darbishire, L., and Seed, P. T., 2004. Is graded exercise better than cognitive behaviour therapy for fatigue? A UK randomized trial in primary care. *Psychological Medicine*, 34 (1), 37-49.
- Riessman, C. K., 1987. When gender is not enough: Women interviewing women. *Gender & Society*, 1 (2), 172-207.
- Riessman, C. K., 1990. Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine*, 30 (11), 1195-1200.
- Riessman, C. K., 2002a. Analysis of personal narratives. In: Gubrium, J., and Holstein, J. Eds. *Handbook of interview research*. Thousand Oaks, California: Sage Publications, 695-710.
- Riessman, C. K., 2002b. Doing justice: Positioning the interpreter in narrative work. In: Patterson, W. ed. *Strategic narrative. New perspectives on the power of personal and cultural stories*. New York: Lexington Books, 193-214.
- Riessman, C. K., 2004a. A thrice-told tale: New readings of an old story. In: Hurwitz, B., Greenhalgh, T., and Skultans, V. Eds. *Narrative research in health and illness*. Malden, Massachusetts: Blackwell Publishing.
- Riessman, C. K., 2004b. Narrative analysis. In: Lewis-Beck, M. S., Bryman, A., and Futing Liao, T. Eds. *Encyclopedia of social science research methods*. London: Sage Publications, 705-709.

- Riessman, C. K., 2004c. Narrative interviewing. *In*: Lewis-Beck, M. S., Bryman, A., and Futing Liao, T. Eds. *Encyclopedia of social science research methods*. London, UK
- Riessman, C. K., 2005. Exporting ethics: A narrative about narrative research in south India. *Health (London)*, 9 (4), 473-490.
- Riessman, C. K., and Quinney, L. (2005). Narrative in Social Work: A Critical Review. *Qualitative Social Work*, 4, 391-412.
- Right to Education Website. 2008. Available from: <http://www.right-to-education.org/content/age/table.html>. [Accessed on 18/04/2008]
- Riley, M. S., O'Brien, C. J., McCluskey, D. R., Bell, N. P., and Nicholls, D. P., 1990. Aerobic work capacity in patients with chronic fatigue syndrome. *BMJ*, 301 (6758), 953-956.
- Rook, G. A., and Zumla, A., 1997. Gulf war syndrome: Is it due to a systemic shift in cytokine balance towards a th2 profile? *Lancet*, 349 (9068), 1831-1833.
- Ross, M. W., Mansson, S. A., Daneback, K., Cooper, A., and Tikkanen, R., 2005. Biases in internet sexual health samples: Comparison of an internet sexuality survey and a national sexual health survey in sweden. *Social Science & Medicine*, 61 (1), 245-252.
- Rowe, K. S., 1997. Double-blind randomized controlled trial to assess the efficacy of intravenous gammaglobulin for the management of chronic fatigue syndrome in adolescents. *Journal of Psychiatric Research*, 31 (1), 133-147.
- Rowe, P. C., Barron, D. F., Calkins, H., Maumenee, I. H., Tong, P. Y., and Geraghty, M. T., 1999. Orthostatic intolerance and chronic fatigue syndrome associated with Ehlers-Danlos syndrome. *Journal of Pediatrics*, 135 (4), 494-499.
- Rowe, P. C., Bou-Holaigah, I., Kan, J. S., and Calkins, H., 1995. Is neurally mediated hypotension an unrecognised cause of chronic fatigue? *Lancet*, 345 (8950), 623-624.
- Royal College of Physicians, 1996. *Chronic fatigue syndrome (council report CR54)*. London.
- Royal College of Psychiatrists, L., 2000. *Eating disorders in the UK: Policies for service development and training (council report CR87)*, London
- Saidi, G., and Haines, L., 2006. The management of children with chronic fatigue syndrome-like illness in primary care: A cross-sectional study. *British Journal of General Practise*, 56 (522), 43-47.

- Saisch, S. G., Deale, A., Gardner, W. N., and Wessely, S., 1994. Hyperventilation and chronic fatigue syndrome. *QJM*, 87 (1), 63-67.
- Sankey, A., Hill, C. M., Brown, J., Quinn, L., and Fletcher, A., 2006. A follow-up study of chronic fatigue syndrome in children and adolescents: Symptom persistence and school absenteeism. *Clinical Child Psychology & Psychiatry*, 11 (1), 126-138.
- Seale, C., 2004. *Social research methods: A reader* New York: Routledge.
- Seligman, M., 1987. Adaptation of children to a chronically ill or mentally handicapped sibling. *CMAJ*, 136 (12), 1249-1252.
- Semple, A., 2008. *Edinburgh Evening News*. 16th May 2008. Edinburgh.
- Servaes, P., Prins, J., Verhagen, S., and Bleijenberg, G., 2002. Fatigue after breast cancer and in chronic fatigue syndrome: Similarities and differences. *Journal of Psychosomatic Research*, 52 (6), 453-459.
- Sharkey, T., 1995. The effects of uncertainty in families with children who are chronically ill. *Home Healthcare Nurse*, 13 (4), 37-42.
- Sharpe, M. C., Archard, L. C., Banatvala, J. E., Borysiewicz, L. K., Clare, A. W., David, A., Edwards, R. H., Hawton, K. E., Lambert, H. P., Lane, R. J., and Et Al., 1991. A report--chronic fatigue syndrome: Guidelines for research. *Journal of the Royal Society of Medicine*, 84 (2), 118-121.
- Sidebotham, P. D., Skeldon, I., Chambers, T. L., Clements, S., and Culling, J., 1994. Refractory chronic fatigue syndrome in adolescence. *British Journal of Hospital Medicine*, 51 (3), 110-112.
- Silver, E. J., Bauman, L. J., and Ireys, H. T., 1995. Relationships of self-esteem and efficacy to psychological distress in mothers of children with chronic physical illnesses. *Health Psychology*, 14 (4), 333-340.
- Slattery, M., 1985. *The ABC of sociology*. London: Macmillan Education Ltd.
- Slee, P. T., 2002. *Child, adolescent and family development*. 2nd ed. London: Cambridge University Press.
- Sleigh, K. M., Marra, F. H., and Stiver, H. G., 2002. Influenza vaccination: Is it appropriate in chronic fatigue syndrome? *American Journal of Respiratory Medicine*, 1 (1), 3-9.
- Smith, J., 2008. *Qualitative psychology: A practical guide to research methods*. 2nd ed. London: Sage.

- Smith, M. S., Mitchell, J., Corey, L., Gold, D., McCauley, E. A., Glover, D., and Tenover, F. C., 1991. Chronic fatigue in adolescents. *Pediatrics*, 88 (2), 195-202.
- Soderberg, S., Lundman, B., and Norberg, A., 1999. Struggling for dignity: The meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, 9 (5), 575-587.
- Soderberg, S., Lundman, B., and Norberg, A., 2002. The meaning of fatigue and tiredness as narrated by women with fibromyalgia and healthy women. *Journal of Clinical Nursing*, 11 (2), 247-255.
- Sparkes, A. C., 2005. Narrative analysis: Exploring the whats and hows of personal stories. In: Holloway, I. Ed. *Qualitative research in health care*, 1st ed. Berkshire, UK: Open University Press, 191-209.
- Steffen, V., 1997. Life stories and shared experience. *Social Science & Medicine*, 45 (1), 99-111.
- Stevens, R. 1983. *Erik Erikson: An Introduction*. New York: St. Martin's.
- Stewart, J. M., Gewitz, M. H., Weldon, A., and Munoz, J., 1999a. Patterns of orthostatic intolerance: The orthostatic tachycardia syndrome and adolescent chronic fatigue. *Journal of Pediatrics*, 135 (2 Pt 1), 218-225.
- Stewart, J. M., Gewitz, M. H., Weldon, A., Arlievsky, N., Li, K., and Munoz, J., 1999b. Orthostatic intolerance in adolescent chronic fatigue syndrome. *Pediatrics*, 103 (1), 116-121.
- Stewart, M. J., Ritchie, J. A., McGrath, P., Thompson, D., and Bruce, B., 1994. Mothers of children with chronic conditions: Supportive and stressful interactions with partners and professionals regarding caregiving burdens. *Canadian Journal of Nursing Research*, 26 (4), 61-82.
- Stores, G., Fry, A., and Crawford, C., 1998. Sleep abnormalities demonstrated by home polysomnography in teenagers with chronic fatigue syndrome. *Journal of Psychosomatic Research*, 45 (1 Spec No), 85-91.
- Straus, S. E., Tosato, G., Armstrong, G., Lawley, T., Preble, O. T., Henle, W., Davey, R., Pearson, G., Epstein, J., Brus, I., and Et Al., 1985. Persisting illness and fatigue in adults with evidence of epstein-barr virus infection. *Annals of Internal Medicine*, 102 (1), 7-16.

- Stulemeijer, M., De Jong, L. W., Fiselier, T. J., Hoogveld, S. W., and Bleijenberg, G., 2005. Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: Randomised controlled trial. *BMJ*, 330 (7481), 14.
- Surawy, C., Hackmann, A., Hawton, K., and Sharpe, M., 1995. Chronic fatigue syndrome: A cognitive approach. *Behavioural Research Therapy*, 33 (5), 535-544.
- Suris, J. C., Parera, n., and Puig, C., 1996. Chronic illness and emotional distress in adolescence. *Journal of Adolescent Health*, 19(2), 153-156.
- Swanink, C. M., Melchers, W. J., Van Der Meer, J. W., Vercoulen, J. H., Bleijenberg, G., Fennis, J. F., and Galama, J. M., 1994. Enteroviruses and the chronic fatigue syndrome. *Clinical Infectious Diseases*, 19 (5), 860-864.
- Taanila, A., Jarvelin, M. R., and Kokkonen, J., 1999. Cohesion and parents' social relations in families with a child with disability or chronic illness. *International Journal of Rehabilitation Research*, 22 (2), 101-109.
- Tahmaz, N., Soutar, A., and Cherrie, J. W., 2003. Chronic fatigue and organophosphate pesticides in sheep farming: A retrospective study amongst people reporting to a UK pharmacovigilance scheme. *Annals of Occupational Hygiene*, 47 (4), 261-267.
- Taillefer, S. S., Kirmayer, L. J., Robbins, J. M., and Lasry, J. C., 2002. Psychological correlates of functional status in chronic fatigue syndrome. *Journal of Psychosomatic Research*, 53 (6), 1097-1106.
- Takahashi, Y., Ohta, S., Sano, A., Kuroda, Y., Kaji, Y., Matsuki, M., and Matsuo, M., 2000. Does severe nutcracker phenomenon cause pediatric chronic fatigue? *Clinical Nephrology*, 53 (3), 174-181.
- Ter Wolbeek, M., Van Doornen, L. J., Kavelaars, A., and Heijnen, C. J., 2008. Predictors of persistent and new-onset fatigue in adolescent girls. *Pediatrics*, 121 (3), e449-457.
- Theorell, T., Blomkvist, V., Lindh, G., and Evengard, B., 1999. Critical life events, infections, and symptoms during the year preceding chronic fatigue syndrome (CFS): An examination of CFS patients and subjects with a nonspecific life crisis. *Psychosomatic Medicine*, 61 (3), 304-310.
- Thomas, M. A., and Smith, A. P., 2006. An investigation of the long-term benefits of antidepressant medication in the recovery of patients with chronic fatigue syndrome. *Human Psychopharmacology*, 21 (8), 503-509.

- Thompson, W.G. 1990. Alternatives to Medicine. *Canadian Medical Association Journal*. 142: 105-106.
- Treib, J., Grauer, M. T., Haass, A., Langenbach, J., Holzer, G., and Woessner, R., 2000. Chronic fatigue syndrome in patients with lyme borreliosis. *European Neurology*, 43 (2), 107-109.
- Tunstill, J. E., 2000. *Children and the state: Whose problem?* New York: Continuum International Publishing Group Ltd.
- Tymestrust. 2004. *Young hearts*. UK: Bookfile.
- Unwin, C., Blatchley, N., Coker, W., Ferry, S., Hotopf, M., Hull, L., Ismail, K., Palmer, I., David, A., and Wessely, S., 1999. Health of UK servicemen who served in Persian Gulf war. *Lancet*, 353 (9148), 169-178.
- Van De Luit, L., Van Der Meulen, J., Cleophas, T. J., and Zwinderman, A. H., 1998. Amplified amplitudes of circadian rhythms and nighttime hypotension in patients with chronic fatigue syndrome: Improvement by inopamil but not by melatonin. *Angiology*, 49 (11), 903-908.
- Van Hoof, E., De Becker, P., and De Meirleir, K., 2006. Pediatric chronic fatigue syndrome and munchausen-by-proxy: A case study. *Journal of Chronic Fatigue Syndrome*, 13 (2-3), 45-53.
- Van Middendorp, H., Geenen, R., Kuis, W., Heijnen, C. J., and Sinnema, G., 2001. Psychological adjustment of adolescent girls with chronic fatigue syndrome. *Pediatrics*, 107 (3), E35.
- Venters, M., 1981. Familial coping with chronic and severe childhood illness: The case of cystic fibrosis. *Social Science Medicine [A]*, 15 (3 Pt 1), 289-297.
- Vercoulen, J. H., Hommes, O. R., Swanink, C. M., Jongen, P. J., Fennis, J. F., Galama, J. M., Van Der Meer, J. W., and Bleijenberg, G., 1996a. The measurement of fatigue in patients with multiple sclerosis. A multidimensional comparison with patients with chronic fatigue syndrome and healthy subjects. *Archives of Neurology*, 53 (7), 642-649.
- Vercoulen, J. H., Swanink, C. M., Fennis, J. F., Galama, J. M., Van Der Meer, J. W., and Bleijenberg, G., 1996b. Prognosis in chronic fatigue syndrome: A prospective study on the natural course. *Journal of Neurology, Neurosurgery & Psychiatry*, 60 (5), 489-494.
- Vereker, M. I., 1992. Chronic fatigue syndrome: A joint paediatric-psychiatric approach. *Archives of Disease in Childhood*, 67 (4), 550-555.

