

**On being a mental health service user and becoming a
Service User Representative: An autoethnography**

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Thesis

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Copyright Statement

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Abstract

This thesis is my autoethnographic account as I pursue a career as a Service User Representative with the Dorset Mental Health Forum over several years leading up to 2010. This is a period of change in both the social care and health worlds as they impact on to people suffering from mental distress. In this period are introduced Personal Budgets and a three-year pilot scheme to look at the viability of rolling out Personal Health Budgets, in which Dorset is selected as one of 20 sites nationally. There is also a change of government from a Labour administration to a coalition of the Conservative and Liberal Democrat parties, but this does not seem to have changed the planned modernisation of both social care provision and healthcare provision started by the outgoing Labour government. Also in this period we see the wide-ranging revision of the Mental Health Act 1983.

My original contribution to knowledge is in describing the development of a service user representative model that works well in Dorset, UK. This thesis is not about the history and development of the mental health service user involvement but I do offer a précis of the history of service user representation for those unfamiliar with it.

This thesis is laid out in roughly chronological order. I try to show how I changed my views with the help of other people over the period. I also try to explain what it is that ails me. The reason I do this is to paint a picture of a person who is in general "normal" but suffers from mental disorders that sometimes alter the way he sees the world. It is with this backdrop that I ply my trade of being representative of and to other mental health service users.

I lead the reader from a consideration of method and methodology and ethics, through the precursors of my mental illness, to how that illness has been treated by the National Health Service, and how it impacts on my role. The main way that I do this is by offering a vignette of my life and then immediately afterwards analysing that vignette in the light of emergent themes. In this way, I ensure that the emergent themes are themselves based in a reality that can be accessed to some degree by the reader.

There were challenges along the way including personal ones, such as having to take time out from my studies to attend courses of psychological treatment and having several heart

attacks leading to hospitalisation, as well as the usual ones of finding people to contribute to my research.

I end this thesis by offering a model that service users may find illuminating when setting up their own service user representation services.

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I wish to express my love and appreciation for my wife who has suffered my loss to the word processor for long enough.

Thank you all.

Introduction

The purpose of this thesis is to offer an original contribution to knowledge by describing the development of a mental health service user representative (SUR) model that works well in Dorset, UK. This thesis is not about the history and development of the mental health service user involvement movement, which has been described elsewhere, for example Chamberlin (1990) for the USA, Wallcraft and Bryant (2003) and Clark and Glynn (2006) but I offer here a précis. Service user involvement is not a new phenomenon but one that can be dated back to as early as the 1620s, and then on to John Perceval's service user-led advocacy group, the Alleged Lunatics Friend Society group in 1845. Although Perceval may be seen as a service user after his time spent in Brislington Hospital in the 1830s, true service user-led representational organisations really began to come to prominence in England after Enoch Powell's 1961 "water towers" speech sounded the death knell for large psychiatric institutions. Often critical of NHS provision, such groups began to form in the 1970s, such as the service user-led *Mental Patients Union*, and continued into the 1980s with organisations such as the *Nottingham Advocacy Group*, paralleling the introduction of *Care in the Community* by the Conservative administration of that time. Although this was not a new proposal, it having been promulgated as a way of saving money while at the same time improving patient care since at least the 1950s, it helped in a new age in service user-led organisations. However, these years were also years of struggle during which service users were often not heard. The main charities, *Mind* and the *National Schizophrenia Fellowship* (later *Rethink* and later still *Rethink Mental Illness*) were more focussed on either professionals or relatives, and were not, and still are not service user-led organisations (Clark and Glynn, 2006). The 1980s saw a lot of work being done towards mental health service users having a voice in their own care. Coming from a place where even basic self-advocacy was absent, this was an important step forward:

"in the early 1980s advocacy was never talked about. There wasn't any. It wasn't on the menu at all. So we weren't properly involved in our own care and treatment because there was no advocacy. We were not involved in the development of services in any meaningful way either. We were not involved in consultation. We were

not involved in training. We were not involved in research. We were not involved in providing our own services. We simply weren't involved."
(Clark and Glynn, 2006, pages 39-40)

In 1985, the *Mind/World Federation for Mental Health Conference* encouraged the collaboration of Dutch and US patient groups and UK user/survivor groups for the first time, but in the UK 1986 was really the time when things began to happen with a conference in Nottingham, *Mind Link* beginning, and *Survivors Speak Out* being started (Clark and Glynn, 2006, page 33). More radical, more campaigning groups were also created at this time, one of which was called *The Campaign Against Psychiatric Oppression* (CAPO) and the other one was called *British Network for Alternatives to Psychiatry* (BNAP).

CAPO was a service user-only network group and quite small while BNAP was a network made up of mental health workers alongside service users. Another service user-only group was the *Mental Patients Union*. The 1990s saw continued growth of individual organisations, from about 50 in 1990 to over 600 in the 'naughties' (Clark and Glynn, 2006, page 46), but equally this period was a time of struggle to get the service user voice heard by the commissioners and providers of services. Most people took a sceptical position and there was a great deal of obstruction against almost everything service users tried to do. Two of the techniques used were lengthy considerations of precisely who was a 'service user', and to question their 'representativeness', of them being 'typical' service users (Clark and Glynn, 2006, page 41). The key to national involvement seems to have been seen as a networking one, where disparate organisations work together to one overarching aim, though achieving this is said to be extremely hard work as some service users only want to hear their own voice (Clark and Glynn, 2006, page 24). In the naughties under a Labour administration, groups continued to be created with the *West Dorset Mental Health Forum* (later *Dorset Mental Health Forum*) being one of them and the *National Service Users' Network* (NSUN) being another. This was the period when I got involved and I remember the almost daily struggles we had to ensure our voice was heard at least, if not acted on. But things were becoming easier and people were starting to listen to us. However, even today, although service user engagement may be seen as enshrined, service users are being manipulated by promises of

‘partnership working’. Much of the progress to where we find ourselves today is the result not of partnership working but of working in opposition, and ‘service user involvement isn’t just about working with people, it’s sometimes about working against people’ (Clark and Glynn, 2006, page 43).

The model to be described is one of mental health Service User Representatives (SURs) acting as paid employees of a user-led organisation (ULO), a charity that has been specifically tasked with advancing the views of mental health service users, and offering relevant news and information. The ULO would employ other more able service users as officers to ensure the SURs are supported in their work and, similarly, ensure consistent high quality from the SURs in their work. Funding would be sought from the ULO’s customers, for example those organisations who would value hearing their views and sharing their plans. This funding would not be dependent on the ULO pursuing the customer’s agenda.

This thesis aims to explain my world through autoethnography to a standard that will, by examination, qualify for an award of Doctor of Professional Practice from Bournemouth University. My world is that of mental health service users and their peers and representatives in Dorset, and I explore it through an analysis of my own life and work. Using the autoethnographical method will inevitably involve reflecting on my relationships with other service users, their carers, and others. These references and reflections have been strictly and severely anonymised and in some cases refer to an amalgam of individual views as if they were from one person. Care is taken with retaining the authenticity of these views by referral back, where possible, to the authors of the independent parts of an amalgam. Where that has proved not to be possible, I have sought review of those parts with my supervisors. The exception is where staff of Bournemouth University have given their informed consent to appear in this text. At this point, I think I need to be really clear that I am not presenting the voice of others but my experience of those people’s expressed experiences. Ethically, autoethnographic methods are necessarily risky in some ways because they reveal so much from the standpoint of the observer, meaning the researcher’s reality is not veiled as in other research methods. This has to be accepted as a given by the researcher. As to other people, the nature of an autoethnographic study is as an organ for reflection and learning about how the

situation affects the researcher. The thesis should be approached with this in mind.

Mental health service users are those people who use services designed by the social services or National Health Service to help people suffering some form of mental distress. Currently, this is divided into three parts: primary care, secondary care, and tertiary care. Primary care is very broadly that care that is controlled by the general practitioner and includes services such as IAPT (Improving Access to Psychological Therapies). Secondary care is that care beyond the remit of the GP, for example hospitalised care, care from a psychiatrist, or care under the auspices of the Care Programme Approach system that allows a care coordinator to involve various agencies to develop a more complex care plan for an individual living in the community. Tertiary care is the sort of care that you would get from attending, for example, Combat Stress and their PTSD services. My SUR ‘constituents’ might come from any of these groups.

The layout of this thesis departs from that normally found in a doctoral thesis in that I have deliberately used the first person convention. This is because it gives more impact to the writing, makes it more personal, more understandable, more accessible to this strange and shadowy world, and because of the intensely reflexive nature of text. Additionally, I have not numbered paragraphs sequentially, and I have used a conversational style of writing that I hope will foster a sense of companionship as we move through the story together, enhancing the text and the reader’s understanding and feeling for the world of a mental health service user. Navigation has been eased for the reader by using chapter headings and numbering the pages, but this thesis could have been written without those somewhat arbitrary barriers. The reader will also find that different fonts have been used for different aspects of the writing, for example poetry and direct quotes and the vocalisation. This is to visually delineate those different areas of writing as well as to break up the great ‘block of text’ that is usually found into more eye-pleasing and manageable chunks. Other conventions such as referencing have been observed.

The evolution of the various parts of this thesis is broadly chronological and expresses a journey from my being ‘simply’ a mental health service user – and how that occurred – through to becoming a Consultant Service User Representative or,

more modernly, a Consultant Peer Specialist with Dorset Mental Health Forum, a journey enabled in no small part by my doctoral studies, both becoming more complex yet moving towards a clearer focus through time. It is based on original research, through a rigorous investigation of practice, supported by relevant references and shows how my practice has developed over the years with the help of my studies at Bournemouth University. In this, I mean both my academic and personal skills and qualities have benefitted from engagement with the processes of learning, reflecting, presenting and writing that have so inhabited my working days for the past few years. Learning, because I have been introduced to and discovered a vast array of tools for qualitative research, delivering training and seminars, and writing papers and essays for books. I have also peer reviewed many journal articles for the *Journal of Psychiatric and Mental Health Nursing*. Reflecting, because I have been introduced to the benefits of self-reflection through practices such as reflexive writing and mindfulness. Presenting and academic writing skills have been honed over the period so that I have had, for example, several chapters accepted for books (for example, Grant, Biley, and Walker, 2011), and I have written and delivered practical training sessions to various levels of local government and nursing staffs.

The first part of the thesis deals autoethnographically with method and methodology as they inform and underpin this study. It is an evocative description of the move from just looking for a model of service user representation work to seeking out the reasons behind why one would want to do that work, followed closely by a journey through the deliberations that ended in autoethnography being chosen as method.

Next, I explore what it means to become a mental health service user during 2006 to 2010, a period of change in both the social care and health worlds as they impact on people suffering from mental distress. In this period are introduced Individual Budgets, later known as Personal Budgets in England and Wales, and a three-year pilot scheme from 2009 to 2012 to look at the viability of rolling out Personal Health Budgets, in which Dorset is selected as one of 20 sites nationally. There is also a change of administration in 2010, from Labour to a coalition of Conservative and Liberal Democrats, but it doesn't seem to have altered the planned modernisation of both social care provision and healthcare provision started by the Labour government. I undertake original research to explore how I developed this societal

role into the more specialised one of a mental health Service User Representative or SUR. I start by asking “What’s the difference?” and furnish the answer through a look at the differences between being an individual user of mental health services among many such users and survivors, and aspiring to represent those people's views to statutory service managers and the like. This part of the narrative is supported by relevant references to the literature.

This is followed by various aspects of my development into a person who uses mental health services, such as the anecdote of war in which I explore an event from the past and its long term effects on me. This is followed by an account of the final car crash of a series of three, which experience sent me over the edge and ‘switched on’ my complex Post Traumatic Stress Disorder (PTSD) and clinical depression. In *Where are the sirens?* I describe and explore how complex PTSD affects me on a daily basis, even while relaxing on a holiday. I delve into other aspects of the illness and its associated side effects. An often hidden part of mental health troubles is exposed in exploration of my feelings around the advice one is given about loss of libido. I write about an attack of dissociation as a journey through a dissociative event, to illustrate how often control is lost and the effects it can have before, during and after the act, both to self and others. I look at why I self-harm: Is it a cry for help? Or a trigger releasing pent up stressors? Or what is it? This is followed by another common aspect of being mentally unwell, that of medication. Application of medication can often alleviate symptoms of mental distress but this subject is not without its critics. However, this is a story to illustrate how very much I have been in the hands of practitioners working under the medical model of care. Again, this is a progression illustrated by relevant references and based on original research.

I then look at the world of the mental health Service User Representative (SUR) in more detail and, specifically, how that world informs my role. Here we are at the meat of my practice development project. I look at aspects of a SUR’s job during tutoring with the Expert Patient Programme, how I access as well as offer support to others after a death of ‘one of our own’, and how electronic media can be used to help support SURs at a distance. *A Conversation with Harry* is part of an anonymised interview with an experienced mental health professional, an interview that helps to expand the service provider’s take on what it is like to be engaged with

a SUR on an NHS executive committee. As far as my researches have taken me, this is a unique interview and is used as a vehicle to reflect within myself on how the work of the SUR is potentially powerful, and not just something that I do to make me feel good about myself. Another aspect of SUR work is the designing and delivering of training to an assortment of agencies and is here illustrated through a description of part of a training session on 'Recovery in Mental Health' that I and another SUR carried out for service provider front-line workers. The text moves to describe aspects of my professional progression focusing on some of my work away from Dorset via the tale of two trips to The King's Fund in London and subsequent reflections on the uses of name badges. However, my main thrust is to describe the work done by me, a mental health service user, as a SUR in Dorset. Reflecting on how I am perceived by others and how that subsequently affects the way they treat me, I examine aspects of presentation of self in general and why that is important interpersonally. This is followed by a story showing how I enhance the general opinion of SURs among health and social care workers by going that little bit further and helping to erect their Christmas tree. This section ends with a reflexive piece on recovering from chaos into a new reality.

The final part of the thesis offers conclusions and recommendations flowing from a discussion on the lessons learned, and critiques and looks over the limitations of the study. Specifically, I offer a model of service user representation within a world bounded by mental health issues, families and carers, benefits system, work, and the NHS and social services, all based on my original contribution to knowledge through this study. This model works well in Dorset, UK, and is one of mental health service user representatives (SURs) acting as paid employees of a user-led organisation (ULO), a charity that has been specifically tasked with advancing the views of mental health service users, and offering relevant news and information. The ULO would employ more able service users as officers to ensure the SURs are supported in their work and, similarly, ensure a consistent level of quality from the SURs in their work. Funding would be sought from the ULO's customers, for example those organisations who would value hearing their views and sharing their plans. This funding would not be dependent on the ULO pursuing the customer's agenda.

I have used original pieces of poetry written in the midst of the worst parts of my distress in order to more fully illustrate my state of mind at that time. They form part of the backdrop to my work as a Service User Representative and, I suggest, should be viewed as such.

According to their published regulations, from which I liberally draw the following, the granting of a Doctorate of Professional Practice by Bournemouth University demands that four streams of learning and development are completed at the time of submission of the thesis: That the thesis is based on original research; that there is a systematic review that offers meta-synthesis or meta-analysis of previous work - but this systematic review requirement has been modified to that of research of the relevant references; that there is a detailed account of a practice development project; and that there is a narrative report that connects the other three pieces. The thesis needs to represent a substantial theoretical and informed contribution to my area of professional practice, and narrative and critical reflections on practice with evidence of practice development. The examiners will be looking to see that the thesis contains a comprehensive review of literature and evidence related to the area of investigation. They will be seeking to see if my thesis shows a sound understanding of the selected methodology to the research approach and appropriate effective skills development and undertaking of the research enquiry. Finally, the examiners are to consider whether the thesis provides evidence of originality and an integrated approach to synthesising the contributions to knowledge and practice that my original research makes. Well, that is what the University regulations state and it is my belief that all these points have been covered in the following thesis.

This narrative study of my life as a SUR combined with the levels of analysis I offer is all my original work. I am not aware of a similar thesis having been written or book having been published that covers this ground in quite the detail I have here. My original contribution to knowledge is in describing, through this autoethnographic study of myself, the development of a service user representation model that other areas might make use of in their programmes. Another aspect of the study is that it offers support should the reader be undergoing mental distress, in that it shows that he or she is not alone. And thirdly, this thesis illuminates an aspect of the world of mental distress that is sometimes overlooked. In this I mean the

assumption that people who are suffering from a mental disorder are somehow not as intelligent as those who do not. This view is often bolstered by populist language such as "nutter" and so on. Such language needs to be curtailed. In my experience, many sufferers from mental disorder are highly intelligent and have attained high academic standards. I know many masters of arts and sciences as well as several who hold doctorates and occupy academic positions within universities yet still suffer from a mental disorder of 'a nature and/or degree' requiring medical care. Some of these are leading lights in the service user representation world.

Method and Methodology

Shifting From ‘Model’ To ‘Solace’

There are few things that can be said with any certainty about our lives as human beings ... But one thing does seem to be true. Nobody really wants to become a user of psychiatric or mental health services. (Beresford, 2010, page 7)

There is a knot within, a hard place that lies deep inside the layers of life, a nut suspended above and away from any contact yet closely guarded and surrounded by layer upon layer of softer, more disposable me. The secret is to be able to fashion a safety net below the nutshell so that when it finally breaks down, the contents will only fall safely into the net. (Peacocke, 2000a).

We are sitting, the three of us, in the meeting room at Dorset Mental Health Forum in Dorchester, Dorset. I have booked it for the afternoon so no one will disturb us as we chat. The room is over-warm and a bit airless because it is very difficult to control the electric storage heaters and Carol mentions this, but there is nothing I can offer to do to alleviate her discomfort. Fran seems fine.

Carol and Fran are my supervisory team at Bournemouth University where I am in my second year of a part-time Doctor of Professional Practice (should that be the noun or the verb?) and this is the latest of a series of developmental meetings where my ideas and skills have been channelled, validated and honed to what they are now.

We are all middle-aged (Carol is the shortest and Fran the tallest). Carol is an expert on the social sciences and feminism in research, and is looking at me through challengingly intelligent eyes. And Fran? Well Fran is Fran. He is trained as a mental health nurse, as I am, and has a seemingly unending interest in all I do . . . which is nice.

We sit quietly for a moment chatting inconsequentially and then Carol brings the meeting to order by asking me what I am looking for from them today. I stutter and

shift because even though I have called the meeting and should be ready for it, I have been rather depressed for the last month and feel anxious and inadequate among them. I fight this feeling, because that is all it is, and settle down to making inroads into what I have spent the past month doing.

Me: I spent a whole seven hours transcribing our last meeting.

Fran: Was it a productive thing to do?

Me: It had to be tried.

I realise as I say it that this is a non-committal answer but really don't feel this is even close to the nub of today's supervision, so let it pass. Carol appears to see this.

Carol: What's in your head that you want to discuss today?

Perceptive? I think so! Frightening? Maybe. Challenging? Definitely! I still toy around the main themes in my head; themes of focus and moving forward my studies, and go off at a slight tangent, negotiating my place in the conversation, in the interactions taking place.

Me: I've done the transcript and some reading around writing.

Carol: You were going to do some reading around methodologies?

Challenged again, I become defensive mainly because I feel guilty about not having done as much reading as I would like. I wonder whether I need to mention this or whether it is irrelevant to the main line of the discussion. I decide to ricochet a comment off, and interject at a slight angle.

Me: Yes, I've got that. But I haven't been able to read everything!

She sees my discomfort, I think, and backs away, looking down and breaking eye

contact and validating my response.

Carol: No. No.

I feel slightly stronger because of her understanding and expand my bald statement a little to colour my efforts.

Me: I'm reading the Ellis (2004) book and the writing books (Emerson *et al.*, 1995; Holt, 2003). I also have a book on narrative analysis (Wengraf, 2001), and Denzin and Lincoln's (2005) third handbook.

Carol: There won't be much in Denzin and Lincoln to help you with your autoethnography, though.

Me: But I can use it to look at other things, other methodologies, like we discussed. If I were to argue why other methodologies did *not* fit, then I can start with this as a source book.

Fran, sitting back observing us, decides to draw this topic to a close.

Fran: It's a good starting point . . . and Denzin's work alone is a good starting point.

The conversation then roams around who the two sociologists, Denzin and Lincoln are and their reported lives, leading on to my own writings that are autobiographical in nature rather than autoethnography. But, as Fran says, they are a start for me.

I still feel that our conversation has not arrived at where I was hoping it would, but the words of Tom Wengraf (2001) run through the backrooms of my mind, observed but not disturbing the other processes going on: "In the same interview, both informant and interviewer may be constantly switching roles through a medley of historic 'interview identities' without ever realising what they are doing." (page 18) I wonder how much this is directing our interview here, today, now?

I have extreme difficulty thinking back to 1976 to 1986: is this a conscious decision or an inability?

I feel drawn, run down, debattered, custard creamy, yellowish colour, smoky flavour, and on unsolid ground - like on a skateboard. I am frightened; anxious; tired; nervous; defensive; ugly and stupid as usual; scruffy; sad; brainless; weary; sad again, really; sad and tired; sick and tired; sick and tired of being sick and tired; just wish it was all over, because I feel trapped.

Extract from a transcript of a therapy session, 1999

I feel I have to continue on the thread I've started, even though there seems to be a bit of negative feedback coming my way – be strong. We talk a little about my previous writings and I make a copy for Carol. Fran is more interested in seeing new work.

Fran: *My perception of what constitutes an autoethnography is that it is primarily your experiences and your observations but of course they can be coloured, illustrated with the views of others. Your life now - in your current role - that's what excites me, so that you're keeping a diary, basically, that might incorporate . . .*

As ever, Fran's words fade away as his thoughts overtake him. I assume he means one thing but he might well mean another. The moment passes and I will probably never know.

We settle down to discussing the verity of using other people's voices or representing them in another way in my writing. Fran suggests reflecting on the representative work; on the way I gather other people's experiences and voices to pass on to the committees as a *Service User Representative* (SUR). I explain how I capture people's voices, their own words, that I can then use as authentic flashback sections in my writings to illustrate to readers *how* I collect views and opinions from other service users. This leads on to more comfortable territory for me, as I have been reflecting on this aspect of my work for some years.

The problem is, you see, this is a socially acceptable stereotype. Perhaps there is no centre to the nut but that it is indeed solid - or maybe rotten? Question: how can I stand back and look at the nut if I am inside it? I think that this is a distraction, a sleight of hand to pull attention away from the real me. The real me has created the universe in which we stand, and in which the nut and its incumbent reside. The real me can as easily switch it all off at a whim.

(Peacocke, 2000a).

We move to discussing the differences between my justifying my representativeness as a SUR by loading it with these voices, or whether it is better to describe the way *I* apply my *own* experiences. The two supervisors express a concern about the focussing of the data rather than casting my net too wide and finding myself swamped beneath a pile of interesting, but somewhat irrelevant, information.

Fran: The story is not necessarily this text, the story is you going and finding out a gap in your knowledge, and how you get that filled. The actual story itself is probably peripheral to the main focus: the stories you are collecting is not data for the ProfDoc.

I must be looking a little sceptical at this, but I am not feeling that way, not even a wee bit. What I am feeling is a twinge of cerebral excitement, a flush of new insight beginning to well up from my hippocampus to caress my grey matter and counter the impulses emanating from my amygdala to swill and swirl like the tide coming in and washing the dust from Lyme Regis' fossil-rich foreshore.

I reflect on the ethics of this way of doing things. If I am to study myself as Fran says, then other people must only be reflectors for my own actions, not as data in themselves. This would make the very difficult if not impossible business of trying to get formal ethical approval for every part of my study before beginning it unnecessary as no-one else will be involved in it, only me. I think maybe that the shadow behind my eyes is sending the wrong signals, so regain concentration on what is being said.

Fran: The autoethnography is *your* experience of doing this - full stop.

This is getting better and better. I feel my ideas being validated by these two experienced academics and I am starting to pull out of my initial nose-dive.

Fran: The autoethnography is in you *finding* this absence of knowledge ...

Yes. Yes.

Fran: ... and *wanting* to go out and find these Real-Life accounts.

Yes. Yes. Yes!

Fran: So, it's *that* bit that is the *critical* bit; about how you *set about* actually getting hold of *somebody* who can supply you with true accounts of whatever it might be.

I ponder ...

One of the problems is that the "me" stays the same throughout. I am slowly coming to the opinion that, as one of the philosophers said, that there is no "me" and "I". The way we stand back and look at ourselves, the "I" that watches the "me" has been created as a thought-pattern, and that in effect what happens is modern people have split that and say yes there is an "I" that watches the "me" perform. And he says it is not actually true, what's happening is, the "I" and the "me" are the same, and they are actually creating the world that the person is in. (Mead, 1934)

And I am starting to feel a bit like that way. And I am thinking that if that is the case then there is something wrong, whereas before it was, "I" am OK. it is the 'me' that is wrong. I seem to filter input all the time. What I think was said, was not said. What I heard was all I wanted to hear. It was filtered." I worry that this might happen quite a lot.

Extract from a transcript of a therapy session, 1999

Carol: Being a Service User Representative for mental health services means you have to be a big sponge - because it cuts across all sorts of different areas that you can't, necessarily, embody yourself. In collecting these data, are you saying that this is the work a Service User Representative would *normally* do, or are you saying that since being on the ProfDoc you have identified that a Service User Representative has these gaps in knowledge and this is how you would fill them?