- Viner, R., Gregorowski, A., Wine, C., Bladen, M., Fisher, D., Miller, M., and El Neil, S., 2004. Outpatient rehabilitative treatment of chronic fatigue syndrome (CFS/ME). *Archives of Disease in Childhood*, 89 (7), 615-619.
- Walford, G. A., Nelson, W. M., and McCluskey, D. R., 1993. Fatigue, depression, and social adjustment in chronic fatigue syndrome. *Archives of Disease in Childhood*, 68 (3), 384-388.
- Wallander, J. L., and Varni, J. W., 1989. Social support and adjustment in chronically ill and handicapped children. *American Journal of Community Psychology*, 17 (2), 185-201.
- Wallman, K. E., Morton, A. R., Goodman, C., Grove, R., and Guilfoyle, A. M., 2004. Randomised controlled trial of graded exercise in chronic fatigue syndrome. *Medical Journal of Australia*, 3,180(9), 444-448.
- Ware, C., 1992. Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, 6 (4), 347-361.
- Ware, N.C., and Kleinman, A., 1992. Culture and somatic experience: the social course of illness in neurasthenia and chronic fatigue syndrome. *Psychosomatic Medicine*, 54, (5), 546-560.
- Weber, Z., Rowling, L., and Scanlon, L., 2007. "It's like . . . A confronting issue": Life-changing narratives of young people. *Qualitative Health Research*, 17 (7), 945-953.
- Werbach, M. R., 2000. Nutritional strategies for treating chronic fatigue syndrome. *Alternative Medical Review*, 5 (2), 93-108.
- Wessely, S., Hotopf, M., and Sharpe, M., 1998. *Chronic fatigue and its syndromes*. New York: Oxford University Press.
- West, D., 2007. *The death of the grown-up: How America's arrested development is bringing down western civilization*. Vol. 1. New York: St Martin's Press.
- White, P. D., Thomas, J. M., Amess, J., Crawford, D. H., Grover, S. A., Kangro, H. O., and Clare, A. W., 1998. Incidence, risk and prognosis of acute and chronic fatigue syndromes and psychiatric disorders after glandular fever. *British Journal of Psychiatry*, 173, 475-481.

- White, P. D., Thomas, J. M., Amess, J., Grover, S. A., Kangro, H. O., and Clare, A. W., 1995. The existence of a fatigue syndrome after glandular fever. *Psychological Medicine*, 25 (5), 907-916.
- Whitehead, L. C., 2006. Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine*, 62 (9), 2236-2245.
- Whitehead, W., Palsson, O., and Jones, K.R. 2002. Systematic review of the comorbidity of irritable bowel syndrome with other disorders: What are the causes and implications? *Gastroenterology*. 122 (4), 1140-1156.
- Whiting, P., Bagnall, A. M., Sowden, A. J., Cornell, J. E., Mulrow, C. D., and Ramirez, G., 2001. Interventions for the treatment and management of chronic fatigue syndrome: A systematic review. *Jama*, 286 (11), 1360-1368.
- Wilson, A., Hickie, I., Lloyd, A., Hadzi-Pavlovic, D., Boughton, C., Dwyer, J., and Wakefield, D., 1994. Longitudinal study of outcome of chronic fatigue syndrome. *BMJ*, 308 (6931), 756-759.
- Wilson, S., and Argyropoulos, S., 2005. Antidepressants and Sleep: A Qualitative Review of the Literature. Review Article. *Drugs*. 65(7):927-947.
- Winter, R., and Munn-Giddings, C., 2001. *A Handbook for Action Research in Health and Social Care*, New York: Routledge.
- Wood, B., and Wessely, S., 1999. Personality and social attitudes in chronic fatigue syndrome. *Journal of Psychosomatic Medicine*, 47, 385-397.
- Wright, B., Ashby, B., Beverley, D., Calvert, E., Jordan, J., Miles, J., Russell, I., and Williams, C., 2005. A feasibility study comparing two treatment approaches for chronic fatigue syndrome in adolescents. *Archives of Disease in Childhood*, 90 (4), 369-372.
- Wright, J., and Cottrell, D., 1997. Chronic fatigue syndrome in children. In: Lynch, S. ed. *Psychosocial aspects of chronic fatigue syndrome*. London: Balliere Tindall, 449-471.
- Yousef, G. E., Bell, E. J., Mann, G. F., Murugesan, V., Smith, D. G., McCartney, R. A., and Mowbray, J. F., 1988. Chronic enterovirus infection in patients with postviral fatigue syndrome. *Lancet*, 1 (8578), 146-150.
- Zhang, Q., Zhou, X. D., Denny, T., Ottenweller, J. E., Lange, G., Lamanca, J. J., Lavietes, M. H., Pollet, C., Gause, W. C., and Natelson, B. H., 1999. Changes in immune parameters seen in gulf war veterans but not in civilians with

chronic fatigue syndrome. *Clinical & Diagnostic Laboratory Immunology*, 6 (1), 6-13.

Appendix A

Copies of Participant Information Leaflets and Sample Consent Forms

PARTICIPANT INFORMATION LEAFLET

Part 1 – to give you first thoughts about the project

Study title

Improving Understanding of Chronic Fatigue Syndrome (CFS)

We are asking if you would agree to take part in a research project to find the answer to the question: “How does CFS (also called M.E.) affect young people?”

Before you decide if you want to join in it’s important to understand why the research is being done and what it will involve for you. So please read this leaflet carefully. Talk about it with your family, friends, doctor or nurse if you want to.

Thank you for reading this

NB. Where the word “parent” is used, please read parent/guardian i.e. those who have parental responsibility, which may include a legal representative e.g. grandparent.

Why are we doing this research?

We feel that not many people understand what it’s like to have CFS as a young person and so we’d like to find out how it affects you so that we can help inform other people.

Why have I been asked to take part?

You have been asked to take part because you have CFS and are aged between 11 and 18 years old.

Do I have to take part?

No, it is completely up to you and your parents. If you do,

- ⌚ You and your parent will be asked to sign a form each giving consent to participate.
- ⌚ You will be given a copy of this information sheet and your signed form to keep
- ⌚ **You are free to stop taking part at any time during the research without giving a reason.** If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part?

If you agree to take part we will ask you to take part in an interview when you come into Clinic for your normal appointment or, if you don’t feel well enough for that, one of our team will come out to visit you at home. We will be asking questions about how CFS affects young people’s lives – family, school, friends, and so on. It is nothing to worry about, it will be a relaxed interview where you get the opportunity to tell your story. Each interview will take about an hour in all, but we will can break

that hour down into two or three sessions on different days so that you don't get too tired.

What are the possible benefits of taking part?

The information you and others provide will help us to build up a picture of what it is like for young people who have CFS/ME. It will allow us to write a report which will assist doctors and other medical professionals who are involved in helping young people, like yourself, with CFS/ME. We hope that this report will give people a better understanding of how life is for those with CFS/ME, how it affects your thoughts and feelings, your relationships with your friends, your school-life, and so on.

What are the possible risks?

We cannot see any risks to you joining in. If you become too tired or uncomfortable during the interview we will stop and continue another day.

Contact Details:

You can find out more about this study and ask any questions you may have by contacting the Research Assistant:

Melinda Williams-Wilson

Rheumatology Department, Poole Hospital NHS Trust, Longfleet Rd, Poole. BH15 2JB

Tel.: 07956 937912

Email: cfsresearch@hotmail.co.uk

Thank you for reading so far – if you are still interested, please go to Part 2.

–

Part 2 - more detail – information you need to know if you still want to take part.

Will anyone else know I am doing this?

Yes –

- The small research team will see your medical notes and keep an eye on the study to make sure the research is being done properly.
- Your family doctor (GP) will be told you are taking part.

All information collected will be kept strictly confidential.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

The Research Assistant will be paid for conducting the research project, funding will be from a body external to the NHS.

Who has reviewed the study?

Before any research goes ahead it has to be checked by an Ethics Committee. They make sure that the research is OK to do. This project has been checked by the Dorset Research Ethics Committee.

Who is involved in the research?

The following people are members of the Research Team:

- ⌚ Doctor Selwyn Richards - Consultant Rheumatologist and specialist in CFS
- ⌚ Professor Peter Thomas - Professor of Health Care Statistics and Epidemiology, Dorset Research & Development Unit and Bournemouth University
- Professor Kate Galvin - Head of Research, IHCS, Bournemouth University

- Melinda Williams-Wilson - Research Assistant
- Barbara Goodchild - Lead Occupational Therapist, Dorset Children’s CFS Service

Thank you for reading this – please ask any questions if you need to.

If you agree to take part and wish to know the results of this study please include a contact address in the space below and we will send you an information sheet when the study is finished.

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CONSENT FORM FOR CHILDREN
(to be completed by the child and their parent/guardian)

A Detailed Assessment and Characterisation of CFS in Adolescents.

Child or young person to circle all they agree with please:

- | | |
|--|--------|
| Have you read (or had read to you) the information leaflet? | Yes/No |
| Has a member of the Research Team explained anything you may not understand and/or answered any questions? | Yes/No |
| Do you understand what this project is about? | Yes/No |
| Have you asked all the questions you want? | Yes/No |
| Have you had your questions answered in a way you understand? | Yes/No |
| Do you understand it's OK to stop taking part at any time? | Yes/No |
| Are you happy to take part? | Yes/No |

If any answers are 'no' or you **don't** want to take part, **don't** sign your name!
If you **do** want to take part, please write your name and today's date

Your Name _____

Date _____

Are you happy for us to inform your GP of your involvement in the study? Yes/No

Parent/guardian

Print Name _____

Sign _____

Date _____

Are you happy for us to inform your child's GP of his/her involvement in the study?
Yes/No

Thank you for your help.

PARTICIPANT INFORMATION SHEET
PARENTS/ GUARDIANS

Part 1.

Study title

Improving Understanding of Chronic Fatigue Syndrome (CFS)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- ⑩ Part 1 tells you the purpose of this study and what will happen to you if you take part.
- ⑩ Part 2 gives you more detailed information about the conduct of the study.

*Ask us if there is anything that is not clear or if you would like more information.
Take time to decide whether or not you wish to take part.*

What is the purpose of the study?

We are conducting a research study into adolescents with CFS (also called M.E.), within which we will listen to and report the effects that CFS has on young people's lives. This is a PhD research project, conducted under the supervision of two professors who work within the medical field, and a Consultant who specialises in CFS/ME.

Why have I been asked to participate?

You have been asked to take part because you have a child already participating in the study and we would like to also gain your views on how having a child with CFS has affected yourself, your child and your family.

Does I have to take part?

No. It is up to you to decide whether or not to take part. You are free to withdraw from the research at any time and without giving a reason. Your decisions about this will not affect the standard of care your child will receive.

What will happen if I agree to take part?

The consent process

If you are happy to take part, and are satisfied with the explanations from your research team, you will be asked to sign a consent form.

What do I have to do if I agree to take part?

You will be invited to Poole Hospital at a time that is convenient to you to take part in a relaxed interview which will last about 45 minutes. During this time you will be asked questions about how having a child with CFS has affected your life, your child and your family. Anything you do not wish to answer you can simply say so and the interviewer will move on to a different topic. This session is to hear your views and opinions so **you** will be the person leading the discussion.

What are the possible benefits of taking part?

We cannot promise the study will help your child directly, but the information we gain might help improve the treatment of young people with CFS and raise awareness of the condition.

What are the possible risks?

We cannot see any risks to you being interviewed.

What happens when the research study stops?

Any collected data will be kept for the legally required length of time and then destroyed. All information given will be kept confidential.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

A contact number for complaints:

Dr. Selwyn Richards, Rheumatology Department, Poole Hospital.