Before I can proffer an answer to the question, one that has been welling up at her voicing the two different approaches to my work, Carol rushes characteristically on.

Carol: Because . . . putting a lens on what you do would make you reflect on it in a different way than you would have done just being a Service User Representative(?)

I am not at all sure whether the question mark should be there or not as I cannot quite make out whether she is voicing an opinion or a rhetorical question or whether she requires me to answer. So I don't.

Fran: Service users would tend to have very little beyond their own experience . . .
. which is very interesting . . .

Fran disappears from view once more and Carol takes up the reins to drive this particular horse forwards.

Carol: Whatever particular *position* you take will incorporate *your own* perspective; but does being a Service User Representative - where you then begin to have relationships with a wide variety of people around a particular topic - does this in any way *explode* your awareness of that topic? You *are* dialoguing with doctors and nurses and . . .

Carol's rather extended descriptions of the people I already *know* I interact with gives me time to begin processing just *what* she is saying. It seems to me she sees

two very different things: The first is a Mead-ian (1934) *me* as an SUR with insight enough to realise that the *I* does not know it all but must gather authentic voices to report to my audiences; the other seems to be that this realisation only occurred after my starting the ProfDoc course and so begin to reflect on what I *should* be doing.

While she speaks, I think back to my discussions in late-2004 with Shaun, our Services Manager at the Forum. He had this dream: He wanted to set up a team of representatives to carry the views of mental health service users into the heart of the committee world of both Dorset County Council (DCC) and North Dorset Primary Care Trust (NDPCT); both fund-holding and commissioning bodies; both places where important decisions were made, decisions important to the care of people suffering the effects of severe mental illness; both places where we, the service user, had no real say in the care we were given. This was during the time when it appeared to me that no-one was offering people disabled by mental health issues any proper voice in decision-making at all, even though discussion papers like the Ladder of Citizen Participation had been out since 1969 (Arnstein, 1969). Indeed, much of the legislation was either being ignored, as in the case of Direct Payments, or was being ‘Tick-Box’ observed – the worst kind of tokenism - by, for example, rolling in a token ‘mental health patient’ to glean his or her ‘views’ and then comprehensively ignoring them, or not even bothering to report them in official reports and Minutes from the meetings.

Shaun seemed to want demi-professionals to be engaged with these bodies. He wanted people with direct experience of mental health services to be trained in committee work, collect constituents’ perspectives, and go to the committees and meetings to put forward their informed views. Crucially, he wanted them to report back formally in order to help inform other service users. He and I felt this would force the two major Dorset fund-holders to sit up and take notice of users’ views.

I remember being quite sceptical at first but then became enthused with his energy. I thought: “He dreams!” and I found that engaging and refreshing in the mad world I’d dropped into some years previously. Our discussions bloomed and blossomed, and shot out, vine-like, helical tendrils to propagate our ideas among the other members of the Forum. A more thorough planning stage ensued. He challenged us to dream

along with him and, having nothing better to do, we did.

We thrashed out a plan to start moving the first three SURs out into the mental health community while he touted for places on committees, recruitment panels, inspection teams, and training sessions. He was successful in all these areas primarily through our being able to display professionalism - as SURs, *not* as mental health professionals - to the statutory services' decision-makers.

My mind draws itself from the past and back to the over-warm meeting room with the ancient white sash windows bright with streaming silvery sunlight; Carol was still talking.

Carol: . . . on behalf of service users. It isn't just that one service user experience you are taking in there; you are also taking in all sorts of negotiating skills and a particular position, which in some places will be privileged and in some places won't be validated at all.

Fran: Service User Representatives may be seen to hold a certain position as being able to represent a very disparate, certainly not homogeneous group of individuals. So, the reality of it is that as individuals they can only represent, in the first instance, their own experiences and perceptions. But, as you're suggesting, you need to see in a much wider sense what might be going on. So there is that tension there, which is very interesting.

As I consider how my musings of a moment before mesh with what Fran has just said, Carol springs in with another observation from the past.

Carol: I have always heard you talk about speaking with other people and their experiences and problems. I was wondering whether this is something you have realised, having done this, and whether you are now trying to find the evidence to support this diversity in experience - and lock it into text?

Fran: I think this would be quite exciting. I don't know if this is emergent. Is

what you are saying that being a Service User Representative is about being much more than being a service user?

I decide it is time to bring out my memories and try to express them so as to clear up these misunderstandings a little. I think back to the academic writing seminar I attended in Bournemouth University as the word 'novice' pops into my head unbidden. The lecturer was quite clear: "You are *not* novices, so your dissertation *must not* display this." I agree, and also that this rule needs to be displayed during academic conversations and arguments as well. I also reflect on the statistics around the percentages of influence on a listener during a face-to-face communication that I learnt during a course with the PCT: Words = 7%; Tone of Voice = 38%; Body Language = 55%. I adjust my position to indicate openness to new ideas and interpretations while showing confidence in being in control of my own data.

Me: That is why we train them. The ECT service user story illustrates this as it is completely different to my views as someone who has never had ECT, and runs contrary to the positions of many organisations. Yet *he* is the expert here. This has made me think that I need to revisit *my* beliefs before trying to represent service users about ECT in committee.

Electroconvulsive therapy or ECT is a medical procedure carried out in hospital. It involves the patient or service user to be anaesthetised and have anticonvulsants applied by one doctor, an anaesthetist, whilst another doctor, a psychiatrist, applies an electric current of various voltage to pass through the brain of the patient and cause convulsions. Experience has shown that such therapy can help control mental illnesses such as depression and schizophrenia. The procedure is wrapped around with controversy, yet is just about the only medical procedure that can be applied under force of law and against the expressed wishes of the patient who is to undergo the treatment even if they have an otherwise legally binding document, such as an Advance Directive, expressing their wish never to undergo ECT. The Mental Health Act 1983/2007 specifically allows doctors to order the application of ECT in order to save life irrespective of whether the patient wants it or not. Although it may seem that such Draconian methods would not be readily applied, in Dorset they are applied

quite often. I know this personally because I sit on a committee to which such reports are submitted.

The pros and cons of this procedure, which I have never personally experienced, have left me in something of a predicament. Quite a few of my constituents have undergone the procedure, but how can I represent their views not having had ECT myself? The best I can do as a SUR is to converse with and listen to the experiences of those who have undergone it and try to represent their views as honestly as I can. What follows is a story about ECT and the effects it can have on one, written by another SUR of DMHF in 2008. This story illustrates one route that a SUR can take to broaden his or her knowledge. It is similar to the other vignettes in that it reveals something but is not data in and of itself. It is used purely as an illustration of how I gather and present materials and then, importantly, reflect on them in the course of my work as a SUR.

ECT: A Personal Story

This is an account of my personal experience of having had ECT (Electro-Convulsive Therapy, or Treatment). I hope to debunk some of the myths of ECT, especially that it is torture, inhumane etc - it is nothing like 'One Flew Over The Cuckoos' Nest'.

Here is a bit of background information that led up to me receiving ECT for the first time. My first ever admission to a psychiatric unit was one month before my 17th birthday in January of 1990. I was displaying increasingly bizarre symptoms and was taken by my mother and her then partner to an adolescent unit which was part of an old asylum. After evaluation at the adolescent unit it was their belief that I was too ill to be held at the adolescent unit and instead should be detained in the adult secure unit.

I was placed under various Sections, until I was then on Section 3. During my stay, I was prescribed ridiculously high doses of Haloperidol that led to an Hallucinogenic Crisis that must rank as one of the worst experiences of my life. Being a 16yr old experiencing their first acute episode of extreme psychosis and being confined on a secure adult unit with some very ill individuals is far more frightening than the prospect of ECT.

The severity of my psychosis reduced sufficiently so that I no longer represented a danger and after 2 weeks I was transferred to an adult open ward. I was still very ill at this stage and was experiencing altered perception and thought processes. After about two months, my symptoms had still not been controlled so the option of ECT was discussed.

My mother agreed with the idea and signed the consent forms (I think because of my age an adult had to sign, plus my mental state meant I couldn't make an informed decision). I will now give you a totally honest account of my first experience of having ECT.

I was taken to the ECT suite in a wheelchair, I remember it being quite a long way past lots of smaller detached wards and then eventually leading up to the main complex. I didn't feel particularly nervous and the member of staff that took me to the ECT Suite reassured me anyway.

I arrived at the ECT Suite. The staff were very pleasant and made me feel comfortable. When it came time for me to receive treatment I was lying on a gurney and they prepared to administer anaesthetic. I was advised to count down from 10 to 1 as I felt a warm tide of anaesthetic pass through me, which I personally love. I only managed to count down to about 7. What I'll describe next is rather strange and I'll admit was a little disconcerting.

The last thing I remember I was lying down receiving anaesthetic, the next thing I know I am sitting in a room with a half drunk cup of sweet tea in one hand and a half eaten biscuit in the other. I have no recollection of how I got there and of drinking the tea or eating the biscuit. It is as though I suddenly just clicked back into consciousness and had been operating on autopilot (it is standard procedure for you to be given refreshments after ECT until you feel comfortable enough to be taken back to the ward).

I wouldn't say the confusion I experienced after my first ECT was that negative an experience but upon arrival back at the ward I did develop an excruciating headache. I asked for painkillers and was refused. This was down to a particularly sadistic Staff Nurse and shouldn't really cloud your views on ECT too much.

After each successive ECT I became more and more comfortable with the procedure, I didn't have any more confusion after each successive treatment either. I completed the course of six ECT and after each treatment my

symptoms of Hypomania greatly improved. I think I may have received an additional two ECT after the course of six to get me really level. All said - I was in hospital for three months (discharged one month from the commencement of ECT).

In 1993, I had my third admission to hospital. I was detained under Section 3 on a secure unit in a hospital in West Wales. I was extremely psychotic and again the use of ECT was advised after several weeks of not responding to anti-psychotics. I received ECT and if I recall I was discharged straight home after seven weeks of detention. Had I not received ECT, there is no doubt the duration of my stay would have been longer.

Don't listen to ill-informed people who spread misinformation about ECT. Take it from one who's been there, it can be a success. If you are given the opportunity to have ECT to alleviate symptoms of distress you may be experiencing, take it. What have you got to lose?

Carol: And it is *just* this process, of how you do that, that you need to get down on paper. That's the bit that builds up a very compelling and convincing story about the role of being a Service User Representative.

Fran: We need to really hold tight to the idea that being a Service User Representative is *much more* than merely being a service user.

Me: Which fact is missed by many commissioners and providers, who see us as *just* service users.

Fran: You could then make a strong claim for them to supply formalised statutory training, turning lay SURs into professionals ... which then leads us down the slippery slope of asking: "Is this a grassroots model or a professional model?"

Fran is looking decidedly uncomfortable again, and Carol is thinking, eyes a long way away and brow furrowed – body language = 55%. I believe, and always have done, that there is no strict demarcation between amateur and professional except in as much as payment goes. Yet there *is* a *distinct* difference between Novice and

Expert (Larkin *et al*, 1980), proven by many experiments and through my own life experiences to be the case, but just who are the ‘experts’ here? Is it the paid employees of the state charged with completing various tasks around mental ill health? Or is it the sufferers of that same mental ill health themselves? I believe the answer to be plain as a pikestaff, and that it is the mental health service user who is the expert here. Therefore, for these same employees of the state to view mental health services users’ representatives as amateur and therefore of offering a less than valuable opinion than professionals, i.e. these same paid employees of the statutory services, I find inimical especially to the self-image of already damaged individuals such as people with mental health challenges.

At this point, we revisit my original 2006 thoughts and plans on how to set about conducting a doctoral-level study at Bournemouth University, and to take part in the Doctor of Professional Practice course itself in particular. I had them listed down:

SERVICE USER INVOLVEMENT – MYTH OR REALITY?

“It has to be about more than people feeling good about themselves – or does it?”

Shaun Byatt, West Dorset Mental Health Forum, 2005

1. What exactly do we mean by the term ‘service user involvement’? As the mental health community reflects the whole community, to which communities does the term apply? Some areas are:
 - a. Mental health.
 - b. Elderly care.
 - c. Macmillan Nursing.
 - d. Midwifery.
 - e. Chronic disease management.
 - f. Young persons’ care.
 - g. Learning difficulties care.
 - h. Medical services.
 - i. Primary Care services.
 - j. Expert Patients Programme.
 - k. Patient and Public Involvement Forums.
 - l. Representation of incarcerated people:
 - i. HM Prisons and YOIs,
 - ii. Detention Centres,

- iii. Special Hospitals,
 - iv. Secure units,
 - v. People restrained in hospital under a MH Section.
- 2. What was the source of the idea for service user involvement?
 - a. Government Policies.
 - i. Fiscal considerations.
 - ii. Statements by the Health Minister.
 - b. Consumer focus?
 - i. Did the encouragement of service user/carer involvement come through a policy of “The Consumer”?
 - ii. Where did it all start?
 - iii. Misgivings?
- 3. Models of service user involvement?
 - i. West Dorset Mental Health Forum
 - ii. Somerset Users Forum
 - iii. etc
 - b. Other research, i.e. USA models.
- 4. Does service user involvement actually work?
 - a. Are projects better if led by service users or statutory/employed professionals?
 - b. How strong is the service user voice in actuality?
 - c. Do Service User Representatives have ‘teeth’?
- 5. Who does service user involvement benefit?
 - a. What do we mean by ‘benefit’?
 - b. Who accrues these benefits?
 - i. Politicians?
 - 1. The New Mental Health Act
 - ii. Public Purse?
 - 1. Funding
 - iii. Service users and their carers?
 - iv. Organisations and their professionals?
 - v. Voluntary sector and their workers?
- 6. Local and National models of best practice.
 - a. Research across England and Wales NHS Trusts to:
 - i. List provision in their areas,
 - ii. Elicit service user group views from those areas,
 - iii. Elicit service provider views from those areas.
 - b. Establish the range of services available. Look for:
 - i. Advocacy
 - 1. Trained service survivors/users?

- ii. Meeting places
 - 1. The Clubhouse Model?
 - a. What is it and how is it being emulated.
 - b. Is there a movement away from it, and why.
 - c. Other models in use.
 - c. Are workers with experience being used on:
 - i. Consultative committees.
 - 1. Consultation levels?
 - 2. Value given and perceived, of their work?
 - ii. Stigma and labelling: Is labelling continuing?
- 7. Do service users want to be involved?
 - a. Individuals or groups?
 - b. Assumptions.
 - c. Would the users / carers prefer a service run by professionals?
- 8. What are the Pitfalls? (FLCC photograph as one example . . .)

NB: Basically, is it better to take a top-down or bottom-up approach to service provision, or a bit of both?

- 9. Origins of service user involvement in provision of mental health care?
- 10. Research-based?
 - a. Mental Health Act?
 - b. Tensions between the recovery and medical models?
 - c. Psychology?
 - d. Sociology?
- 11. Delivery differences across the country?
 - a. Areas and fundings?
 - b. Statutory and voluntary sectors?
 - c. Commitment?
 - i. Are service users actually employed or are their representatives professionals?
- 12. Geography?
 - a. Urban – v – rural?
 - b. Patches and areas?
- 13. Is service user involvement myth or reality?
- 14. Suggested best practice and the way ahead: Recommendations

(My initial notes from early 2006.)

I remember feeling unsure that my ideas were even valid, yet subsequently my research proposal passes through the University's Research Committee in 2007, though the ideas and methodology moves to mixed methods, and Carol has praised

me; something I never accept very well is praise, and both she and Shaun take me to task on this point at an earlier meeting after my research proposal is accepted in 2007, while I listen somewhat red-faced.

Carol: You are smart enough and . . . and . . . devious enough - and I mean that word in a nice way - to know how to protect your back while you are going forward.

Shaun: Yes . . . yes.

Me: Ummm . . . ?

Carol: And I think you do have to realise how exceptional you are in those abilities. Now, I know where you've brought all those . . . you can see where they've culminated from: your business life; your military life; all sorts of things . . .

I reflect, as she speaks, on the roles I have played in my life and remember I have written an alphabetically ordered list for another essay:

I am a white Anglo Saxon middle-aged middle-class British male of no fixed religion. I have filled many roles. In my time I have been an adulterer, agnostic, ambulanceman, artist, atheist, barman, battlefield soldier, bomb disposal officer, bully, burglar, care assistant, Christian, consultant, Corporal, councillor, counsellor, cousin, cuckold, Deck Officer, decorator, depressive, divorcee, dogsbody, driver, enemy, father, fiancé, fool, foster-father, Freemason, friend, grandson, great-grandson, husband, hypnotherapist, idiot, infantryman, intelligence operative, killer, lavatory cleaner, liar, magazine editor, manager, marksman, mental patient, nephew, nurse, Peer Specialist, pilot, plumber, poet, prison officer, psychologist, sculptor, security guard, Sergeant, Service User Representative, shop assistant, son, spy, step-father, step-son, storeman, student, suicide risk, taxi driver, thief, uncle, veteran, victim and writer. Such is my burden. It is what has made me. It is what I am, but I am also more than this. I am me, and I know what I know. Sometimes this knowledge seems to be out of step with reality around me, and then I am labelled 'depressed' or 'at risk of self-harm' or some such, and all is inner conflict. At other times, the world

and me are in harmony - then all is well.

(Peacocke, 2000a.)

Carol: . . . have got you where you are, but other people don't have, nobody else has those unique life experiences that bring that together and hones it in the way you've honed it.

Shaun: That's why we have advocates here, 'cos our advocates help people to get their thoughts together; that's what they are doing most of the time. They're not actually fighting the cases, they are helping people by saying 'where do you want to go with this?' and help them.

Me: I know where I want to go. I didn't know in the first six months of the course. I'd written it down, but I didn't *see* what exactly I wanted.

Shaun: But that was agreed, wasn't it, at the time?

Me: Yes. Because we worked on the write-up quite a long time before I . . .

Shaun: Yes. And Carol's very clear to you that is what you *should* be doing. You shouldn't be making your conclusions before . . . you needed to just wallow in it, I suppose, get it stuck and get tucked into it, have it all around you. And be chaotic about it as well, and enjoy the chaos.

Me: A friend of mine who was brought up in Hong Kong said that the Chinese say that praise is a gift that you should accept gracefully.

Carol: Yes.

Me: So, thank you for that.

Carol: But I want you to internalise it. At the moment you are . . .

Shaun: ... very hard on yourself.

Carol: I want you to internalise it and make it a part of how you see yourself. I think what you do is, you've got very polite about it and you no longer come up with a mumbled rationale, you've stopped doing that bit but what I don't think you've done, I don't think you've internalised it. So when I came in this morning and said, 'Congratulations,' to you, you looked at me as if to say, 'What the bloody hell have I got to celebrate!' . . .

Me: Yeah. I wondered what you were talking about.

Carol: Alright. And then I said, 'You have got through the Research Committee,' and you went . . . puff . . . or whatever, but you walked off. You wouldn't actually stand there and absorb that, that actually that's a huge achievement for anybody.

Me: Yes. But I've got faith in you and you said it would go . . .

Carol: Nah! Nah! Now. I'm going to stop you using those two words: 'Yes, but . . . ' because what you are trying to do is rationalise it. *I* didn't get through the Research Committee with my proposal, *you* did.

I feel suitably chastened and think back to the original Research Proposal, how wide it was, and how the changes that have happened to me since joining the course were reported on my annual summary, or RD9 form.

A major departure from my initial research effort was a shift of my intellectual focus from such publications as I had been monitoring to a more in-depth look at mental health service user issues, starting from the standpoint of the disability movement as a whole.

Extract from Bournemouth University Monitoring Form RD9, 27 SEP 07

I also began to recall how it had been at the beginning. I remember how I felt and

what I thought when I first chatted to people about my attending this course. I remember what I asked myself, too, because I wrote it all down at the time in what the police like to call a '*Contemporaneous Record*'.

How ill do I think I really am? I get mixed messages and it is incredibly difficult to answer. Rather than judge levels of illness, it's better to think along the lines of mood - what is it like and how is it affecting various functions such as concentration, relationships. The impression is that my mood is severely low a significant proportion of the time, even though mood levels do alter day-to-day. I am clearly not functioning to any degree to what used to be the case - which indicates that there is still significant impairment. Pain sometimes masks my mood, and my ability to maintain a train of thought is sometimes very low. Once I could maintain five or six project lines at once, but now there are times when I have trouble cooking a meal. Yet it does not appear to be mood-correlated.

Sometimes life is a strain, trying to maintain things while all you really want to do is disappear. And it keeps going through my mind that it won't be long now. I do not think I will be around much longer. I will go and do the interview but I do not really believe I will get on the course - mind you, I did not believe I would get on the interview. If I get on the course, I don't believe I will pass it. If I got on the course now, I would not be able to do it; and if I do get offered a place and find in September that I am unable to do the course work, I will have to defer it for a year and let somebody else have the place. It is not something I would want to have a go at and fail because that would really knock me back. But it's all rather academic, as I don't expect to survive beyond August or September anyway. This is a passive view rather than saying, "I will give myself until then and then give in to the desire to kill myself." It is just acceptance of the inevitable.

To see it in respect of the Falklands and Northern Ireland: you can say that the amount of failure in any objective sense was very small but seemed to be huge; and the amount of success in an objective sense was quite large but just felt as if it didn't matter at all. What I'm saying there is about my whole life as I see it.

The core problem is that when I look back on my life I don't see the hours of success, I just see the moments of failure. I need to accommodate them and not see them as the future disasters I seem to think they are. The divorces were my entire fault, and this new relationship will fail, too.

The idea of failure is linked with the apparent success of these relationships,

but they were always on the edge of failure - always walking the edge of failure. It's like I said in the poem, that I am running from the edge - the edge of madness, the edge of failure, the edge of suicide - like I am trying to remain in the centre a large column of normalness, of sane and safe normality, that I use cerebral effort to distract myself from introspection and pull myself from the edge. I need the course to keep me safe and sane.

(Peacocke, 2000a.)

The proposed study, looking back, reads very differently to the way I work now. It is stilted and embedded in the Modernist views on research. I began to embrace post-modernist views after reading about it in a book by Alvesson (2002); but to return to the original application:

I want to research how partnering between mental health service users and providers is actually happening in England; the differences between rural, semi-rural and urban areas; and to compare and contrast differing modes of service delivery by looking at the effects each way of doing things has on it's service users. The philosophy of consultation is embedded in s.11 of the Health and Social Care Act of 2001, itself feeding from and birthing other regulations, and there has been plenty of time for people to comply.

The way I intend to do this is to research what is happening now; to look at the effects on the service users of those areas; judge its efficacy in aiding in service provision; and come to a conclusion as to the best way to do things for all concerned, service users, carers, and the providers of services in order to maximise care.

I would conclude with a discussion on whether mental health service user involvement in England is myth or reality, and whether this is changing for the better, worse, or is remaining static as the service providers change and mutate around them.

I would also try to establish best practice for others to follow.

Extract From 'Listening To Patients: Towards Developing A Model of Service User Representation', 23 JAN 07

How the world changes in a few years! About the only things that are the same are the talking to people and the goal of trying to establish some sort of useful model of best practice for people to follow.

So, initially, I attend an interview with Jerry and all is fine. We sit opposite each other across a large circular wooden table and lean on our elbows. I suddenly think I must be looking slovenly, not the impression I want to give, and sit up straight again. Jerry continues to lean, but he is not the one on trial here, is he? I explain clearly and precisely what my situation is, why I want to do the course – my motivations – and how my illness affects me from time to time. He appears to understand very well and suggests I read some stuff and meet some of the current students while they eat lunch.

The students are sprawled all over the place chewing on a variety of foods, and I feel quite jealous of their closeness and camaraderie. I also feel as if I am intruding into their private world; but they don't seem to mind at all and answer my inane questions fully and honestly. At the end, I ask if they think I would 'fit in' with a study group. The consensus is that, yes, I would fit in very well. I feel encouraged and go home with a light heart to prepare my application. I am loaded with printed paper and references to web pages. I sigh with relief as I pass this milestone. As I drive, my Liverpool University Professor's voice whispers secretly in my head: "If you want a PhD, just go and do it." I am, Laurence, I am, but my uncertainty still remains deep within me.

I am torn. On the one hand, I want to carry on as I have been going as a service user and nothing else. On the other hand, I am driven to educate myself and the peak of an education would be to achieve a doctorate. The thing about doctorates is that I feel I need to do something that will be useful, because to spend four or more years studying a subject that in the end as no practical value seems to me to be a waste of time; that will be doable, in that I will be able to achieve a final result which is being granted a doctorate; and that will hold my interest, because I don't want to get into a situation where the subject becomes of no interest to me yet I am driven to complete the study just for studies sake, which would be awful. I think the subject that I have chosen fulfils those three criteria. So much for a doctorate, now to consider the type

of study I wish to do. A traditional PhD is a very lonely path to follow, and I am not sure that I have the necessary wherewithal to go it alone. I will need help. I have seen from visiting the group that they help each other over the bumps and difficult patches that they encounter as they study. This is quite a departure from the normal route of ploughing your own furrow. I find it quite enticing. The way they help each other smacks of the way we help each other as Service User Representatives in DMHF and this is a model with which I am quite comfortable. My musings as I drive, one eye on the road and one eye on my future, determine me to at least have a go.

Every time I get anywhere near a success something comes along and drags it away without a 'by-your-leave' and leaves me picking up the pieces yet again to the inward strains of Hearts and bloody Flowers by some poxy pipe band from Edinburgh better heard outside my head than inside it but I suppose I deserve everything I get!