Tel.: 01202 448613

If you are still not satisfied, the normal NHS complaints mechanisms will be available to you. You can access this by contacting the Patient Advice and Liaison Service (PALS) on 01202 448499 or emailing pals@poole.nhs.uk

Will my taking part in the research project be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact Details:

Melinda Williams-Wilson

Rheumatology Department, Poole Hospital NHS Trust, Longfleet Rd, Poole. BH15 2JB

Tel.: 07956 937912

Email: cfsresearch@hotmail.co.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time and all collected data can be destroyed immediately. This decision will not affect the quality of care your child receives.

What if there is a problem?

Complaints:

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (Tel.: 07956 937912). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm:

In the unlikely event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (Poole Hospital NHS Trust) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

All procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998. If you join the study, all information which is collected during the course of the research will be kept strictly confidential. Any information which leaves the hospital will have all identifiable information removed so that you or your child cannot be recognised from it. Any transcripts and audio-tapes of interviews will be kept in a secure locked cabinet on hospital grounds, for a period of up to five years after the study is completed. All electronic data will be kept on a secure computer and access to the data will be secured by use of specific passwords known only to authorised persons within the Research Team. Any publications or reports that may be produced would ensure that your child is not named.

What will happen to the results of the research study?

The information gathered may be used for publication and will be used in a final thesis/report, however no identifiable information will be used so as to protect participant anonymity.

Who is organising and funding the research?

This is a self-funded PhD research project.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by Dorset Research Governance.

Thank you for reading this – please ask any questions if you need to.

If you agree for your child to participate and wish to know the results of this study please include a contact address below and we will send you an information sheet when the study is complete.

Name & address for results of study to be sent to

.....

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CONSENT FORM - PARENT/GUARDIAN

Title of Project:

A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS/M.E.) in Adolescents

Name of Researcher: Melinda Williams-Wilson

- ⑩ I confirm that I have read and understand the information sheet dated **Please initial box** (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

- ⑩ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected.

- ⑩ I have parental responsibility for the child named below and I have previously agreed for him/her to take part in the above study

Name of Child: _____

My Name: _____

Signature: _____

Today's Date: _____

PARTICIPANT INFORMATION SHEET
PARENT EMAIL INTERVIEWS

Study title

A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

⑩ Part 1 tells you the purpose of this study and what will happen to you if you take part.

⑩ Part 2 gives you more detailed information about the conduct of the study.

*Ask us if there is anything that is not clear or if you would like more information.
Take time to decide whether or not you wish to take part.*

What is the purpose of the study?

We are conducting a research study into adolescents with CFS (also called M.E.), within which we will listen to and report the effects that CFS has on young people's lives. This is a PhD research project, conducted under the supervision of two academic professors from Bournemouth University who work within the medical field, and a Consultant who specialises in CFS/ME.

Why have I been asked to participate?

You have been asked to take part because you have a child already participating in the study and we would like to also gain your views on how having a child with CFS has affected yourself, your child and your family.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You are free to withdraw from the research at any time and without giving a reason. Your decisions about this will not affect the standard of care your child will receive.

What will happen if I agree to take part?

The consent process

If you are happy to take part, and are satisfied with the explanations from your research team, you will be asked to sign a consent form.

What do I have to do if I agree to take part?

You will engage in a 'rolling email interview' with the researcher who will over two or three email exchanges ask you questions about how having a child with CFS has affected your life, your child and your family. Anything you do not wish to answer

you can simply indicate as such and move onto the other questions. The most critical thing is that we are trying to establish **your** views, opinions, feelings and thoughts and so require answers to be typed as fully as possible.

What are the possible benefits of taking part?

We cannot promise the study will help your child directly, but the information we gain might help improve the treatment of young people with CFS and raise awareness of the condition.

What are the possible risks?

It is possible that prolonged use of computers may lead to neck and/or back problems, therefore it is advisable that when sat at a PC for an extended length of time correct posture and appropriate seating is ensured as well as making sure that short breaks are scheduled into working time.

What happens when the research study stops?

Any collected data will be kept for the legally required length of time and then destroyed. All information given will be kept confidential and presented in any reports and the final PhD thesis in an anonymised fashion.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

A contact number for complaints:

Dr. Selwyn Richards, Rheumatology Department, Poole Hospital.

Tel.: 01202 448613

If you are still not satisfied, the normal NHS complaints mechanisms will be available to you. You can access this by contacting the Patient Advice and Liaison Service (PALS) on 01202 448499 or emailing pals@poole.nhs.uk

Will my taking part in the research project be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact Details:

Melinda Williams-Wilson

Rheumatology Department, Poole Hospital NHS Trust, Longfleet Rd, Poole. BH15 2JB

Tel.: 07956 937912

Email: e9080119@bournemouth.ac.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time and all collected data can be destroyed immediately. This decision will not affect the quality of care your child receives.

What if there is a problem?

Complaints:

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (Tel.: 07956 937912). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm:

In the unlikely event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (Poole Hospital NHS Trust) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

All procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998. If you join the study, all information which is collected during the course of the research will be kept strictly confidential. All email communication will be conducted through the secure Bournemouth University server which is password protected and only accessible by the researcher. Any publications or reports that may be produced would ensure that yourself and your child are not named and that any identifiable data has been removed.

What will happen to the results of the research study?

The information gathered may be used for publication and will be used in a final thesis/report.

Who is organising and funding the research?

This is a self-funded PhD research project.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by Dorset Research Governance.

Thank you for reading this – please ask any questions if you need to.

If you agree to participate and wish to know the results of this study please include a contact address below and we will send you an information sheet when the study is complete.

Name & address for results of study to be sent to:

.....
.....
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.....

CONSENT FORM - Parent Participation in Email Interviews

Title of Project:

A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS/M.E.) in Adolescents

Name of Researcher: Melinda Williams-Wilson

- ⑩ I confirm that I have read and understand the information sheet dated Jan 2009 (version 5.11) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- ⑩ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected.
- ⑩ I have parental responsibility for the child named below and I have previously agreed for him/her to take part in the above study
- ⑩ I understand that this is a student study whereby the researcher has the backing of a supervisory team of two professors and a consultant who will be approached with anonymised data for advice should she require additional support, and if information is disclosed during the email interviews which the researcher believes requires more individual support I will be advised to approach the Dorset Adolescent CFS Service for more individualised support and attention.
- In the appropriate space below I have provided a sample password by which I can be identified in order that the researcher can be sure she is continuing email communication with myself during the interview process.

Name of Child: _____

My Name: _____

Signature: _____

Password: _____

Today's Date: _____

Appendix B

Paper Trail of Ethics Applications

Employer: POOLE HOSPITAL NHS TRUST
LONGFLEET ROAD
POOLE, DORSET, BH15 2JB

HONORARY CONTRACT

Name of Employee: Melinda WILLIAMS

Job Title: Honorary Contract

Location: Poole Hospital NHS Trust, Longfleet Road, Poole

1. Date of commencement

Your placement with the Trust will commence on 2 September 2005.

2. Collective Agreements

A copy of collective agreements reached in the JCNC can be obtained from the Trust Intranet.

3. Normal Hours of Placement

The normal hours of your placement will be in agreement with the Line Manager.

4. Professional Indemnity

The Trust will provide you with professional indemnity for any act or omission within the scope of your placement.

Professional indemnity will not be provided for acting outside the scope of the honorary contract.

5. Personal Property

The Trust accepts no responsibility for damage to or loss of personal property, with the exception of small valuables handed to their officials for safe custody. You are therefore recommended to take out an insurance policy to cover your personal property. Compensation for damage to personal property, which occurs in the course of your duty, will be at the discretion of the Trust.

6. Trust Property

You will be expected to take all reasonable care for use and security of Trust property. Upon termination of your placement with the Trust for whatever reason you shall forthwith return all Trust property, which may be in your possession or under your control. If so requested, you will sign a statement on leaving confirming that you have complied with this requirement.

7. Change of Address/Personal Circumstances

During the course of your placement your home address and personal circumstances might change. If so, the Line Manager must be notified immediately so that records can be kept up to date.

8. Acceptance of Gifts and Hospitality

You should exercise the utmost discretion in accepting offers of gifts or hospitality from contractors or their representatives or from other organisations or individuals concerned with the supply of goods or services. These matters are dealt with in some detail in the Trust's document "Guidance on Acceptance of Gifts and Hospitality", a copy of which is available from your Line Manager, Human Resources Department or on the Trust Intranet. In cases of doubt individuals should either consult the Line Manager or decline acceptance.

9. Confidentiality

You are required to maintain an appropriate standard of confidentiality. In the discharge of your placement you may often be in possession of confidential and personal information concerning individual patients and staff, including personal information kept on computer or other media. You **MUST NOT DISCLOSE** such information either at work or elsewhere except in the proper discharge of your duties. A breach of confidentiality will be regarded very seriously. You shall not, during or after termination of your placement, use improperly or disclose to others any confidential information about the Trust, its policies, plans, practices or finances. The mechanisms to air concerns about health care matters are set out in the Trust's policy 'managing staff concerns about health care matters'.

10. Data Protection

The Trust will hold personal information about you that will include details such as your name, address, age, and emergency contact details. The Trust may also hold sensitive personal information, (i.e. sensitive personal data as defined in the Data Protection Act 1998) about you, for example health and sickness information, criminal records and trade union membership.

Personal information may be obtained from various sources including your application form, references and medical assessments. The Trust will process your personal information, including any sensitive information for purposes connected with your placement, including for example, references.

By signing this principal statement you explicitly consent to the processing of your personal information as described above.

11. Declaration of Criminal Convictions

If during the course of your placement you are arrested, charged or convicted of any criminal offence you must notify the Line Manager.

12. Research Governance

Poole Hospital NHS Trust manages all research in accordance with the requirements of the Research Governance Framework. As an employee of this Trust you must comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver Research Governance. You must contact our Research Governance Manager prior to commencing research.

13. Inventions

Any invention or intellectual product relevant to the activities of the Trust where such an invention or intellectual product is made in the course of your placement (whether specifically assigned or not) and which might reasonably be expected to result from the course of your placement will be the property of the Trust. Use elsewhere or publication of such inventions or products will be subject to Trust copyright and to the approval of the Trust Board. In cases of doubt, definitions contained within Section 39 of the Patents Act 1977 will be relied upon.

14. Health and Safety

You are reminded that under the Health and Safety at Work Act (1974) it is your duty take reasonable care for the health and safety of yourself and of other persons who may be affected by your activities at work. You are required to co-operate fully with the Trust and others in connection with arrangements to meet statutory duties and responsibilities under the Act, including undertaking health and safety training. Every department has a copy of the Health and Safety Policy.

15. Managing Diversity

The Trust has adopted the document 'Managing Diversity' which promotes dignity and respect for all our employees and aims to provide a working environment free from unlawful discrimination,

victimisation or harassment.

16. All NHS Staff must adhere to the requirements of the Freedom Of Information Act 2000. In relation to information requested by legal entities, (i.e. anyone, regardless of age, nationality or location) the deliberate altering, defacing, blocking, erasure, destruction or concealing any record held by the public authority, with the intention of preventing disclosure, is a serious breach of the Act. For such an action, an individual member of staff can be personally liable. Such actions will therefore be dealt with under the Trusts disciplinary procedures. Freedom of Information access requests have to be processed by the Trust as "applicant blind".

Staff not involved with Freedom of Information processing cannot, and should not, make enquiries, or attempt to find out, who may have requested what information, or for what reason.

17. Implementation of the Working Time Directive in the NHS.

To enable the Trust to meet the requirements of this Directive please can you delete the following as appropriate:

I do not have other employment

I do have other employment and do/do not work more than 48 hours a week

If the above information changes, I agree to notify my Line Manager.

Please sign and return one copy to acknowledge safe receipt, and to confirm that you have read and understood the Principal Statement.

Signed on behalf of Poole Hospital NHS Trust:.....
Date:
Signature:
Date:

Thomas
2/9/05

[Handwritten Signature]

02-09-05



National Research Ethics Service

Dorset Research Ethics Committee (REC)

Poole Hospital NHS Trust
D Block [Eddie Hawker Wing], Room 20
Longfleet Road
Poole, Dorset
BH15 2JB

18 May 2007

Ms Melinda Williams
Research Assistant
Rheumatology Dept., Poole Hospital NHS Trust
Longfleet Road
Poole BH15 2JB

Tel: 01202 442 737
Fax: 01202 442 954
Email: caroline.hemsley@poole.nhs.uk

Dear Ms Williams

Full title of study: A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents.
REC reference number: 07/Q2201/50

Thank you for your letter of 01 May 2007, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information was considered at the meeting of the Sub-Committee of the REC held on 17 May 2007. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised].