(Peacocke, 2000a.)

My original focus remains, and that is to survey services and attempt to determine the efficacy of the service user voice in planning, commissioning and delivering mental health services, and how these services hold up to comparison with other areas of England.

I spread my net wide, too wide it now transpires, but wide I spread it. I also want to survey other service user organisations in the charity and voluntary or 'Third' sector and see how they are doing with their representatives, how far up the ladder of participation they have clawed their way. In the end, I want the study to be useful or at least utilitarian, though Fran and Carol are adamant that the goal is not utilitarian products but passing this doctorate by following the programme and doing the necessary work. I agree, but it would be nice to be able to offer the mental health world writ large a model of service user participation that minimises risk (to all sides of an equation like this) and maximises service user voice and influence. I believe this to be a model that can be used across the Western world, as one thing is very much like another here and there, and would love to be the initial author of such a thing. Ah well, *c'est la vie*.

I remember coming to the end of preparing my paper. I entitle it: “*Listening to patients: developing a model of service user representation*” and begin it with a quote from Shaun, my manager: “It has to be about more than people feeling good about themselves – or does it?” This, I feel, sums up the whole of my study, so I submit the paperwork and wait.

Soon, I am called forward for a more formal interview at one of the Christchurch Road offices of Bournemouth University, and sit nervously as the panel members quiz me about my submission and what it all means in practice. There has been a gap of a couple of months, a summer, I think, between my submitting the application and being called for this interview. During this gap the world of user representation has moved forward so that I feel, deep down and hidden from these observers, that my proposal is no longer extant, contemporary, up-to-date. This leaves me a bit wobbly, but everyone is very kind.

A second undermining occurs the night before when I reread my submission and actually wonder *who* has written it – but this has always been the way of things with me as I still wonder who exactly wrote my Master’s thesis (Peacocke, 2000b) - even though the painful memories of 3 AM mornings writing it while the wind and rain rages up Mount Pleasant through the orange Liverpool night outside the Post-Graduate Centre’s grimy picture windows live on inside me. I reflect a little and relax into ‘interview mode’, as my military instructor calls it on the day I retire from the Army.

This is my first meeting with Carol, and I remember her quite clearly, sitting in the sun streaming in the windows behind her to bounce blindingly off the gathered modular tables, framing her hair as a halo. I am appreciative of the beauty of the situation but am also aware of her look of astonishment as she says: “That seems to be enough for ten PhDs!” I worry that I have overdone things again, over-egged the pudding, thrown my net much too wide for a successful study for this University, screwed up at the application phase. I feel my arms go goose bumpy with apprehension and swallow silently (I hope) from a suddenly dry mouth. I feel a

rejection coming my way and prepare myself for it, tensing my emotional muscles in the old, old ways. Here it comes . . .

Jerry: I think, that is if you have no further questions . . . I think that is all we need now, Richard. I think we will need to chat it over a bit between us and then let you know by post as soon as we can.

He smiles the Hangman's Smile and I steel myself for my traditional ending to all interviews, successful or not, designed to leave the door open for future applications.

Me: No. That's fine. Thank you all so much for listening so patiently. I will look out for your letter, then?

Jerry: Yes. We'll get it out as soon as we can. Don't worry.

Carol: Yes. Thank you for coming over, Richard.

This is unexpected from a panel member, so I am a little more positive as I shake hands all round and exit the room. Walking down the corridors and stairwells little was I to know how very familiar these would become to me.

Soon the dread envelope arrives through my front door to lie bleeding potential failure and other bad news all over the doormat as I stare at it. Jack, my dog, sniffs it and walks away: '*Definitely bad news!*' I tell myself, and nervously bend down to pick it up off the harsh surface on which it is resting. I slash it open with a kitchen knife and disembowel the hatefully precious crisp white sheet from its belly. I read. I have been successful. I reread it and reread it not believing my rather out-of-focus eyes. Yep, accepted! I almost whoop with joy. Success. Good. Now to get stuck in! I carefully fold the letter away again and put it somewhere safe.

Several months later, feeling a little wan for no better reason than having a chemical imbalance of the brain (or so *They* say), I struggle out of bed to collect the mail. The distance is not far from bed to door to kitchen but in the depths of depression it feels

a nightmarish mile. I fall back into bed having downed a glass of warm tap water for breakfast – well, I *did* promise the community psychiatric team care co-ordinator (an approved social worker or ‘ASW’) that I would have *something* for breakfast each day; in this case, today, plain warm water.

The rooms are all in close proximity to each other and on the level as I am living in my first floor flat. I dump the letters into the basin, soak them well, turn and go back to a smelly bed – something to do with not washing for a while?

It buzzes maniacally and buzzes and buzzes, so I pick up the telephone handset from the royal blue bedside table. I am greeted by Jerry’s voice that tells me this year’s intake have almost all quit *en bloc*, leaving too small a cohort to move the course on. Can I wait a year? I am now feeling decidedly down in the mouth. I suppose I have no real choice, so why ask? Just tell me. I am despondent at the thought of waiting a further year but there you go. Nothing else for it but to press on regardless.

Time passes slowly in my feather-pillowed bed and as I snooze, I dream once more
...

Army Dream

(2005)

I am living in barracks - new barracks - attending a mixed-service helicopter pilot course. I have passed all the tests, but have not yet graduated on parade. This is about to happen. I feel that I should not attend the parade as I do not deserve to be there. I lie on my bunk and decide not to attend.

My conscience pricks me and I look past the grey suits and fluffy floral frocks at the dark morning outside my barrack room window. I feel that I must attend. If I do not attend I will be letting down my classmates. If I do attend and am made to look a fool, then I am only letting myself down. I decide to have a shave and get ready.

I cannot find a new razor with which to shave so I use an old and dull one. I cut

myself shaving my chin and bleed onto the ceramics, the trickles of bright red moving. You do get to tell people more quickly from one another. Then I cannot find a uniform shirt to wear, so don't bother to attend the parade after all. It all seems like much too much effort. I watch the parade from the top windows of the building.

I then move to meet my family after the parade at a small and crowded café shadowed by a large forward-leaning old master of a building. They are disappointed that I had not paraded with the others. So was I, but I shrug it off.

I do not feel part of the group anymore.

I suppose if I were to reflect on this time, then it could have been seen as somewhat beneficial for me to be such a slough at the time of the knock-back, as I did not have the energy to react against it for some time. The fact that I had been put back a year seemed to be par for the course and so I wasn't surprised to hear the news. It all seemed like a bit of a dream at the time, a dream similar to that of the dreams I have had, in which I take part but am not a player in the unfolding action. I felt unempowered and in the hands of others. To expand, I felt that the University and the staff and the other course members on the previous cohort and everything to do with it were all *Other* to me (Canales, 2000). I did not feel that I was yet a part of it, merely a pawn in their game. My reality lay in my illness, which at that time was all pervading and debilitating. I lacked the energy to follow anything up and this lasted for quite some time.

When I came to reflect on the situation, I felt that it had some resonance with my time in the Army. Because I had spent two years from the age of 15 to 17 training for the Navy, when I arrived at the training camp for the Army I had great difficulty in changing my way of marching (and, also, my attitude stank) which resulted in me being 'back-squadded', meaning I had to join the class that had started after I had. This resulted in me graduating from my training a month or so later than my original classmates and also that I had something of a black mark against my name from the beginning. However, even after that setback, I still managed a successful career, so this experience tempered my reaction to being 'back-squadded' by the University. Another relevant consideration was that I was being put on hold for something that

other people had done, so I was not responsible for my own delay as I had been in the Army. Such considerations bolstered my determination to begin the course with the next cohort and in the meantime to continue researching my chosen subject. I felt that this would go some way to informing the course of my studies. Anyway, let's go back to that time and see what happens.

Time passes and I become well again and am able to work a little. Shaun and I have many discussions about how the services are developing and I digest many many Government and Quango papers, all seemingly saying the same things, that mental health services will be undergoing radical changes in the next few years, *radical* changes. I note and note. I have now put the course to the back of my mind but continue to research various publications and websites for information to inform my job.

I wait. After a year, I receive a letter from the University saying that they hope to be able to start a new cohort for the next academic year starting, unusually for a post-graduate course, in September, and would I still like to attend as they want to know whether I need the full joining pack of literature (again) before sending it off. I reassure them that I am still interested, and subsequently get sent a pack of regulations and codes of conduct and course profiles and University-this and University-that; and I wilt at the size of the pile in front of me, unable to believe that I would ever be able to get through it all. I mean, look how *small* some of the typefaces are! I'll need a microscope or something. Nevertheless, I manage it.

I Join the Course

In due time the course starts, and I find myself as part of the University, no longer '*Other*'. Part of the course, and the part I value most, is designed to allow the doctoral students to help each other over the inevitable humps and bumps in the road during their four or more years journey. One part of this aspect is the bi-monthly meetings with Kate and Les, where we all get together and chinwag about our time on research while apart, and then ask probing or inane questions of each other. After one such meeting, the whole group went out and we ate lunch together, which was very nice.

The course has another side besides the academic facets of literature reviews and thesis production. One of its main thrusts is to demonstrate that one has undergone professional development because of one's experiences on and away from the course. The way we do this is by maintaining a reflective practice diary or journal. Rather than a chronological reportage of what happens and when, this is seen rather as a series of further musings on key stages in one's journey to the final submission and viva voce four years or more hence.

I have been a part of the Doctor of Professional Practice course for some years now and my Further Musings on how it has impacted my professional world are legion. I am developing a broader understanding of the way policy is shaped and why, through how it is implemented locally and nationally, to seeing why some initiatives fail, some are stopped, and some just trickle away to dust before my eyes. Allied to this is an enhanced personal practice with a sense that I am more able to cope with the demands of being a Service User Representative and can help others to weather their respective storms, too.

A large part of this professional development is closely linked with the subject of my study, the development of a model of mental health services user participation in their own care packages. They are symbiotic, Siamese twins, inseparable in their closeness, part of which is developing a clearer understanding of the role of a Service User Representative and getting that description down on paper. Before I can attempt this, though, I have to pass through the fire of indecision of my first year.

My First University Year

My first year saw me trying hard to apply quantitative methods to my study and each time coming up against the enormity of it all. Slowly I would shrink my ambitions from a survey of the whole of England and Wales, to only England, to only the Southwest of England, to only Dorset's two provider trusts and three service user-led mental health organisations, and yet it *still* seemed too wide! I was annoyed and distraught, depressed and anxious about the future of the study, lost in a welter of Government papers and guidance and websites and everything else awfully

important but awfully long-winded and awfully dry. I stopped.

I recall the scene. The cohort members are sitting in the individual blue fabric study chairs arranged in a semi-circle in the study room. There are two men and the rest are women. As Carol said, during one of our supervision meetings:

Carol: No meeting, no committee, no interaction happens in a void or vacuum. There is always something going on at a psychosexual level - even in this meeting - and there are negotiations that go on about positioning, about roles; and I don't think we talk about that enough [. . .] They are all dogged by all sorts of things: sexuality, gender, construction of roles, who you are. The whole thing about being a Service User Representative is around construction: how are you constructed going into a meeting? How does that differ going across meetings?

I see Carol's point. I have been aware of my ability to manipulate certain women, as well as my weakness at being able to be manipulated by attractive women; and this has, as Carol said (and I'm sure it wasn't a parapraxis), been dogged by the effects of these actions. Sometimes, the subsequent Transference/Countertransference is high enough to trigger an affair. Though that hasn't happened for quite a few years now, it did happen once or twice in the 1970s. What happens to me now is that my damaged sense of Self and self-worth, my wobbly Core Self, my self-image of a balding smelly fat ugly old man acts to keep down any vain or unbecoming thoughts that might obtrude from time to time. Keeps me from harming myself too much by pursuing the unattainable, or what I perceive to be the unattainable. You know, reflecting on this makes me wonder how I ever got engaged to Stephanie in the first place? I wrote a small poem some time ago about how I felt about myself and how I believed others should feel about me. Although written in 1999, this is how I still feel about myself today and I struggle with it every day.

ROUND WE GO

To touch me is to know me,
But to touch me is taboo.
To know me is to hate me;
And I hate me as you do.
To hate me is to love me,
And that's too far for you.
To love me is to kill me,
But just let me do that too.

Richard Peacocke, 1999

Anyway, let's rejoin that initial meeting in the over-warm room with the Bournemouth traffic thundering and screeching outside the windows. I am separating out the students and categorising them quite ruthlessly before they have even spoken to each other or to me! I do that. I make snap judgements as to character and likeability within perhaps the first thirty seconds and then it takes a great deal to shift me from my initial assessment. Mind you, it is not so often that I am proved wrong, but that doesn't mean doing that is useful or helpful – it's just what I do. I am quite sure I'm not alone either.

So here we are, seated roughly in a pow-wow circle, with Kate and Jerry and Les seated amongst us but slightly divorced from the student group as one might expect. Our energy levels are on the up because of the anxiety for what might happen, and this increases the levels of libidinous thinking in people in general and me in particular – this is often quite a natural reaction to stress and fear (Block, 2005). I glance around the room and establish a pecking order of students based purely and shallowly on their perceived attractiveness, and then I forget all about it to try to concentrate on listening to Jerry as he tries, in his turn, to explain the inexplicable – University administrative processes. I half listen and think that they are as good and as bad as Liverpool University's and Surrey University's and Bath University's, so don't mind them really. They are always there and are always a bit of a Curate's Egg.

Les and Kate sit quietly, no doubt making their own internal assessments of us as I have done of them, as Jerry rumbles and mumbles and squeaks and growls ever onwards through his maze of administration and cut-off days and library loans and phone numbers and access to the University website and on and on: *Ad infinitum ad nauseum*.

I let my thoughts drift away as the poor chap with the thankless but necessary task continues as just a soothing murmur in the background. I can smell the aromas of fresh coffee, dusty sun-warmed corporate carpet and ladies' perfumes, and they make an interesting combination and an interesting task to unravel them and take them back to their sources. The sun is bright enough and low enough to cause harsh shadows to fall in front of us towards the tutors or whatever they are called today: Tutors, teachers, lecturers, supervisors, or whatever, they all seem to do the same thing which is to help and guide the student to a successful doctoral conclusion, and if they are not doing it then they are not doing their jobs.

Jerry's voice suddenly stops and he smiles as he sees all the rapt faces with blank expressions staring at him.

Jerry: There is quite a lot there but you have plenty of time to mull things over. Please do email me or come and see me if you have any questions about these regulations at all, and I will do my best to sort it out for you.

Les: Thank you, Jerry. Jerry is going to leave us now as he has a lot to do and we need to get on. Firstly I would like to introduce Kate who is a professor here and in charge of this department. I am Les and you will, I am sure, get to know us both a lot better as we go forward. We will meet with you on these allocated days, but please do look at the notice boards so that you will know which room to come to, because a lot of major building works will be taking place so we might need to alter venues at short notice.

And so the morning goes on. I have brought sandwiches because I expect to be here

all day, with *Principles of Enquiry* lectures in the afternoon, but these are being held on Wednesdays, which my Forum work stops me from attending. Crazy, eh? Advertising one timetable and using another when it comes to it. Sigh!

The main point I am trying to make is that, at the time of this first meeting I was still set in a Modernist frame or paradigm. How this was altered into a Post-modernist outlook has been suggested as one central strand to the thesis, and I explore this further in the methodology section. I think the main point is that I came away from my two Masters courses with a quantitative outlook on science. This is not surprising as the first course was focused around a dry study of the psychology of driving and low level speeding, and the second course was in forensic and biological anthropology, during which we dealt with dead bodies and dry bones. I recall in both cases feeling that there was more to be had from the studies than we were looking at. In the first study, my questionnaires came back covered in extra information written by the respondents to amplify their answers. These extra notes were at the time ignored and I felt that this was a weakness in my study, but the environment in which I was studying was one that did not encourage qualitative thinking and so I reluctantly didn't follow that up. I recall with my second course, querying whether people who studied gravesites and so on had any consideration for the people who had been interred. The answer came back that they did, but this was not emphasised on the course where the qualitative aspects of things were not discussed. In both cases I felt dissatisfied with the results of my studies even though they were accepted heartily by the schools and I passed the courses.

Another suggested strand is the process I employ to harvest my constituents of their own individual 'truths' and use them to modify my views. Consequently, I discuss these tactics further on in this thesis. Some people have some labels, others have others, but the majority of people work to their own world views, and the longer they are exposed to their illnesses, the longer they are under the 'care' of the community mental health team members, the more difficult it becomes to shift them and get them turn up to rallies and so on. But the 2007 revision of the Mental Health Act 1983 is not really helping matters in that people can be detained in the community under Supervised Community Treatment or SCT, section 17A, meaning that people

who before would be treated in the community under section 17 after having been detained under section 3, with all the checks and balances inherent in that, are now detained under section 17A under what is called a CTO or Community Treatment Order, it being renewed after the first six months and then annually thereafter, and potentially existing for quite a long time without very many questions being asked of the professionals. This is a worry. On the one hand, people get used to being under the CTO with its implications of being cared for by the professionals and so engendering a feeling of security, and on the other hand feeding into risk aversion beliefs in the staff themselves, with yet again feelings of security for them.

I was clear in those days of where I was going and what I was doing, but all that was about to change, as I was soon to find out. I have already alluded to a shift in my thinking away from quantitative towards qualitative research paradigms. I have been unsure for sometime about the right route to follow and am finding great frustration in my seeming inability to do the simplest thing, to design a questionnaire to elicit data for my Shye's Smallest Space Facet Analysis (Shye *et al.* 1994). I have my copy of SPSS, which had cost very little, and I have attended the week-long course on SPSS and its utility in crunching vast arrays of numbers, and bought the book – but I knew all this as it was what my Master's dissertation was based on after all. Yet, I am still unable to develop a plan of action; I do not even have a central question in order to move the study forward.

This sad state of mind causes me to pick up whispers to look at qualitative research methods, and I do, and I discuss these further below in the methodology section. I think the main point here is that I am beginning to move methodologically from a purely quantitative stance through mixed methods to a more qualitative way of looking at things. These are more loose and flexible, and seem much more suited than any questionnaire-based quantitative number-crunch. But, because I am an old stick-in-the-mud and hard to convince, I look at mixed methods first and attend a seminar on it. Subsequent attendance at Kip's Performative Social Sciences Masterclass during which we are exhorted to bring performance into the social sciences to enhance understandability, to use music and form and other artistic means to explain the results of our social science studies, finally convinces me that I have the necessary imagination and emotion-writing skills to attempt a full-on

qualitative research paper.

I review my past writing to assess what I had done before and find several poems and stories from when I first became unstable.

NUMB

It feels numb inside my head,
With sounds blocked by the hissing
And pain only at surface level.

It feels numb inside my heart,
With loved ones banging on the walls
Yet all the gates locked from outside.

It feels numb inside my mind,
With thoughts wheeling and plunging
From great heights to endless messy depths.

It feels numb inside my soul,
With a struggling child trapped forever
Inside a crystal cage.

Richard L Peacocke, 2000. Dorset

I re-read them and am quite impressed, again wondering who wrote them and realising again that it had to have been me! I am heartened and feel much more positive about my own abilities.

I remember my meeting with Fran where we discuss approaches to my work. I stand and play with his musical bowl while he suggests autoethnography as a way forward for my particular subject. I know nothing about the method but say I will look

around it and decide before we meet again. He is much gentler than that and stresses it is not an instruction but merely a suggestion, but I am always harder on myself than anyone else would be. That has always, again, been one of my problems and usually leads to breakdowns and dissociation and other mental illnesses.

I know deep inside that there is nothing I can do to stop it as my life slowly - so painfully slowly - unravels before my eyes like a cartoon character's woolly jumper. I had hoped against hope that if I worked harder and longer, and shoved it deep beneath the surface, that all would be well in the end (because doesn't everything always turn out for the best in the end?), but that just made things worse. As I piled layer upon layer of new life-skin across the pustulating boil of the hurt-unresolved, it did not decrease but grew more compressed and concentrated. There began a competition between the outward pressure of the boil and the containment strength of the life-skins. This competition had, in the end, to be resolved: but then who thinks of the future when the present is going so well?

(Peacocke, 2000a)

So, what exactly am I going to write about? The discussion has been and gone and Fran and Carol again help me formulate my thoughts, help my loose ideas congeal into a definite plan of action, help me to see what is needed and how I am going to do it. I realise, as they speak, that none of the ideas are theirs, but mine. They are helping me along a path and now I have to push on alone for a while.

My ideas have matured from the descriptive study leading to a model of participation outlined in my application papers, through my research review where I move closer to the qualitative paradigms of research of words vs numbers, subjective vs objective, and discovery vs proof, with the characteristics of qualitative research being research carried out with an exploratory and descriptive focus, an emergent design, data being collected in a natural setting, with the emphasis on human-as-instrument, and with early and ongoing inductive analysis (Creswell, 1994). One thing that I need to polish up on is my methods of data collection. These need to be multi-method in focus involving an interpretative and naturalistic approach to its subject matter (Denzin and Lincoln, 1994, page 105), yet still echoing to my Modernist past, to my current focus on producing an autoethnographic study. This

shift has been somewhat problematic, as I came to this programme as a 'hard' scientist, one used to the mathematical method of working such as I described above, of a method of working that is putatively dependable and precise, and am having to rethink the whole thing from a perspective 180° away from my previous ideas.

Previously, I was divorced from the action, as it were. I would be surveying the population sample I had selected (in whatever way) and making assumptions from analysing the collected data, to come to a conclusion and a developed model – all 'proven' as 'true' by smallest space analysis and other statistical methods.

My new thinking is the other way around. As I say, 180° the other way round. My journey there passed through a halfway point of considering mixed methods research.

Literature reviewing will occur mainly in first year but then continuously throughout the period of the research project. The review aims to identify two strands to the research, that of the administrative view through Government papers and the like and that of the underlying philosophical currents driving changes, through perusal of academic and social science literature.

Qualitative research based on interviews with actors. I have not delved into the details of the who, what and how this involves, but my previous works and the issues thrown up by that will drive it, as will engaging with service users and carers.

Quantitative research based around postal and/or internet-based questionnaires. Again, design will be driven very much by the results of the literature review and unfolding events.

I think the main point is that this is envisaged as being a combination-methods research project where objective-subjective and qualitative-quantitative dichotomies will be avoided, and service users and carers' direct personal knowledge and experiences will be engaged. This is in line with the latest emancipatory paradigms in social science research theory .

Extract from my RD6 Initial Review, 11 April 2007

My mind returns to the meeting between Fran and Carol and myself being held in the bright-windowed over-warm and stuffy meeting room at the Forum, where we revisit my original ideas and the changes that have led to my current philosophical and methodological stance. I suggest that the focus of my study falls between the two extremes, and seems to weave a path between them, also; that the original idea has slipped and changed, morphed, into '*Solace*'.

Carol: You are both of those things and all the points in between. That's your autoethnography; that initially your perceptions of doing this research were about producing something very clinical, cool, professional-in-inverted-commas, but now the pendulum has swung the other way and it is now much more to do with service user experiences and how you have put that to good use in the role that you've got. And there is all that stuff in the middle which is to do with adding to that professional persona that you came into this programme with - you do that by accessing other people's stories and taking them in, so that the person who goes in to represent other service users has a much different perception that they take into a room. And I think that's a huge piece of work and plenty for your thesis. If you map how you got from the 'Model' to 'Solace', wanting to be a Prof Doc, wanting your professional and academic skills to be recognised, into 'actually this is about solace; this is about people finding peace and being received well', that's a huge journey in itself. And, in the end, you can still have both because you understand the role of Service User Representative in terms of the 'Solace', but what you are doing in terms of tasks and achievements is to do with the beginning bit. That's absolutely fantastic, isn't it?

Fran: I think it's a matter of finding a balance between the two potential theses. All of a sudden you discover Performative Social Science...

Me: The performative social science resonates because I suddenly saw what I do all the time is perform - for example, by the way I dress. I manipulate

people's initial perceptions by offering signals - and those signals count. Kip's course formalised what I thought about what I was doing. [...] But the first thing is to focus on the core issues, and I felt the core fell somewhere between the two extremes. The movement between that and where I am now is something I would like to map.

Carol: And being a good Service User Representative is about movement between those two places. It's about the movement between the performing and having a role in a very prescribed sense in relation to other organisations, etcetera, but it's also about that seeking Solace and making sure that subjective experience always fronts what you do in your role. You seem to have moved from the detached position of almost looking at something as though through a microscope into saying: "Actually, that's me under the microscope!"

Fran: Yes. Real World stuff . . .

We then settle down to discussing studying how to write and how Carolyn Ellis views autoethnography in her 2004 book, *The Ethnographic I*, and how my skills drop into this view.

Carol: Could you write a chapter, without thinking about it too much? About the journey you've taken and how it's been for you - including all the feelings attached to it? From the beginning to now? Because that would probably prove to you that you are capable of writing in an holistic way rather than clinically.

Fran: I think that is a very good idea.

Carol goes on to explain in some detail how she envisages this new piece of writing will appear and how it will steady my course between the two viewpoints as I journey down the research and writing road stretching out ahead of me. Fran suggests a further refinement in the story being paralleled by the story of my life . . .

Fran: . . . and the Prof Doc is part of that, because your life is so closely intertwined with what you do and who you are that the Prof Doc is part of that - not the other way round.