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form. [

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority.
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England.

products (CTX) or substantial amendments to CTXs, please use the EC approved notice of amendment form (Annex 2 to ENTR/CT1) at <http://eudract.emea.eu.int/document.html#guidance>.

To be completed in typescript by the Chief Investigator in language comprehensible to a lay person and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available at
<http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm>.

Details of Chief Investigator:	
<i>Name:</i>	Melinda Williams
<i>Address:</i>	Rheumatology Dept. Poole Hospital NHS Trust Longfleet Road Poole. BH15 2JB
<i>Telephone:</i>	07956 937912
<i>Email:</i>	cfsresearch@hotmail.co.uk
<i>Fax:</i>	

Full title of study:	A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents
Name of main REC:	Dorset
REC reference number:	07/Q2201/50
Date study commenced:	26 th June 2007
Protocol reference (<i>if applicable</i>), current version and date:	
Amendment number and date:	1. 04 July 2007

Type of amendment (indicate all that apply in bold)

(a) *Amendment to information previously given on the NRES Application Form*

Yes **No**

If yes, please refer to relevant sections of the REC application in the "summary of changes" below.

(b) *Amendment to the protocol*

Yes **No**

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) *Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study*

Yes No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

Yes **No**

Summary of changes

Briefly summarise the main changes proposed in this amendment using language comprehensible to a lay person. Explain the purpose of the changes and their significance for the study. In the case of a modified amendment, highlight the modifications that have been made.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

The enclosed document – The DePaul Pediatric Health Questionnaire has only recently been published in the Journal of Chronic Fatigue Syndrome. It is a specific measure for children and adolescents with CFS and as such is a questionnaire that we feel imperative to our study as a precursor to the qualitative interviews. (I have also enclosed a copy of the original journal article that the questionnaire relates to).

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

We cannot foresee any ethical issues arising from the inclusion of this extra part of the research

List of enclosed documents		
<i>Document</i>	<i>Version</i>	<i>Date</i>
DePaul Pediatric Health Questionnaire	8.0	July 2007
Original journal article questionnaire taken from		

Declaration

I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.

I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name:

Date of submission:



National Research Ethics Service

13 July 2007

Ms Melinda Williams
Research Assistant
Rheumatology Assistant
Longfleet Road
Poole
BH15 2JB

Dorset Research Ethics Committee (REC)

Poole Hospital NHS Trust
D Block [Eddie Hawker Wing], Room 20
Longfleet Road
Poole, Dorset
BH15 2JB

Tel: 01202 442 737

Fax: 01202 442 954

Email: caroline.hemsley@poole.nhs.uk

Dear Ms Williams

Study title: A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents.
REC reference: 07/Q2201/50
Amendment number: 1
Amendment date: 04 July 2007

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 12 July 2007.

Ethical opinion

Addition of a Paediatric Health Questionnaire. The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Original research paper: A pediatric Case Definition for Myalgic Encephalomyelitis & Chronic Fatigue Syndrome		
Notice of Substantial Amendment (non-CTIMPs)	1	04 July 2007
Questionnaire: Paediatric Health Questionnaire	8.0	01 July 2007

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

<http://www.doh.gov.uk/nres/ourwork/ourwork.htm>

To be completed in typescript by the Chief Investigator in language comprehensible to a lay person and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available at
<http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm>.

Details of Chief Investigator:	
<i>Name:</i>	Melinda Williams-Wilson
<i>Address:</i>	Dept. of Rheumatology Poole Hospital NHS Trust Longfleet Road Poole BH15 2JB
<i>Telephone:</i>	07956 937912
<i>Email:</i>	cfsresearch@hotmail.co.uk
<i>Fax:</i>	

Full title of study:	A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents
Name of main REC:	Dorset
REC reference number:	07/Q2201/50
Date study commenced:	26 th June 2007
Protocol reference (<i>if applicable</i>), current version and date:	
Amendment number and date:	2. 05-03-2008

Type of amendment (indicate all that apply in bold)

(a) Amendment to information previously given on the NRES Application Form

Yes *No*

If yes, please refer to relevant sections of the REC application in the "summary of changes" below.

(b) Amendment to the protocol

Yes *No*

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

Yes *No*

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

Yes **No**

Summary of changes

Briefly summarise the main changes proposed in this amendment using language comprehensible to a lay person. Explain the purpose of the changes and their significance for the study. In the case of a modified amendment, highlight the modifications that have been made.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

During the interviews with adolescents that have been conducted to date some parents have accompanied their children and have commented during the sessions. It has become clear that separate interviews with the primary care-givers (usually mothers) would enhance the study by adding a new dimension of experiences gained by those closest to the children with CFS. I have therefore decided, and had agreement from my supervisor (Professor Galvin), that a select number of interviews with mothers would be beneficial to the final research report. To this ends the research protocol needs to be amended slightly and the wording on the parent's information leaflets and consent forms need revision.

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

List of enclosed documents		
<i>Document</i>	<i>Version</i>	<i>Date</i>
Revised protocol	5.5	March 2008
Revised participant information leaflet	5.9	March 2008
Revised consent form	5.11	March 2008

Declaration

I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.

I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name:

Date of submission:

19 March 2008

Ms Melinda Williams
Research Assistant
Rheumatology Department
Longfleet Road
Poole
BH15 2JB

Dear Ms Williams

Study title:	A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents.
REC reference:	07/Q2201/50

Amendment number:	2
Amendment date:	05 March 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 13 March 2008.

Ethical opinion

The members of the Committee present decided that they could not give a favourable ethical opinion of the amendment, for the following reasons:

The Sub Committee considered that the recruitment process still has a bias potential in it. A global invitation to mothers to request participation is acceptable, but the selection process needs clarifying and writing fully in an

accompanying letter. It is not acceptable to choose those mothers who have an eagerness to please or promote the CFS cause.

We regret to inform you that the amendment is therefore not approved. The study should continue in accordance with the documentation previously approved by the Committee.

Modifying the amendment

You may modify or adapt the amendment, taking into account the Committee's concerns. Modified amendments should be submitted on the standard Notice of Amendment form. The form should indicate that it is a modification of the above amendment.

A revised Notice of Amendment form must be submitted at least 14 days before you plan to implement the amendment. The Committee will then have 14 days from the date of receiving the notice in which to notify you that the amendment is rejected, otherwise the amendment may be implemented.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Protocol	5.5	01 March 2008
Participant Information Sheet	5.9	01 March 2008
Participant Consent Form: Parent/Guardian	5.11	01 March 2008
Covering Letter		03 March 2008
Notice of Substantial Amendment (non-CTIMPs)	2	05 March 2008

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q2201/50:
correspondence

Please quote this number on all

Yours sincerely

Mrs Rachael Caroline Hemsley
Committee Co-ordinator

E-mail: caroline.hemsley@poole.nhs.uk

Enclosures	List of names and professions of members who were present at the meeting and those who submitted written comments
Copy to:	Mary Burrows, Research Governance, Poole Hospital NHS Trust

Dorset Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 13 March 2008

Name	Profession	Capacity
Dr David Jones	Head Pharmacist & Vice Chair	Expert
Dr Brian Quilty	Consultant Rheumatologist / Vice Chair	Expert
Ms Stephanie Wheeler	Retired Senior Lecturer & Chair	Expert

Also in attendance:

Name	Position (or reason for attending)
Mrs Rachael Caroline Hemsley	Committee Co-ordinator

NOTICE OF SUBSTANTIAL AMENDMENT

For use in the case of all research other than clinical trials of investigational medicinal products (CTIMPs). For substantial amendments to CTIMPs, please use the EU-approved notice of amendment form (Annex 2 to ENTR/CT1) at <http://eudract.emea.eu.int/document.html#guidance>.

To be completed in typescript by the Chief Investigator in language comprehensible to a lay person and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available at <http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm>.

Details of Chief Investigator:	
<i>Name:</i>	Melinda Williams-Wilson
<i>Address:</i>	Rheumatology Dept. Poole Hospital NHS Trust Longfleet Road Poole. BH15 2JB
<i>Telephone:</i>	07956 937912
<i>Email:</i>	cfsresearch@hotmail.co.uk
<i>Fax:</i>	

Full title of study:	A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents
Name of main REC:	Dorset
REC reference number:	07/Q2201/50
Date study commenced:	26 th June 2007
Protocol reference (if applicable), current version and date:	

Amendment number and date:	2. 27-05-2008 (NB Response to previous amendment application)
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Type of amendment (indicate all that apply in bold)

(a) *Amendment to information previously given on the NRES Application Form*

Yes **No**

If yes, please refer to relevant sections of the REC application in the "summary of changes" below.

(b) *Amendment to the protocol*

Yes **No**

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) *Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study*

Yes **No**

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

Yes No

Summary of changes

Briefly summarise the main changes proposed in this amendment using language comprehensible to a lay person. Explain the purpose of the changes and their significance for the study. In the case of a modified amendment, highlight the modifications that have been made.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

We note that clearly there are biases in conducting interviews in a small number of parent/carers or individuals with the given condition in qualitative research. However, this proposal is to look at differences and similarities between the adolescents with chronic fatigue syndromes report of the impact of their illness on their lives and that of their key carers/parents. To perform this analysis it is essential to interview the parents of the adolescents already interviewed for part of this qualitative study so it would not be appropriate to interview parents of those adolescents who hadn't already taken part. It is not, however clear, as you have stated in your letter of 19th March that these parents or carers would have a specific eagerness to please or to promote the CFS cause. These are unselected mothers or carers of adolescents who have already volunteered to take part in qualitative research projects. The very nature and principle of which is to understand the impact of the illness, therefore interviewing their primary care givers is going to provide further another aspect to the impact the illness has on a family. Therefore, we would be very grateful if the committee would reconsider this minor extension to the study.

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

We cannot foresee any ethical issues arising from the inclusion of this extra part of the research

List of enclosed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter for Substantial Amendment 2 Modification	---	27 th May 2008

Notice of Substantial Amendment MODIFIED	2	27 th May 2008
Notification from REC of failed Amendment 2	---	19 th Mar 2008
Protocol	5.5	Mar 2008
Parent PIL	5.9	Mar 2008
Parent Consent Form	5.11	Mar 2008

Declaration

I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.

I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name:

Date of submission:

16 June 2008

Ms Melinda Williams-Wilson
Rheumatology Dept.
Poole Hospital NHS Trust
Longfleet Road
Poole BH15 2JB

Tel: 01202 442 737
Fax: 01202 442 954
Email: caroline.hemsley@poole.nhs.uk

Dear Ms Williams

Study title: A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents.
REC reference: 07/Q2201/50
Amendment number: Modified Amendment 2
Amendment date: 27 May 08

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 12 June 2008.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)		
Covering Letter		27 May 2008

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

The National Research Ethics Service [NRES] represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

An advisory committee to South West Strategic Health Authority

Further guidance is available at
<http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm>.

Details of Chief Investigator:	
<i>Name:</i>	Melinda Williams-Wilson
<i>Address:</i>	Dept. of Rheumatology Poole Hospital NHS Trust Longfleet Road Poole BH15 2JB
<i>Telephone:</i>	07956 937912
<i>Email:</i>	cfsresearch@hotmail.co.uk

Full title of study:	A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents
Name of main REC:	Dorset
REC reference number:	07/Q2201/50
Date study commenced:	26 th June 2007
Protocol reference (if applicable), current version and date:	5.6 15-10-2008
Amendment number and date:	3. 15-10-2008

Type of amendment (indicate all that apply in bold)

(a) Amendment to information previously given on the NRES Application Form

Yes **No**

If yes, please refer to relevant sections of the REC application in the "summary of changes" below.

(b) Amendment to the protocol

Yes **No**

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

Yes **No**

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

Yes **No**

Summary of changes

Briefly summarise the main changes proposed in this amendment using language comprehensible to a lay person. Explain the purpose of the changes and their significance for the study. In the case of a modified amendment, highlight the modifications that have been made.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

I have already obtained ethical approval for a substantial amendment (2) pertaining to interviewing parents of children involved in the study (in June 2008). I now seek a minor adjustment to the protocol, to change the interviewing technique from face-to-face exchanges to email interviews and outline the main reasons for this amendment below.

In this age of technological advancement the World Wide Web (WWW) and Email (Electronic Mail) have provided new methods of data collection. The term 'computer-mediated communication' (CMC) has been coined to label such methods. Email has been used for a diverse range of projects from research into psychological effects of the 9/11 attacks (Nielsen and Levin, 2005). to questions about intimate issues such as sexual health (Ross et al., 2005). It has been found to be a particularly efficient and productive mode of research in those with chronic illness, (Kralik et al., 2000). Studies have been conducted into the effectiveness of email and internet related research methods compared to traditional methods of data collection and have found there to be little difference in efficacy between the two, (Gosling et al., 2004; Ross et al., 2005).