We discuss ideas around acceptance and I am all the time mulling over that these two people really think I can do this. They, foolish people, have faith in me; a faith I lack. I have fallen at so many final hurdles that this will probably be the latest and greatest fall yet – saving my divorces and relationships going West in the face of my increasing illness. Fran, I think, is starting to fret a little about time, so he seems to initiate the end game for us.

Fran: I think it is important now to get something down on paper towards the transfer - perhaps more than the two or three pages that Carol suggests.

Carol: It will give us something to help Richard with, because the dates are rushing towards us . . .

Fran: Yes. Some sort of Chapter One would be good for our next meeting.

We discuss technical writing matters and issues around detail and mood and atmosphere, and then I broach the subject of a start time for the writing.

Me: The last time we met you said the story could start then and now you are suggesting I start at the beginning - there is a change here that is confusing . . .

Fran: Well, I think you should start now, here.

So I have.

*

As was said within it, the story you have just read is an introduction to the subject matter of this thesis and to the ways in which it will be presented. It is a description of the move from just looking for a model of service user representation work to seeking out the reasons behind why one would want to do that work. As such it encompasses discussions between me and my helping team embedded in embedded within my lived experience at the time.

I will illustrate and explain this doctoral journey through the use of autoethnographic vignettes. The reasons behind the use of autoethnography are that we will be observing my life through my eyes and how I react to things through my feelings – I will be putting myself under the microscope, if you like – and that the evocative nature of the stories will have an emotional impact on the reader. These original researches, based on personal observations, will be given more depth and richness, more phenomenological thickness and *punctum* (Van Manen, 2008), or the semiotic notion of punch to the writing, through the examination of my personal story rather than coldly explaining what happens in general and trying to analyse that. Any passing reference to other people will be purely that, a passing anonymous reference that is used to lead to a series of self-reflections on my role as an SUR, and in no way is it to be regarded as a descriptor or criticism of their work or personal life stories. To attempt such would be unethical. The system under review is that which changes a person from being a *Normal* (Goffman, 1963) to a user of mental health services, and the modifications to that stigmatised self required for the person to morph into a professionalised Service User Representative, or Peer Specialist as they are becoming known, without losing meaningful contact with his or her peers.

The above story of the journey is necessarily long because it sets the scene for all subsequent stories in this collection as well as laying the ground for developing my thesis and explaining how the thesis sits within the Bournemouth University rules and regulations for the granting of a Doctorate in Professional Practice.

I also show development in my work that is associated with this doctoral journey. This is evidenced by my professional progression throughout the period of this study: I developed from a very part-time office help-meet and nothing much more at the beginning of this study, through my involvement in service provision and

commissioning as a Service User Representative with West Dorset Mental Health Forum – as well as developing our website, suggesting a new name for our charity to allow for expansion across the whole of Dorset, and writing articles for our magazine – to my current employment as a Consultant Peer Specialist with Dorset Mental Health Forum. I have written, developed, marketed and delivered teaching seminars on a variety of mental health-themed subjects to NHS and Council-employed front-line staff at various levels as well as to other Peer Specialists at the Forum; I have progressed through being Vice Chair of a Patient and Public Involvement Forum, carrying out investigations prompted by public concern, and inspections of hospital premises with their resultant reports, to employment as a Mental Health Act Hospital Manager with both Dorset Primary Care Trust (DPCT) and Dorset Healthcare University NHS Foundation Trust (DHUFT) adjudicating on panel hearings of patients’ appeals against their detentions under the Mental Health Act – in this role, we also inspect mental health hospital wards for cleanliness and fitness for use, and check the correctness of detained patients’ personalised care and computer- and paperwork-based files and reports; I have also undertaken inspections of hospital premises for the trusts as a member of various Patient Environment Action Teams; I have been appointed as an Expert Patient Programme tutor; I am Personalisation lead for DMHF; I have worked with Bristol University, the University of the West of England, and national Mind and Rethink Mental Illness charities in research roles; I have worked as a team member with The King’s Fund on a two-year long project to refurbish DPCT’s Electroconvulsive Therapy Suite at Forston Clinic; I have presented parts of my research to various peer groups as well as to a conference of Mental Health Nursing Managers; I have had three vignettes and a poem published in a recent book (Grant *et al.*, 2011) as well as articles in an academic nursing journal; and I have reviewed articles and books and am a volunteer peer reviewer for the Journal of Psychiatric and Mental Health Nursing.

All this has been achieved during the course of this study, and also owes a lot to my mental health development through the course, as well as the coursework reflecting my recovery path. Reflexivity being a core part of my studies has helped me to look inside myself and see how my practice affects me and, thus, other people as well. I found it difficult at first, having been trained in the positivist tradition of research, to effectively access my own feelings no matter those of others. Practice at reflective

journalism and feedback over the period from my supervisory team and peers on the course have all contributed to the development of my reflexive abilities. This movement down my recovery path does not mean I am well and cured from whatever ails me. I remain mentally unwell and under the care of a Consultant Psychiatrist, and in need of psychiatric medications to maintain my current level of wellbeing and recovery.

When all this has been successfully achieved, the useful tools that come out of this new learning will be suitably promulgated via the appropriate media. I intend to write articles for professional journals, and to develop the text of my thesis into a more readily accessible book aimed at a lay readership. I shall also take part in seminars within my subject area.

This journey has given me great satisfaction. From being frustrated at being powerless and unable to influence situations that I saw as being unfair or not equitable or efficient to becoming skilled in the art of communication and thus being able to convince others service users and providers and commissioners of services that there is a better way is a large move forward in my professional abilities.

The next section is described as 'Background' and is offered as a quick guide to the various methods and strategies I have employed during the writing of this thesis.

Following this is a chapter that describes to the reader, in finer detail, how the autoethnographic style of research came into my ken and what I did with it. It is a journey through the deliberations that ended in autoethnography being chosen as methodology, the way I see the world and knowledge and how this might be made known, and method, the means by which I will gather data for this study: The above story showed part of that journey and this puts more flesh onto its bones.

The final chapter for this part of the thesis is a discussion around ethics and how they pertain to autoethnographic study in general and this study in particular. This will take us to the end of part one and round off the method and methodology section.

Background Section

A little thinking around the background to this thesis is required at this stage in order to make the paper more accessible to the lay reader. There are basic aspects of ethics and of representation and representativeness that might be approached usefully, as are issues around being a service provider at the same time as being a service user. Although these topics are covered elsewhere in the thesis in depth, it might be prudent to quickly address them here. However, I imagine that the main topics with which people unfamiliar with the autoethnographic method become uncomfortable are those of the traditional literature search; the finer details of the methodological approach, delineating the pros and cons of the qualitative approach in particular; and a reflection on reflection as a study tool in and of itself.

Maybe we can start with thinking about just why I settled on a qualitative approach rather than a more usual quantitative one expected of a *hard* scientist such as I had been in the past. It is described more fully in the text, but basically I was uncomfortable with the amount of wasted data from my previous studies. When I sent out questionnaires, it was generally accepted that only a proportion of them would come back, and when they did they would have writings in the margins and further explanations on separate sheets of paper, all of which I was ignoring. Why were so few returned? Why the extra information? Why were some defaced and yet returned? What were these people trying to tell me? None of this was being considered, just the tick box score for my database statistical calculations, proving or otherwise my hypotheses. As I reflected on this phenomenon, I became more uncomfortable but lacked guidance as to where to go to look for answers to my questions. I was working in a hard science environment and such questions tended to be frowned upon - but tantalising hints of other approaches came my way once in a while. I recall during my Masters studies into forensic and biological anthropology decrying the seeming lack of personalisation when examining skeletal remains. I got a message back from, I think, a Nottingham University lecturer saying she felt exactly the same way and that many of her colleagues did so, too.

When I began the doctoral journey, I was still wedded to the quantitative way of

looking at things. I was, at the same time, conscious that there was another way. I, therefore, took some time and researched qualitative study methods in quite some depth, even producing a playlet to illustrate my journey thus far in my studies to the other students. I attended several qualitative Masterclasses but it was the revelation of attending Dr Kip Jones' Performative Social Science masterclass that finally convinced me of the correctness of my choice of approach. In this two-day class, Kip explained that everybody is at all times 'playing a part' and that examination and manipulation of these 'parts' can elicit and transmit to others valuable social information not accessible in other ways. I had already researched many qualitative methods but felt none really fit the bill as far as my study was concerned. I recognised that there were certain disadvantages to adopting a qualitative method such as the researcher of a study being necessarily heavily involved in the process, being stripped and laid bare, which has ethical considerations attached to it. An autoethnographic study only uses one person - the researcher - so, although ethical considerations must of necessity always apply even here of course, often reflections on practice are based on conversations with others. These conversations reveal perspectives which are useful to reflect on but they do not constitute formal 'data' of any sort, and only give the researcher a subjective view of the study and its participants. There may also be an in-built 'blindness' to other relevant aspects of the subject that a more statistical approach might have pulled out.

Further reflections on the disadvantages of using a qualitative method reveal that the demands of qualitative research and especially autoethnography on the researcher are clearly onerous. For example, often my studies would lead to ruminations on my own situation and a temporary worsening of my mental health, my mood. Happily, this also worked the other way and helped me to understand myself more fully. However, this to-ing and fro-ing often left me enervated and listless and so the study had to take a back seat until strength returned. On another tack, qualitative research fails to provide factual information which might help fill in the context for readers, for example the numbers of service users who become SURs in a particular area, or measuring the impact SURs might have had on the quality or provision of services. There are no doubt issues around generalisability with all qualitative research across a particular service or phenomenon, and influencing practice and policy often relies on this as its 'evidence', particularly around the notion of effectiveness in services or

treatments. However, qualitative research cannot usefully 'test' the efficacy of a model such as the one I have developed for the same reasons, in that different parameters and measures need to be taken which would require the use of a different methodology. Further, NICE currently maintains a Positivist stance toward evidence and this very powerfully limits access to the allocation of public money for treatments and services to those which have been 'proved' effective (particularly around cost/benefit analysis using traditional quantitative methods and analysis). This is lately starting to come under challenge as reported in the press, whereby the importance of people's personal stories have been highlighted leading decision-makers to effect changes, and there may be more changes based on such stories in the future. This is because the evocative power of subjective lived experiences revealed through qualitative research is beginning to have an influence, particularly in terms of mental health and wellbeing and around the privileging of the service user voice in shaping and delivering services. I believe this was one of the original reasons behind the enlightened move towards using 'Experts by Experience', encouraging the growth of the service user-led movement in the UK, and encouraging service providers to listen and take heed of the service user voice. It must also be cost-effective - without any 'proof' being offered here beyond the lived experience observation that financially hard-pressed Healthcare Trusts and Councils continue to use and pay for our services.

The literature search, central to any form of research, is quickly dealt with. As I describe, I started with an idea, that of service user representation within the mental health world, and as a part of my work at DMHF read and précised reams of Government papers, the *Grey Literature*. Many of these quoted references that I followed up. At each stage, I noted the details of the sources I had used, as well as usable quotes, alongside a précis of the whole text to remind myself later about what I had read. I soon accumulated a large collection of photocopied pages and a pile of magazine articles. These initial readings led to further texts and so on. So, the basic research was completed quite easily. The more in-depth reading began in earnest when I began my formal studies at the university. I started by visiting the library and asking for some guidance to get started from the staff there. They were more than happy to help and pointed me to several core books and articles, for example on ethics and post-modernism in the social sciences. Again, these led to further

readings, some serendipitously by being near each other on the library shelves, and others by following their references to source and seeking out their core material where possible. As the reading became more focussed and intense, I found it was necessary to purchase books not held by the library, some from the USA by mail order. There were also core books that I felt it was necessary to own so that I could refer to them more frequently over a longer time frame than the library loan system allowed. And some I liked so much, I just wanted to own a copy for my library at home. This is how the literature searches progressed, diving down many dead ends and cruising along boulevards of knowledge, until I felt I had accumulated enough material to make a reasoned judgement on whichever topic I was pursuing at that time. This search is reflected throughout the text of the thesis as it occurred and a comprehensive reference list is at the end of the thesis.

I expand more on my journey further into the thesis, but to address it quickly here we can look at how this journey has affected me. In general, ethically researchers have been less careful about the effects our researches will have on ourselves than on others, and without such consideration, we might become almost inadvertently wounded by our discoveries. This is covered further in the ethics section below. To address another aspect of concern, by looking deeply at why I do things as I do, and did things as I did, I understand more about the mechanisms underlying my work and life. I have become much less self-critical, more understanding and tolerant of others. Did I see these changes coming? Absolutely not. Do I regret passing through this process? Again, no. However, I think that these potential changes should be viewed as an ethical consideration for anyone else thinking of pursuing this or a similar course of study.