There are a number of advantages of using email interviews (Hunt and McHale, 2007), as follows:

Cost There is no travelling involved for either participant or interviewer, no need for recording equipment and no transcribing costs.

Range of Participants Those who would ordinarily find it troublesome to travel to a face-to-face interview venue (in this case, individuals who do not drive needing to travel from the far side of Dorchester to Poole Hospital to participate), are accessible.

Time for Reflection Both interviewer and interviewee have the opportunity to reflect upon what has been asked or said, and can take time to formulate responses. The email interview is conducted within a single script, despite occurring over a small number of exchanges, and so it allows either party to scroll back to past 'conversation' within the script and reflect upon what has been spoken about previously.

Freedom The impersonal nature of email interviewing can act as a benefit, allowing individuals the freedom and 'distance' to say things that they may have found intimidating or embarrassing to speak about in person.

Working with Numerous Interviews Simultaneously The collection of data can occur more rapidly (especially without the need for waiting for transcriptions), and there is the advantage of interaction between interviews, e.g. if something interesting arises during one interview the researcher can use this information in other interviews that are currently underway.

Interviewer Effects During face-to-face exchanges both participant and interviewer may be affected by visual characteristics or actions of the other person – this problem is eliminated during email interviews.

As with any data collection techniques there are naturally inherent limitations or disadvantages which I will list below (Hunt and McHale, 2007), followed by ways of dealing with said problems.

(1) **Sample Problems** There are problems associated with sampling

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

List of enclosed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Revised protocol	5.6	Oct 2008
Revised parental participant information leaflet	5.10	Oct 2008
Parental consent form	5.12	Oct 2008

Declaration

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name:

Date of submission:



Dorset Research Ethics Committee (REC)

Poole Hospital NHS Trust
D Block [Eddie Hawker Wing], Room 20
Longfleet Road
Poole, Dorset
BH15 2JB

29 October 2008

Ms Melinda Williams-Wilson
110 Portland Road
Bournemouth BH9 1NF

Tel: 01202 442 737
Fax: 01202 442 954

Dear Ms Williams-Wilson

Study title: A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents.
REC reference: 07/Q2201/50
Amendment number: 3
Amendment date: 14 October 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 16 October 2008.

Ethical opinion

The sub-committee has reviewed your amendment and has given an unfavourable opinion for the reasons below. The applicant can submit a modified amendment taking account of the REC's concerns.

The Committee have concerns regarding the use of the e-mail interview:

1. Prolonged use of computers / VDU & keyboards are potent causes of neck, arm and back pain, eye strain and fatigue.
2. It is well known that e-mail can cause a lot of psychological distress as sometimes replies are sent off too hastily.
3. It is not a secure method of communication – unless *encryption* is used at *both* ends.
4. Unlike face to face contact there is no safeguard for dealing with any severe distress felt by the participant during or after the interview.
5. There is real potential for 'misidentity'.
6. There is potential for major disclosure of serious events in the participant's history. This would be very difficult to deal with by e-mail.

The Committee have reviewed the article by Hunt and McHale (2007) cited by the researcher in support of this amendment but tend towards the view of the authors that:

"The e-mail interview method is in a state of infancy..... There is clearly a need for research to establish the reliability and validity of the method. There are serious limitations to the method that any practitioner must recognize, particularly concerning the identity of the participant....."

The Committee considered that the referenced article concerning 'pen pals' correspondence was not a scientific support for this approach.

An advisory committee to South West Strategic Health Authority

NOTICE OF SUBSTANTIAL AMENDMENT

For use in the case of all research other than clinical trials of investigational medicinal products (CTIMPs). For substantial amendments to CTIMPs, please use the EU-approved notice of amendment form (Annex 2 to ENTR/CT1) at <http://eudract.emea.eu.int/document.html#guidance>.

To be completed in typescript by the Chief Investigator in language comprehensible to a lay person and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available at <http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm>.

Details of Chief Investigator:	
<i>Name:</i>	Melinda Williams-Wilson
<i>Address:</i>	Rheumatology Dept. Poole Hospital NHS Trust Longfleet Road Poole. BH15 2JB
<i>Telephone:</i>	07956 937912
<i>Email:</i>	cfsresearch@hotmail.co.uk
<i>Fax:</i>	

Full title of study:	A Detailed Assessment and Characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents
Name of main REC:	Dorset
REC reference number:	07/Q2201/50
Date study commenced:	June 2007

Protocol reference (if applicable), current version and date:	5.6 - Oct 2008
Amendment number and date:	3b Jan 2009

Type of amendment (indicate all that apply in bold)

(a) *Amendment to information previously given on the NRES Application Form*

Yes **No**

If yes, please refer to relevant sections of the REC application in the "summary of changes" below.

(b) *Amendment to the protocol*

Yes **No**

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) *Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study*

Yes No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

Yes No

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

List of enclosed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copy of Letter from REC re Sub-Amend 3		29-10-2008
Letter of recommendation from School of Health & Social Care		Jan 2009
Research Governance Review Group Checklist for Reviewers		Dec 2008
Article by Prof Parker re email interviews		2008
Revised Project Protocol	5.6	Oct 2008
Revised PIL	5.11	Jan 2009
Revised Consent Form	5.13	Jan 2009

Declaration

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name:

Date of submission:

EP/EC/ethics/MW/Dec 08
16th December 2008

Melinda Williams-Wilson
110 Portland Rd
Bournemouth
Dorset
BH9 1NF

Dear Sirs,

**Re: Melinda Williams's ethical consideration from SHSC
School Postgraduate Committee**

Ms Williams-Wilson's request for an amendment to the data collection methods for her PhD, further to a proposal that has already successfully passed through LREC, has been peer reviewed by Bournemouth University, School of Health and Social Care Postgraduate Committee.

The Committee supported the proposed changes and the reviewer, Professor Jonathan Parker, having published in the area of email data collection and ethics, will offer her assistance and advice regarding the proposed changes and in carrying out the data collection.

The School has expertise in this new method of data collection and Melinda will be closely supervised in this regard.

Yours Sincerely



Dr Eloise Carr

Chair of School Postgraduate Committee



03 February 2009

Ms Melinda Williams-Wilson
110 Portland Road
Bournemouth
Dorset BH9 1NF

Dorset Research Ethics Committee (REC)

Room 20, D Block [Hawker Wing]
Poole Hospital NHS Trust
Longfleet Road
Poole
Dorset
BH15 2JB

Telephone: 01202 442737
Facsimile: 01202 442954

Dear Ms Williams-Wilson

Study title: A Detailed Assessment and characterisation of Chronic Fatigue Syndrome (CFS) in Adolescents
REC reference: 07/Q2201/50
Amendment number: 3 (modified)
Amendment date: January 09

Thank you for submitting the above amendment, which was received on 20 January 2009. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter 29 October 08 refers).

The modified amendment has been considered on behalf of the Committee by the Chair.

Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Protocol	5.6	01 October 2008
Participant Information Sheet	5.11	01 October 2008
Participant Consent Form	5.13	01 October 2008
Notice of Substantial Amendment (non-CTIMPs)	3	01 January 2009
Letter of recommendation from School of Health and Social Care		01 January 2009
Research Governance Review Group Checklist for Reviewers		01 December 2008
Article re. email interviews		2008

Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

An advisory committee to South West Strategic Health Authority

Appendix C

Sample Transcript of Interview with Adolescent

‘Amy’ Transcript

MWW – How long have you been poorly?

AMY – I think from about July 2006

MWW – And during that time due you think that you have improved or sort of reached a plateau?

AMY – At first it got worse and then when I started getting treatment and stuff, it got better and now it’s got a lot better than when I first got ill

MWW – Was there a trigger point for it?

AMY – Yeah, I had glandular fever really bad

MWW – Right, and how long did you have to wait before you got diagnosed with ME?

AMY – I think it was quite a while – 8 months

MWW – I can’t remember how old you are?

AMY – 17

MWW – 17, and were you in school or in college?

AMY – School. I tried to get in when I could but I couldn’t get in for like a whole week - I just went when I could get in really

MWW – Was that at the end of school, like in the last year of school?

MUM – She took ill in the June so it was just before the end of term so really it didn’t affect her until she went back to school in the September and so then she was quite bad and only visited in school a couple of times a week

MWW – So did you just think it was glandular fever that was on going?

MUM – Umm yes

AMY – That’s what my doctor said it was, he said it was just ‘cos my immune system was down. That’s what we thought it was but then it didn’t seem to get any better

MUM - It gradually got worse ‘cos you’ve got glandular fever you think you’ll go through a period where the virus wears off but no, this was going the other way and she was progressively getting worse and worse and worse. And of course we were going back to the GP and saying well this isn’t normal you know she cannot get out

of bed, she's got no energy, couldn't do anything and it was actually the school that sort of said well this isn't quite right, she's not getting into school and it was her English teacher that said – do you think it's ME? – and said no 'cos we'd never heard of that, you know. And that's when we sort of went back to the doctor and suggested it

AMY – 'Cos we looked it up on the internet as well and I had quite a few of the symptoms, and that's when we went to the doctor

MUM – ...or went *back* to the doctor 'cos we had been continually seeing the GP quite a few times in between and it was just – oh, be patient. But you know when your child's ill and you know when it's not right and the doctors saying to be patient it's like... You can actually see her getting weaker and weaker and weaker and it's really difficult

MWW – And how was the GP when you suggested that?

MUM – He was actually pretty ok, 'cos we went for a war you know prepared cos we didn't know anything. And we found about the clinic at Wareham and he referred us straight away and so yeah he was pretty good, he did do the referral and it was about 2 months before we actually got the appointment

MWW – And how did you get on?

AMY – Yeah ok, it was easier 'cos I finally realized that it wasn't just something that I didn't know was wrong with me, I knew that the OT was someone that knew I was ill and not just like you know horrible and she would like say – this is how you feel – and so it made it easier 'cos I wasn't on my own, she knew about it

MUM – And actually someone saying 'yes this is an illness, there is something actually physically wrong with you' rather than thinking that, not that she was going mad but, because she couldn't understand why she was feeling like that, to have somebody give you a diagnosis... then we could deal with it because up until then we didn't know what we were dealing with

MWW – So the not knowing was harder then...

AMY - Yeah 'cos as soon as we found out what it was, it was ok right now; this is what we can do to make you better. But before 'cos we didn't know what it was we didn't know what we did if it made it worse or better, so we just couldn't do anything

MWW – So before you had the glandular fever were you generally quite healthy?

AMY – Yeah didn't really seem to get ill, just like odd colds and coughs and stuff but never...

MUM – She'd never been ill

MWW – You've got asthma

AMY – Yeah, I've got asthma but it's really mild I had it worse when I was little but have sort of grown out of it when I got older

MWW – So generally healthy. So it was a bit of a shock then?

AMY – Yeah 'cos I was like always doing things like after school every day and like in school all the time, it was like really weird suddenly just not being able to do anything

MWW – Quite frustrating. So you touched on school there, did you enjoy your school?

AMY – Yeah, I used to love school, in every day, I always used to try my hardest at school, I used to get A's and A*'s all the time

MUM – It was at our first meeting with the OT... because she was an A grade student and sometimes when she was poorly she would really sort of force herself into school knowing that it was going to make her feel even worse but school was everything to Amy because she was very intelligent and very bright and knew exactly what she wanted to do and the first interview we had at the Clinic she actually said – 'well what's more important - your health or school?' and Amy answered – 'school'. So we had to kind of change that slightly because it was her GCSE year so it was exceedingly important. She had exams, it was important to Amy that she was at school and all her coursework was completed and that was just adding more pressure and more pressure and more pressure and that's when we sort of hit a stone wall 'cos she was trying to do all those things and it was making her worse. We had to say -well you can't do all this, something has got to give, you've got to ease back – and for Amy that was one of the hardest decisions I think she has ever tried to make

MUM – Now we know a bit more about it, 'cos if you'd said to us ME before we would have probably said well, 'hypochondriac', 'cos it wouldn't have fitted in with the way that we were but now it fits her totally because yes, she was a high achiever. She was dancing like ballet and everything, like 5 nights a week and yeah, but that was like her relaxation. That was her doing something really physical and active wouldn't be relaxing, but that was Amy's hobby, she had her academic side and her

dance was her relief and then all of a sudden she couldn't do either and when she was 15 at the time it was exceedingly difficult at the time

MWW – Did you find that a bit scary?

AMY – Yeah 'cos I just wondered what the hell was wrong with me, like since I've got ill, well all of my life I've been busy and not ever seem to get tired and I always seemed to not get stressed about any school work, I always used to just get on with it and to suddenly be like... it was a bit of a shock

MWW – So do you do any schoolwork at all now?

AMY – Yeah, I do my exams in a few weeks. My A levels

MWW – So you got through your GCSE's, how many did you get?

AMY – 9

MWW – Oh my word!!

MUM – Yeah but she had to cut back 'cos she was doing like ??? so she had to cut back on some of the subjects 'cos she just couldn't cope and that was because she was doing GCSE Dance and that was one of the first ones 'cos she couldn't do...we agreed to sort of cut down from the amount of work that she was actually doing but we're so, so proud of her

MWW – Yeah, amazing, you should be really proud as well, fantastic. So how did you do that, did you have a tutor from home or did you go to school?

AMY – No, school helped a lot 'cos my Head of Year was like 'well we'll say to you that you can come into school like break time every day so that you don't have to worry about getting up. You can just say that you'll come in at that time', and my teachers helped by like giving me work to do at home when I did feel better like in the evening or something. They were like really helpful and if I just wanted to sit down and talk about things like catching up at break time or lunchtime they would, and they'd like give extra worksheets and stuff so...

MWW – So that would help you because I'm not sure all schools would be so accommodating...you're lucky there I think...

AMY – I think that possibly it might have been that...well my teachers knew it wasn't just me sort of faking it

MWW – A change of character then

MUM – Yeah they knew that she wanted to do it but it was her health that was preventing her from doing it, so the school was very supportive. Even now like now she's doing her A levels, she started off doing 4 and has had to drop down to 2 'cos

of obviously the stress of everything. It's all compounded 'cos you think it's going away, and then the minute you've got a little bit of stress, like with the A levels, it sort of comes back with a vengeance, so we agreed that rather than Amy trying to push herself too much and making herself really quite poorly, we have agreed a sort of compromise ***laugh*** something that she can cope with knowing that if she does improve vastly, that she can always pick up the subjects again

MWW – So those 2 that you are doing, do you do any classroom hours for those?

AMY – Yeah, I get into school everyday, at about 10 o'clock

MWW – So how have your friends been through that?

AMY – Umm, at first they were a bit sort of... 'cos at first I would have to suddenly say – no, I can't go out – they didn't really invite me to do anything but now like, they can see that I'm going into school more, they invite me to do stuff more, and then when they sort of understood it they would invite me to do stuff even though they knew I would like say no. Then sometimes they would come round my house and then go out or just sit and watch a film and get a takeaway or something.

MWW – So it was more like you had to educate them about it and then they kind of understood...that's good. Have you had a core set of friends that you've had all the way through?

AMY – Yeah, pretty much, a few have changed and some have left and gone and got jobs and stuff, my best friends have stayed

MWW – So they have been quite supportive?

AMY – Yeah

MWW – Got a boyfriend?

AMY – Yeh, sort of, touch and go at the moment but sort of yeah

MWW – Has he known you from before you were ill?

AMY – No, only since my health has been bad

MWW – And is he quite understanding of that, 'cos that could be quite a strain if you can't go out

AMY – Umm, not really to that extent, just with my time it's just because of me being insecure through it and so he gets annoyed with that sometimes

MWW – Is he your age?

AMY – No he's 20 ***laugh***

MWW – So you said you get a bit insecure, so is that when you get a bit tired you get a bit blue?

AMY – Umm, yes, ‘cos he goes out weekends and stuff. I dunno really why... I never used to be. When I speak to the psychologist that I go and see, she says that because now with my ME I’m just like, one track thing, so like if something bad happens, it’s like catastrophic rather than, oh well its just like little, just don’t worry about it, or I’ll just be worrying about it all the time

MWW – Does that make sense to you, that explanation?

AMY – Yeah

MWW – So do you have certain ways that you can think round that or try and rationalize it?

AMY – Yeah, I just try to distract myself from thinking and go and do something else like go and listen to music or watch TV or something so I don’t think about things all the time

MWW – Have you got any siblings?

AMY – Yeah I’ve got one brother and an older sister

MWW - Are they at home?

AMY – My sister lives away, she’s married but my brother lives at home

MWW – And has that relationship been difficult or has he been quite understanding? He’s obviously seen you change

AMY – Dunno we always used to fight before anyway ***laugh***

MUM - Yes it has changed dramatically. They are still close but because her brother again is very active, very sporty, umm goes out a lot, Amy does get very, very...

AMY – Jealous

MUM – Jealous. Because he can continue with all his activities and she can’t and that has caused a little bit of friction. Every now and again, nothing major but, yeah, and it’s sometimes very difficult and she’ll take her frustration out on her brother, until she sees the error of her ways and then they’ll apologize and they’ll get on and live. But yes it has caused a little bit of tension

MWW – Bound to really I suppose

MUM – Yes but because he’s younger, and he - especially initially - he didn’t understand, and he couldn’t understand what was going on, because initially we couldn’t understand

MWW – So how much younger is he than you?

AMY – He’s 14

MUM – He like now just walks away. It’s getting better

AMY – Yes ‘cos at first he’d say – ‘you’re just a bunker, you’re just bunking off school all the time’ – and just like to try and wind me up until he realized like when I started seeing people, that I wasn’t like making it up and then he was a bit more understanding. And sometimes now he will just come down and come up to me and he’ll just give me a hug and say – ‘are you ok?’

MWW – Do you think the relationship with both of you has changed; obviously you have had to rely on your mum more than you would have done. Do you think that has caused friction at time or...?

AMY – Umm, We’ve got a lot closer than I think we would’ve been ‘cos I take out.. when I feel bad... I take everything out on mum ‘cos she’s the closest one to me but I think we’ve got a lot closer yeah

MUM – We still have friction but...

AMY – It lasts for like 5 minutes and then we both apologize to each other

MUM – I feel that’s it’s like a normal mother daughter thing ‘cos I’ll say that well I don’t agree with you doing that or whatever. But yeah, from a mum’s point of view, its very, very difficult watching her go through it knowing that there is absolutely nothing that I can do. Umm and then when I’ve done as much, or done my best or whatever, and then she screams at me or whatever, I keep thinking – oh what if I... - I can’t physically do any more. But yes we are, it’s, because Amy knows herself so well now, for it to happen when she was like 15...

AMY – I don’t regret getting ill. In a way I’m sort of glad ‘cos I’ve learned so much about myself, and I’m now closer to mum and in a way, I know that I will get better suddenly so that I know I can take it as like an experience and can be like ok, before I did push myself a bit too much. And so I’ve learned a lot from it

MUM – Not to be recommended I wouldn’t recommend it! **laugh** Yes, but because it effects the whole family, it effects the whole household, we are normally all quite positive people, so yeah, rather than letting it pull us right down, we have managed, how I don’t know, to sort of say – yeah it’s not something I’d recommend that people go out and try, but It’s happening, so like deal with it and deal with it the best way we can. Sometimes we don’t get it right and sometimes she will have days where she’ll feel weak, where she is really bad but we just sort of do all this each day as it comes along as best we can. We just manage to through it like some days you just sort of think – ‘I cannot cope with this anymore’ – ‘cos initially when she was like, I’m tired, I just want to sleep. I said – ‘no, get up’ – and we would have this like

battle to try and force her up. Not realizing that she couldn't, so we'd have like this battle going on and then she'd maybe go out with a friend or the friends would come round and I would be well if you can stay up 'til 10 o'clock, you can go into school tomorrow. If you've got ME and do this then you can go to school. So we had the sort of battle but now we've sort of evened things out and we know, it sounds awful, but when she's faking it, it sounds awful, I know she's not faking it because I know her really well. But it's like sometimes umm, she says she can't get into school today but it's not like that at all and I know when I can sort of say, well with a little bit of extra effort you can, and she does so...

MWW – Do you find that sometimes your mum can read you better than you can read yourself?

AMY – Yeah probably ***laugh*** But I think we both now, as time has gone on I understood what things I can and can't do and can sort of predict when I'm gonna feel bad. So mum sort of says – 'well I don't think you should do that' – 'cos she knows what's gonna happen, but because I want to do it I'm like, getting in a bit of an argument, but then afterwards I realize that oh I should have listened to mum ***laugh***

MWW – So are you close to your dad?

AMY – Umm yeah, but not as close with my dad about this as I am with my mum, still close with my dad but I don't think he understands it as much as mum does

MWW – Is that because mum's been there more; at home more?

AMY – I think so, and because mum's always come with me to see everyone and dad just goes and plays football. Not that he doesn't like...he's not disinterested, it's just that...

MUM – I think it's like a male thing, it's like he is there for her, he's brought us here today and, so that it is a male thing, that I think it's just something his daughter shouldn't talk about. To be fair, because a lot of the time, 'cos like being so active and he's taking our son out so I can be with Amy, so there have been like times where we have arranged to do something together as a family and Amy has been poorly, so I stayed with Amy and my husband and son have just gone off together so... Because Amy's actually getting better now, we can go back to normal, and there's the one thing again that has taught us that family life is precious and when we do have time to do things together, like the 4 of us, then we will sort of try and make

time to go bowling or something. The 4 of us together, something that we can all do rather than my husband and son going off and Amy and I go off so...it's not all bad

MWW – You mentioned the psychologist, is that something you've been linked in with through the Clinic?

AMY – Yeah, She was at the conference, I haven't had her from the beginning, but when I told her, what are they called, boom and bust, I just got really down and really depressed about stuff and the OT like said – 'Would you like to see a psychologist to try and understand why you feel down all the time?' – and since I've been with her, I've been able to think more positively about me being ill and stuff and been able to sort of work through it a bit better, and understood why I do stuff and the feelings that I have a lot better rather than just thinking the worst and being paranoid all the time ***laugh***

MWW – So do you see her on a regular basis or just when you feel that you need a chat?

AMY – Usually about once a month, I think I've seen her twice or three times. Once she came around our house when I had a really bad day and all I could do was like getting out of bed, getting up in my pyjamas. So she came round and after she came round I felt a lot better and stuff. So she's actually been really good. I think that's helped me think better

MUM – I think 'cos you know what the illness is and you know what to do and how to cope with it, but I think it's the actual feelings and what's going on in her head basically and although we're really close, it's like sometimes because sometimes I don't know what I'm saying to Amy if it's right or if it's wrong, or am I making things worse, or making things better and I think that seeing the Psychologist, having someone that she can actually talk to about her feelings umm... has been really good, and that has been the turning point is when she started seeing her that she could understand why she was feeling like that, because I don't understand why she was feeling like that and especially when she seemed to take all her frustrations out on me, you know, I've got really wide shoulders and I'll take it, and then go and cry. But I wouldn't like Amy to see that. But she knows now that sometimes I get as frustrated as she does because I can't do anything to help, you know, I just don't know how to do it and I think that speaking to the Psychologist and knowing what she is going through and what she is feeling is perfectly normal, you know and it's understandable that she feels like that

AMY – ‘Cos the first meeting I had, she gave me this sheet of paper and she was like – ‘do you feel...?’, like is this how you feel – and it was just like, exactly how I felt all the time so then it was like – ‘Oh phew I’m not just like strange!’

MWW – So it sort of legitimized it

AMY – Yeah it was like a thing quite black and white so if something is good then its good but if something is bad then it’s really, really bad and I just think the whole world’s gonna end

MWW – Do you think that’s ‘cos your world has got quite small what you can and can’t do has sort of shrunk hasn’t it?

MUM – Yes it was like, in Amy’s words, like before everything she loved and held dear like her school work, her dancing, her social, ‘cos she was like very, very popular, her social life was slowly being chipped away and it started off you know...

AMY – And it left everything that I didn’t really like as much

MUM – So everything that she loved had gone and it had just left, well it had left nothing. She had no social life as such; she had no outlet because she couldn’t dance. The main subjects that she wanted to do at school, being the dance GCSE, she couldn’t do. Everything was just being chipped away and she didn’t seem to be getting anything back and all she said was – ‘I had to give up so so much’ – and that was really, really difficult, very, very difficult. In fact it was quite devastating for Amy. The first time when we had to, when we agreed with the school to reduce the amount of GCSE’s she was doing

AMY – ‘Cos it was like, if you drop these 2 subjects you will start to feel better and then it didn’t get any better so I had to drop something else and it just carried on like that until like everything had gone and there was nothing else left to get rid of. So I think like that was my worst bit

MUM – Yes, ‘cos she felt she had absolutely nothing

AMY – And then like, it always seemed like something good was going and I was never getting anything good back I was only getting bad stuff back. I couldn’t go and do subjects that I really wanted to do it was like subjects that I said yeah I’d do so that I could just go to school

MWW – And that must have been hard for you as well

MUM – Exceedingly ‘cos it was out of our control because I can’t sit in the classroom with her, but yeah, all the way through it she just kept saying – ‘I just

want Amy back, I want the old Amy back'... ***long sigh*** It's coming gradually, but it's not the old Amy, it's a new Amy

AMY – Yeah, that's what the psychologist is trying to make me think like it's not all gone I can pick it up again in the future and I think it will be like new Amy I will have more knowledge about things and it will help me in the future

MWW – Yes you've grown up a lot from 15 there's a big difference and I guess your aspirations and things have grown just from growing up, so I think you're very healthy ***laugh*** psychologically. Your attitude is fantastic

MUM – Rather than it pulled her right down, it could quite easily have pulled her right down, I wouldn't have allowed that to happen

AMY – And also seeing the psychologist and stuff, she says, well if you feel down about it all the time then everything will seem just down and your ME will probably get worse 'cos you just don't enjoy your life, so I just try and think positive about things and you'll be like 'Oh I'm having a good day and think I'll go to school'

MUM – Yeah, enjoying the things that she could do, although it was very little, if it was sitting curled up on the sofa drinking hot chocolate watching a really weak movie, it was good, she got some enjoyment, it was like taking pleasure in like little things. Not necessarily physical or material

AMY – And like if my friends would come round it was like well everything hasn't gone, just on hold for a bit and I can still do the things I want but just not as much

MUM – Which meant that when she did do it, it became more of a pleasure because...

AMY – I didn't just take it for granted like I did before

MWW – Your half way through you're A levels now

AMY – Yeah I've still got a year left, I'm doing Maths and Psychology

MWW – And what were you hoping to do, something with those subjects in particular?

AMY – Sort of, I want to do maybe Forensic Science

MUM – Again right from when she started senior school, she knew that she wanted to do Forensic Science she was so focused. She knew what she had to do, she knew what A levels she should do, what GCSE's, she knew exactly and we'd been looking at universities and courses since the age of 15. Of course like now it's like having to rethink

AMY – I think that because of me getting ill, it's made me think of new things that I want to do 'cos I do think of being like a family liaison officer or a Forensic psychologist 'cos it was like interesting how the mind works and stuff. Cos interesting 'cos obviously I've started seeing a psychologist and she has helped me through my illness and I think well maybe I could do that for someone else 'cos I've got like the knowledge, 'cos I've been through it. And it was still something like I wanted to do, like forensics. If I couldn't do Chemistry in the end I could do that

MWW – So when you finish these two A levels - will you need to take more?

AMY – Yeah, I'll have to do chemistry and 1 other, I'm not sure what I'll do

MUM – At the start of her A levels she was doing maths, further maths, chemistry and psychology, so the further maths and the chemistry she's had to drop 'cos it was just too much

AMY – They're heavy subjects anyway and they're too hard

MUM – That's like her level of intelligence it is far, far superior than mine but academically she was so bright

AMY – It wasn't that I found the subjects hard, it was just like there was too much pressure from the subjects, like too much work that I had to put in that I had to drop it

MUM – And she didn't have enough energy

AMY – To like go to school and then it would get me stressed because I would get behind so it was just easier to say 'Ok I'll leave it for now and just concentrate on the subjects I can do'

MUM – But again that was with support with the school 'cos it's when we hit a crisis point 'cos we kept saying let's just get to half term and after half term we'll be fine and can go back and start afresh. Then it was Christmas, then it was Easter, then it was summer and after she done her GCSE's, amazingly, we had the whole of the summer when it was really quite good, she was really quite well and then we were thinking go back in September, A levels, a new year, new challenge. Thinking that she would be able to cope with it

AMY – I made mistakes gave myself too much to do

MUM – Yeah, and then a couple of months into the actual course it really hit crisis point because she had been trying so hard and trying to be relatively normal by going into school every day. She just pushed herself too hard and it was crisis point, like

going straight back to the bottom of the hill. Again having to make that decision that something has to go was really tough. Because we thought we were on our way up then all of a sudden back at the bottom again. I think that now, another couple of months down the line, you can see that by making tough decision has really helped her. It sounds awful but sometimes you have to look at the knocks that you give to push you forward, again sounding awful, but making a huge decision which it was for Amy, we couldn't make the decision for her, again with the OT, we had to say 'If you continue like this then you're not going to improve, but we're not going to make that decision for you. It's got to come from you'. But making it has really helped her and she can look back and say – 'Yeah I have made the right decision'. Again you look at it positively

AMY – I was down for a few days 'cos I made the decision that I really didn't want to do that but...if you think about it I would have just got worse and worse

MUM – And she's really grown up and matured in such a short space of time, a real learning curve. Rather than pulling her really down, she's really matured, an amazing human being

MWW – You're fortunate to have such a great support network and it's obviously really helped but its your grit and determination that keeps you holding on and to be sensible at the same time. These things are horrible decisions to have to take especially when you've been doing more than average and then to have to do less than the average person

MUM – Because she kept thinking initially that she'd failed and we said you haven't failed, what you have achieved is absolutely amazing, but what she kept saying was she had failed herself 'cos she new what she was capable of. If there's the 1 little criticism I have of schools is saying that she was predicted 14 A*s for her GCSE's

AMY – Yeah, 'cos we get reviews at school and you get your potential grades and your predicted and all my potentials were A' and A*s then all my predicted were B's and C's and I think...

MUM – Initially they were all A's and A*s

AMY – Yeah, but when I was missing school I was like a failure 'cos I'm not getting the grades that I could get so ...

MUM – Yes but that's the only criticism we had

AMY – 'Cos the school said you've got to try your best and if you don't then...they say, they always give like 84% of people got A's and A*s

MWW – It's a lot to live up to

AMY – And like I used to say I'm a failure and I'm letting everyone down, letting the teachers down, but once the teachers understood, they basically just said that schools have to do that and ...

MWW – I guess they have to do that for the people that aren't like you 'cos they need to give a kick in the right direction 'cos your not reaching your full potential 'cos your not trying. Whereas you're trying more than average so... At the end of next year your friends will be going off to Uni so...

AMY – Not many of my friends are going but I want to so...

MWW – So would you need to do more A levels before you apply?

AMY – Yeah I would, but I was thinking... 'cos if I didn't, we've been looking up good things and bad things that can happen 'cos we don't know. But if I do feel better at the end of this year I can re-do my whole subject in a year next year, and then I'll be able to go. But if I can't I can stay on another year in 6th form, they'll let me do it or I can go to Bournemouth College and do something and then go off to Uni

MWW – So you've got contingency plans

MUM – Yes they keep changing

AMY – 'Cos it makes me feel better 'cos I know that if something bad happens then I've got a back-up plan there so I'm not like, 'Oh now what do I do?'

MWW – Do you think that - we talked about your self-confidence - do you think it has helped seeing a psychologist, 'cos you were very down at one point?

AMY – Yeah a lot, 'cos I used to be down all the time but she has helped me see things more positively and I think she has been quite an important part of making me feel better in myself. Not health-wise but mentally. Yeah, she's been a lot of help

MUM – I agree. When she started seeing her, that was a turning point 'cos when she was down it was horrendous, it was like really down. It was very difficult to try and lift her spirits. I was...

AMY – She taught me how to - if I feel down - pick myself back up and make me feel better, so I'm not down all the time, I only have like 1 down whole day whereas before the majority of my days were like down days and now the majority are good days

MUM - I think understanding the emotional side as well as the physical side of it has really helped

AMY – And it's also helped me get the physical side of it better as well

MUM – Yeah, 'cos it was a 2-way thing

AMY – If I was down, my ME was down, and if I felt good then it would be better, so now I feel better a lot of the time my ME is better

MWW – Problem is when we get ill with anything like the flu; we forget that we're a holistic being. There's different parts, there's the physical part and the emotional part and the mental part and sometimes we forget that and we're so hard concentrating on one thing and kind of segregated ourselves off. Especially when you've got an illness that no-one really understands 100%, you're left with all this confusion. So you're focusing on the physical, 'Well I must try and get better and pace myself' and you forget that we're also made up of the psychological, mental, emotional and everything else and if you can start working all those things in together, each one of those things buffers off the next and you become better

MUM – 'Cos it is actually a very emotional illness. Some days it would be absolute hell she would have no physical energy; she wouldn't be able to get out of bed. We'd just sit there and hug and... We'd both be in tears 'cos it was just so frustrating 'cos we didn't understand what was going on. There didn't seem to be like no penicillin out there that was going to make her feel better. It was emotionally draining some days. We speak about our emotions together, exactly how she was feeling...

AMY – Mum say the exact same thing as the Psychologist does but I probably paid more attention, I don't mean that horribly ***laugh***

MWW – I think that's maybe 'cos she's the professional so she should know what she's talking about??

AMY – Yeah and mum is professional at so many different things

MUM – But I think just having it confirmed and somebody else saying, 'cos as I said I didn't know if what I was saying was making things better or worse or whatever, so having her see the Psychologist was taking the pressure off me as well, which has again improved our relationship 'cos things aren't as tense sometimes so ... all round I think that was a real winner

MWW – Have you taken any medication throughout, either prescribed or complimentary?

AMY – No, someone advised me to take Aloe Vera gel but it tastes disgusting so I gave up and Bee pollen

MWW – A natural remedy

MUM – But again, no drugs whatsoever

MWW – And have you adapted your diet or...

AMY – Not really

MUM - We eat well anyway, we eat a lot of pasta and Amy eats a lot of fish

AMY – I haven't really changed anything, I eat a bit more than I used to

MWW – There's no evidence to say that diet really works though a lot of people do try 'cos they think they should. But if you're eating a sensible, healthy diet that's good enough

AMY – Yeah, sometimes I felt better if eat a piece of chocolate

MWW – Apparently if you eat chocolate with a very high cocoa content - you can get 60-70% - it can give you a little boost, I don't know how scientifically proven that has been but...!

AMY - I've looked at their website but I'm not actually sure!

MWW – So when you first started looking right back at the beginning online, did you find that helpful to look at AYME?

AMY – Yeah, I think that was the first website we found

MUM – Yeah it was

AMY – 'Cos it was really helpful 'cos it basically said there was lots of people out there with it

MUM – And we got all the literature, we've had leaflets and everything...

AMY – Mum phoned them up and spoke to them on the phone as well... it just made me feel that I wasn't the only one

MUM – And I think knowing that there was actually something recognized and putting a name to it and having a diagnosis really helped 'cos up until then everything had just been sort of turned upside down and we were going back to see the GP and he was saying – 'Oh well there's nothing I can give you' – 'cos all the time she was having physical symptoms as well, I mean horrendous sore throats, and he was saying there was nothing I can give you. You would go in thinking 'There has got to be a miracle cure, there has got to be something else out there that will make her feel better'

AMY – I finally feel there's a medicine that makes me feel... the glandular fever went away but everything else was left

MUM – Having the actual diagnosis was like 'Yes we can deal with this, now we know what we're dealing with we can face it head on and we can deal with that'

AMY – I think it was the not knowing that was the worse

MWW – So when you were really poorly, what was your worse physical symptoms?

AMY – Umm the huge mouth ulcers ‘cos I couldn’t eat or anything, and had to drink Complian through a straw and it was horrible

MUM – Yeah the initial glandular fever she had was so bad she couldn’t swallow, she couldn’t swallow her saliva, she was lying in bed unable to move ‘cos she was just so poorly and it took the doctor a little while to even test her for Glandular fever. But she couldn’t swallow and relied on things like Complian, milkshake, chocolate mousse to just try and get her to swallow something and then she started to get sores on her face where her saliva was just dribbling out where she just couldn’t swallow it. Obviously very, very lethargic, just couldn’t get out of bed and that just... eventually the symptoms subsided, the sore throat sort of... then fatigue kicked in and left her like this. She looked like, today she looks lovely, she always looks lovely, but to look at her she looked so ill like black bags under her eyes, she really just looked so ill, and even the doctor was saying you don’t look well but there was nothing, you go in hoping that maybe there’s an antibiotic that will clear it up and feel deflated ‘cos you’ve come away with nothing, exactly the same way as she went into the GP and it wasn’t till like further down the line that we knew what it was and we could deal with it then

MWW – So now you feel like you’re starting to improve?

AMY – Yeah, ‘cos just understanding the illness has made me understand what I can do to make me feel better. So not trying to battle it all the time but just trying to work with it and its got better working with it than trying to fight it

MWW – So do you have a sleep during the day, do you have a routine?

AMY – Quite a few afternoons I might fall asleep about 3 o’clock but it makes me feel better ***laugh***

MUM – Going into school at 10 o’clock rather than going first thing ‘cos it takes her a long time to get herself motivated in the morning, I don’t mean just motivated but to get the adrenalin going. Like today we were going to go into Poole to go shopping but this morning she just didn’t have the energy, so we came straight here. She didn’t get out of bed till 10.15. But I know now that when I go into her in the morning and say its time to get up, the response I get is if she’s having a good day or bad day. Initially I would try and force her, you got to get up now, and try and force it but now I know that if she needs to sleep, if we give her that extra half hour or hour and

let her come to gradually herself, it is far better. She has a better day than trying to force her to get up when she's not quite ready for it

MWW – Do you have problems sleeping?

AMY – Not really

MUM – Not now, initially she did

AMY – I could sometimes stay up till about 2 o'clock in the morning and wonder like why I'm staying up so late when I want to sleep so much in the day, but now I can go to sleep at about 11 and wake up at 9 o'clock in the morning, so much more normal than before.

MUM – Yeah, but she did have problems before of not being able to sleep initially, where she would be really tired, exhausted but couldn't actually fall asleep because her mind was racing, when we didn't know what was going on...it would keep her awake

MWW – Your body can be absolutely dog-tired, but the brain still wants to be up. So you've been knocked back slightly but you seem quite determined to know where you want to go, like you've got this contingency plan that if this doesn't work out, then we can go this route and you seem to be quite positive about it

AMY – Yeah, I think being able to realize that you've got to look to the future and not back helped me to feel a lot better

MWW – Anything else you want to talk to me about?

AMY – I dunno, probably saying that just having the support and everything has been like helpful

MWW – Do you mean family, the service or both?

AMY – Everything, school, the OT, having a psychologist and stuff, 'cos just having the support has been a lot of help

MUM – Again in Amy's words like before she said that knowing the support was there was enough to help cope

AMY – Even if I didn't use it

MUM – But knowing that it was there definitely helped

END OF TAPE RECORDING

Appendix D

Sample Transcript of Email Interview

Sample Transcript of Email Interview with Amy's Mum, 'Charlotte'

MWW - How did it feel to discover your child had CFS?

CHARLOTTE - It was a bit of a relief to know that she was actually suffering from a recognised condition and that we could move forward once we knew what we were dealing with. 😊

MWW - What did you know about CFS prior to diagnosis?

CHARLOTTE - If someone had mentioned CFS to me I would probably have thought that they were a hypochondriac and that the condition was a way of attracting attention to themselves. (Of course I now know differently)

MWW - What was it like achieving a diagnosis?

CHARLOTTE - It was a bit of a relief to know that what she was suffering was a recognised condition and that help was available, not knowing what she was suffering from was really difficult, as all sorts run through your mind. At one stage I even thought that she was suffering from a terminal illness, knowing that it was CFS (although difficult) made it easier to deal with.

MWW - Can you describe an example of being supported by healthcare professionals and/ or not being supported?

CHARLOTTE - I can honestly say that then, and even now our GP has not been of any real support, my daughter is still experiencing physical symptoms, recurrent sore throats, mouth ulcers etc and our GP has basically told her to "live with it", this is sometimes quite distressing for her as the symptoms are often debilitating and she requires time off college. It amazes me that there are no "remedies" for this. On the other hand the Occupational Therapist sessions at the Children's Centre in Dorchester

were a lot more positive and really proved to be the turning point in my daughter "getting better".

MWW - Where and how did you find out information about the condition?

CHARLOTTE - My daughter had been suffering for quite sometime when a teacher at her school suggested that CFS may be the problem, when she came home from school that day we looked up AYME on the internet and everything seemed to slot into place.

MWW - How has having a child with CFS impacted your life? For example, can you describe how it has impacted on the family, on you and your child, on social, work or educational aspects of life?

CHARLOTTE - Our whole family life has altered dramatically. On a family level, when my daughter was first diagnosed and in the initial stages of her illness everything we did revolved around her. We could no longer plan trips out as a family as more often than not she would be too poorly on the day, this would sometimes cause friction as my son would be looking forward to the trip and would be annoyed that it had been called off. Sometimes it would mean that my husband and son would go off and do things together and I would remain home with my daughter. My daughter sometimes felt angry, jealous, and frustrated because she could not join in. To a very small extent this has affected my relationship with my son (aged 15 years) as he spends more quality time with his father. However as time has elapsed and we can deal with my daughter's condition a lot better things have improved and as my son has matured and understands the condition a bit better he is more sympathetic to my daughters needs. On a social level, this was put on halt for a long time as my daughter was my number one priority. Work-wise was not affected to any great extent as I only work part-time, this did offer me some relief from the stresses at home. Educationally my daughter suffered a great deal, being a straight A* student about to take 14 GCSE's was extremely difficult, rows and tantrums ensued as she was forced into dropping some of her subjects which she was not at all happy about. The school, I must admit were on the whole very supportive with the odd teacher making life difficult. Dance was one of my daughter's favourite subjects (and one that she particularly excelled in) and this was one of the first subjects to be

dropped as she was unable to participate in the physical elements of the course, and having the teacher tell her she did not want "quitters" in her class was most hurtful and distressing. Overall with the support of the school and a lot of tears, and hard work she managed to obtain 10 good grade GCSE's, however to my daughter this was an unacceptable situation, which she was "Quite angry" with, as had she not been ill she would have reached her full potential. It is only now sometime down the line that she has come to realise that the amount of pressure she was putting herself under to achieve her goal, was in fact one of the reasons she was so ill. One of the most positive aspects to come out of this is our relationship has gone from strength to strength and we can be very open and honest about our feelings to each other, my daughter is also now very aware of the "signs and symptoms" of when she is pushing herself too far, and will now structure her activities with a great deal of maturity.

MWW - Can you describe examples of negative impacts on the family and family relationships?

CHARLOTTE - As mentioned above, family trips out together could result in a real battle ground if they had to be postponed at the last minute because my daughter was too poorly to attend. Jealousy, was also a bit of a problem, on one hand from my son who did not appreciate "all the attention" my daughter was receiving and from my daughter because she could not partake in activities when she wanted to, but her brother could go off and play football, cricket etc whenever he wanted. Sometimes it felt as if we was walking on eggshells, afraid to make any plans in case they could not be carried through. At the time my relationship with my son was pretty scant, mainly in the fact that the majority of my time and energy was spent looking after my daughter, and his needs were met mainly by his father, this meant that I missed out on attending a lot of his sporting activities and felt that I was "missing out" on seeing the relationship that he had with his father. This situation has now resolved itself after "family chats" revealed that my husband felt the same way about my relationship with my daughter. This was rectified by agreeing that we each spend some "quality time" myself with our son, and my husband with our daughter.

MWW - Can you describe examples of how people in the outside world have reacted? Have other people been supportive and understanding? Can you describe examples of feeling prejudice, ignorance or misunderstanding, and so on?

CHARLOTTE - Close friends and family on the whole were very supportive, and once others were "educated" they accepted the difficulties that we faced ie, cancelling things at the last minute. Generally it did not make a lot of difference to us, those in the know were absolutely fine. Once again the occasions I didn't feel supported were by our GP.

MWW - How has it affected you as a mother?

CHARLOTTE - Hopefully now in a more positive way, I am now a bit more relaxed in my attitude to life, initially I felt total despair because I was unable to help my child, I did not know what to do to help her get better, along with having to watch her suffer and being at a total loss as to how to help her. At the beginning I suppose I was extremely protective towards her and the pressure to keep "everything together" (work, family etc) was tremendous and very stressful. However having gone through this together has highlighted the fact that "stress" can be exceedingly damaging and we now as a family (myself in particular) try to avoid it.

MWW - How has it impacted on your mother-child relationship, can you describe any examples?

CHARLOTTE - Initially I suppose I was "just mum" to a teenage daughter with the usual ups and downs that this relationship can have at the best of times, however the most important factor to come out of this is the incredible relationship I now have with my daughter. It has brought a closeness to us that is very difficult to describe, we shared a lot of extremely low times, cried together, argued and eventually laughed and to have come through this with the bond we have today makes me extremely proud. An example of this would be when on an extremely tough day during a session with the Child Psychologist my daughter admitted that she was only coping with her illness due to the relationship we shared, but had up until that time not mentioned this to me.

MWW - Can you describe examples that have led to you feeling upset, confused, lacking in control, etc? Or examples where you did not feel upset, felt in control, felt clear and not confused.

CHARLOTTE - In the very early stages, before, and just after diagnosis the feeling of utter despair at being unable to help and having to watch my daughter suffer was extremely difficult. I felt totally lacking in control and totally unsupported by our GP, many was the time that I would break down when I was on my own (not wanting my daughter to see how worried I was, and trying to put a brave face on things by pretending that I was coping relatively well, when in fact this was far from the truth. It is only now that I feel that we are all coping remarkably well but the road to this stage was an extremely long and arduous one.

Appendix E

Copy of AYME Functional Ability Scale

AYME Functional Ability Scale (Moss 2005)

Fully recovered

100 percent – no symptoms even following physical or mental activity. Able to study and work full-time without difficulty, plus enjoy a social life.

Virtually recovered

95 percent – no symptoms at rest. Mild symptoms following physical or mental activity; tires rather easily but fully recovered next day. Able to study or work full-time without difficulty, but a slight restriction on social life.

Mildly affected

90 percent – no symptoms at rest. Mild symptoms following physical or mental activity; tires easily. Study/works full-time with some difficulty. Social life rather restricted with gradual recovery over two–three days.

80 percent – mild symptoms at rest, worsened to moderate by physical or mental activity. Full-time study at school/college is difficult, as is full-time work, especially if it is a crowded, noisy or busy environment. Home tuition or part-time study without difficulty.

Moderately affected

70 percent – mild symptoms at rest, worsened to severe by physical or mental activity.

Daily activity limited. Part-time study at school/college is very tiring, and may be restricting social life. Part-time work may be possible for a few hours in the day. With careful pacing out of activities and rest periods, one may discover windows of time during the day when one feels significantly better. Gentle walking or swimming can be beneficial.

60 percent – mild to moderate symptoms at rest. Increasing symptoms following physical or mental activity. Daily activity very limited. Study with others or work outside the home very difficult unless additional support is available, e.g. use of a wheelchair/quiet room for a rest period. Short (one–two hours) daily home study/work may be possible on good days. Quiet, non-active social life possible.

Moderate to severely affected

50 percent – moderate symptoms at rest. Increasing symptoms following physical or mental activity. Midday rest may still be needed. Simple, short (one hour) home study/home activity possible, when alternated with quiet, non-active social life. Concentration is limited. Not confined to the house but may be unable to walk without support, much beyond 100–200m. May manage a trip to the shops in the wheelchair.

40 percent – moderate to severe symptoms following any activity. Care must be taken not to overdo one's lifestyle at this stage. Not confined to the house but unable to walk much more than 50–100m, usually requiring aids such as walking stick/crutches. May manage a wheelchair trip to the shops on a quiet day. Requires three or four regular rest periods during the day. Only one 'large' activity possible per day – friend dropping by *or* doctor's visit *or* short home study (half hour at a time) etc. – with space usually requiring rest day(s) between.

Severely affected

30 percent – moderate to severe symptoms at rest. Severe symptoms following any physical or mental activity. Usually confined to the house but may occasionally take a quiet wheelchair ride or very short, gentle walk in the fresh air. Most of the day resting. Very small tasks possible but mental concentration poor and home study difficult. As mentioned in the report on ME/CFS to the Chief Medical Officer (Department of Health, 2002) and the Department for Education and Skills (DfES) report on access to education for children with medical needs (DfES, 2001), children may be too ill to access any education at all. This should be respected and kept under review.

20 percent – fairly severe symptoms at rest. Weakness in hands, arms or legs may be restricting movement. Unable to leave the house except very rarely. Confined to bed/settee most of the day but able to sit in a chair for a few, short periods. Unable to concentrate for more than one hour a day but can read for about 5–10 minutes at a time.

Very severely affected

10 percent – severe symptoms following any activity. Weakness and pain in arms or legs. In bed the majority of the time but feeling more stable and less dizzy. No travel outside the house. Concentration very difficult indeed. A friend can be seen for 10 minutes or so.

5 percent – severe symptoms almost continuously but may be possible to be propped up in bed for very short periods. Weakness and pain in arms or legs can give rise to paralysis; dizziness and nausea. Small, personal care may be possible (e.g. if washing equipment placed on the bed it may be possible to wash some parts of the body). As with 0 percent, sudden jerking movements can be a problem and what may be described as panic attacks are felt. No TV is possible but a little quiet music or audio book may be listened to for a few minutes. A friend can be seen for a minute for a hug and a few words.

0 percent – Severe symptoms on a continuous basis. In bed constantly, feeling extremely ill even with permanent rest. Severe dizziness makes it almost impossible to be propped up in bed for longer than a few minutes at a time. Light and noise are very painful to the eyes and ears – curtains are closed and earplugs are needed. Severe pain almost anywhere in the body with the skin feeling very cold and extremely sensitive to touch. Unable to care for oneself at all; washing needs to be done a tiny bit at times throughout the day. Nausea and severe fatigue make eating extremely difficult. Liquid-based food preferred – little and often. Occasionally, nasal feeding tubes are required when the energy to chew is completely spent. Any stimulus worsens the feeling of being severely ill, with no movement in the bedroom preferred. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. This is often misread as being ‘selective mute’. Severe adrenaline rushes felt with heightened sensitivity; jumping and overreacting to doors shutting/door bell ringing, etc. Sleep pattern often completely reversed.

Appendix F

Link to Article Published by Medical Journal RILA

<http://ipcauk.org/pdf/3-2/v3n2%204.pdf>