Ethically, we researchers have been very careful about how our studies affect others, whether they might be harmful or hurtful or whether they would tend to make a difference and whether that difference is acceptable, by which I mean whether the risks are outweighed by the benefits. Such considerations were deployed in my including the story of a service user's experience of electroconvulsive therapy (ECT). The story was collected initially as a conversation between several SURs but I found it so interesting that I felt it needed writing down so that I could read it in more detail later on. Now, as we know, the collection of data from live subjects

requires prior ethical approval. However, this was not data *per se*. Indeed, my autoethnographic study does not deal with ‘data’ but with the results of my reflections on my life as a SUR in order to better my practice. This piece of information was included in the study purely as an illustration of one method of reflecting on and modifying my practice. The use of ECT, especially its enforced use under the Mental Health Act 1983/2007, is one of great debate in the mental health world among service users, legislators, and providers, and this debate tends to polarise people. Such polarity is not at all a good thing because, in my opinion, a SUR is there to represent as accurately as possible the views of one’s constituents through the filter or lens of one’s own experiences. If you, the SUR, have no direct experience of some treatment or other, it is incumbent on you to try to find out from those it has affected how they feel about it, good and bad. If these views conflict with your own, well then you have some soul-searching to do. This was the background to my accepting the kind offer from another SUR who had direct experience of ECT, and whose views on ECT differed diametrically from my own but who was aware of my studies and their potential importance of a totally anonymously written piece to enfold in my thesis. The piece was accepted and deployed as an indication, an illustration of a part of my own learning process, of the *how* of gathering and modifying one’s views, not as a vindication of ECT *per se*. That argument is for another place and time. Without the drive to seek out and learn from others, how can you grow? The SUR who believes he or she is the bee’s knees and does not need to follow a rigorous regime of seeking out new knowledge and learning from others’ experiences is, I believe, wrongheaded.

There is another problem. It is that there is a continuing body of opinion, based on what I see as the outdated Americanised views of Erving Goffman (11 June 1922 – 20 November 1982) who in 1963 argued that a service user (or other marginalised person) cannot be a representative of a group, as to be so destroyed the representativeness of that person by lifting him or her from the group to be represented. This view would have it that SURs are not a representational sample of some vague societal concept of a mental health service user subgroup and so as such their views cannot be relied upon. These concepts are passed on from generation to generation of service providers, often almost unconsciously by word and deed, stance and inaction. As such, the ideologic content is determined by *how* the

messages are presented, thereby determining the value of the information offered by the SUR as "reliable" or "unreliable", as "true" or "false". Hence language is essential to what and how people think about their representatives. Deploying this basic argument more widely leads society to question the representativeness of people like its Members of Parliament, yet those people, good and bad, are merely a reflection of the society from which they have sprung. When they are not, we have a hegemony or *Junta* with all the problems they pose. Democracy is based firmly on this concept of flawed people representing each other. Indeed, it is noted below that Lindow (1999) reports on the answer to questions being put about representatives being too articulate or too well to be truly representative of service users as a whole. She turns the question around and asks whether “workers send their least articulate colleague to represent their views, or the least confident nurse to negotiate for a change in conditions?” (Lindow, 1999: page 166).

I think this question of service users being a subgroup of society needs to be carefully considered when talking about representativeness and effective representation. It is plain that were mental health service users a subgroup then they would be a subgroup of up to a quarter of the population and would hardly be able to be considered homogenous. So, for a SUR to even hope to be an effective representative would need the SUR to focus and to represent those views from one's constituents, those people who are or have suffered mental distress who are within your ken, but through the lens of your own suffering modified by ongoing learning and experiences as a SUR itself. This is what makes SURs so very valuable to service providers.

So, a SUR is not only a service user but is a service provider at the same time. But surely this throws up a problem: How can one be both? The answer lies in the nature of the service being provided. The SUR does not set out to offer therapeutic or social services, although there is a body of thought that merely being a SUR is therapeutic in and of itself. This is considered elsewhere when we look at the effects of work on mental health. The service provided by the SUR or Peer Representative is one of knowledge transfer. Service provision, it has long been known, is enriched by the input from service users of how that provision is seen from the users' perspectives. Many commercial organisations use 'Secret Shoppers' to gather information as to

how their services are received by their customers and how those services can be improved, thus hopefully maximising profitability for the enrichment of all. The trouble with health services in general and mental health services in particular, is that such agents cannot ethically be deployed within the system to check it out.

Therefore, forward-thinking legislators have advocated for the support and use of local SURs to provide this service. This requires financial support of one sort or another, and therein lies the rub. Mental health sufferers are very often found on the very periphery of society, scratching along on the minimum of 'benefits', minimal payments by the state to help support them. Now, call me old fashioned, but I have never had a problem with any of our governments using a part of my wages for the support of those less fortunate than myself, but I understand that not all people feel this way. Officials who administer these basic benefit payments for the government have for years been notorious for withholding them at the flimsiest of excuses, and many potential SURs are put off from volunteering because of this real threat of sanctions. Thus, we have one official initiative stymied by another, and so the SURs we tend to recruit are those who can, in one way or another, afford to do the work or are mentally sufficiently able to negotiate their benefits payments. This leads to a skewing of our workforce with the more hard-to-reach portions of society, such as the more seriously ill, working age men, Travellers and Romanies, immigrant groups, youth groups and so on being underrepresented. For a community to benefit fully from a SUR initiative, it has to be financially supported to be able to pay expenses and a reasonably stipend to its workforce. Without this commitment, the SUR organisation becomes much less representative and so much less useful to planners. This thesis offers one model of working that is operational in Dorset for consideration by other areas.

Searching for Method

I have a problem. I am suffering from a dose of writer's block and have been all day, so writing just about anything should help me towards my aim of explaining how I came to the conclusion that I should be writing my thesis in the way I now am, as an autoethnographic study of a Service User Representative, an SUR, in Dorset. As

required by the University, this thesis is based on original research, shows practice development, and research of relevant literature, all linked together within a narrative report. This narrative report will be written in the first person. This is because of its intense reflexivity, its evocativeness. In essence, an autoethnography is by nature reflexive, at the core evocative, and the best way for me to offer the reader the best chance to reflect on my own reflections is to write my narrative in the first person.

Part of my journey towards becoming a more rounded and expert SUR has been to engross myself in studying myself as embedded within a system. Initially, I suppose, it all comes down to being able to write about the history of my coursework so far and some of the changes within me engendered by my studies. So, to begin at the beginning I have to go back to when I first applied to join the Doctor of Professional Practice course back to 2005. However, as part of my job as a Service User Representative, I really begin this study two years earlier, with an in-depth look at the grey literature. I am tasked with digesting and regurgitating - in a readable form - stacks of Green and White Papers, as well as CSIP/NIMHE papers and local Government and NHS regulations. As these papers change across time and develop with changing concepts and through the action of 'flavour of the month' political expediencies, this is a continuing effort. For the past few years, though, my reading has altered under the influence of this course of study so that I have come away from dry regulations and quantitative positivist research ideas into the more broad-based and qualitative post-modernist areas of study and reflection.

But I rush ahead. I want to take you back to when I was working at the (then) West Dorset Mental Health Forum (now Dorset Mental Health Forum or DMHF) as a fledgling SUR and general office helper, and was thinking about my academic career so far. DMHF was a small organisation based in the upstairs offices of an old warehouse in Durngate Street, a picturesque part of Dorchester, the county town of Dorset. At that time I was employed in various simple tasks about the place as a part of my own recovery from mental health problems. These tasks were being carefully managed and were slowly becoming more complex and difficult as my recovery progressed. I had been settled in my chair behind a computer and was wondering what it was all about – as you do – when I decided to try to find out. One of the ways

I devised to do this was by reading, digesting and précising various publications. I would then distribute the resultant forms to the rest of the workforce and in this way, summary in hand, they were saved the bother of reading the whole thing - or would look it up for themselves if it proved to be of interest to them. Such was my working world.

Academically, for years I survived quite happily as an Ammunition Technician in the Army on four 'O' Levels, one at B Grade and three at Grade C. I then approached our unit's Royal Army Education Corps Captain and asked to be enrolled on an Open University degree course. He told me, and I quote: "Sergeants don't do degrees. Sergeants do 'O' levels." I saluted him and left, angered and disheartened. I determined to retire from the Forces as soon as I could. A year or two later I joined the prison service and was sponsored and successfully completed both my Open University psychology degree and Registered Mental Health Nurse registration and diploma courses at the same time, and took over my own Healthcare Centre as its Managing Senior Healthcare Officer. Two years later I retired on mental and physical health grounds. I then very successfully completed a Masters at Liverpool University in Investigative Psychology and a post-graduate Diploma at Bournemouth University in Forensic and Biological Anthropology, and am now nearing completion of my doctoral course – so much for his 'O' levels for Sergeants.

So, from behind my desk at DMHF I apply for the doctor of professional practice course at Bournemouth University, and am called forward for interview with Jerry. I find Jerry to be a pleasant man who seems to care about his course members and has empathy for my challenges. He introduces me to the existing cohort who have not long begun their studies, and who are taking a break eating lunch in one of the rooms nearby. They are very welcoming and settle my mind that this is something I should like to pursue further. There then comes a more formalised interview process with more tutors. This is on another day, taken in sunlit rooms in the Lansdowne Campus buildings, and is surprisingly far-reaching and searching. But this is all described in greater detail below.

I also have an interview with Shaun, my Services Manager at DMHF. Initially, I have much higher hopes for the scale of my study as I have written in my application

script header: '*Service User Representation: Myth or Reality*'. This starts with a quote from Shaun, which came out while he was reflecting on the idea of me studying for a doctorate in this area. He is relaxing back into his comfy chair in his office and gazing dreamily into space when he says: "*It has to be about more than people feeling good about themselves – or does it?*" This strikes me as being at the heart of my proposal, so I note it down. Indeed, why do we SURs do what we do? Surely this is the core of the study and needs to be unpicked during the study as to whether it delineates where the study begins and ends and the evolution throughout. Shaun and I discuss this for a little while and then we move the discussion towards developing a model of service user representation.

Although this idea is embryonic it seems a fruitful one. In fact, the more I think about it the more interesting it seems. I then go on to describe a huge study looking at all aspects of being a mental health Service User Representative and user involvement, to encompass the whole of England and Wales. This will end with Further Musings on whether service user involvement is a myth or reality, and to suggest best practice and the way ahead. This is my idea as it stands in 2005, before I start on this course of study. By 2006, my ideas have changed a little.

The title changes to '*Listening to patients: The philosophy behind consulting users of mental health services about service delivery*': "My study would address this question [of what is the best model to use to enable service user involvement to happen] from a service user's perspective by surveying users and providers across England, assessing and comparing the effectiveness or otherwise of each system, and drawing conclusions based on that assessment." But within the year, I decide that my study will only be surveying users and providers within Dorset, Bournemouth and Poole and have once again changed its title, this time to: '*Listening to patients: towards developing a model of service user representation: The philosophy behind consulting users of mental health services about service delivery*', describing my new aim of researching a model that others would be able to apply to their individual circumstances in order to result in effective and sustainable representation.

I have been thinking about how I will research the subject and am coming down on a mixture of quantitative questionnaire and qualitative interviews and so on.

Qualitative or post-modernist research, broadly defined, means any research method that produces findings not arrived at by means of statistical quantitative modernist procedures, and where the techniques are a meaningfully integrated mixture of both would be termed Mixed Methods Research.

And so begins the long process of refinement and redrafting. By the end of 2007, my title has morphed into '*Mental Health Service User Representation*' and is slowly taking shape. A major departure from my initial research effort is a shift of my intellectual focus to a more in-depth look at mental health service user issues, starting from the standpoint of the disability movement as a whole. This shift has been engendered by conversations within my peer group and with tutors during group meetings and, more importantly, with concentrated discussion with my supervisory team, and co-occurs with a shift of attitude from a formalised observation of discrete areas of interest to a more wide-ranging and catholic collection of data. At this time, though, I am still collecting data and am still wedded to the Modernist approach that has served me so well in my previous studies, even though I have found these methods to lack a certain something in their operations, a certain something I find it difficult to pin down.

Subsequently, it becomes apparent that a lot of data is being either ignored or discarded during modernist studies and I find this worrying. For example, for my MSc I sent out 400 questionnaires, half of which I got back. Of those people who sent the questionnaires back, many made numerous comments in the margins, but because they didn't fit my research question I shelved them for a later time and then never went back to them. On reflection, I find this to be unsatisfactory practice, unethical. Ignoring all their extra input begs the question of whether it is ethical to ignore people's feelings in such a cavalier way. At the time, I saw nothing wrong with doing research in such a way. However, my studies thus far have shown me the error of my ways. Such reflections are central to my decision to change titles and indeed to change the approach to my studies.

By the end of the 2008 season, I have collected a huge amount of data from a myriad of ever-changing Governmental and other sources, often referred to as the *grey literature*. I have written a section of the thesis and write, produce and perform a

short play about my journey thus far (see Appendix A). At this stage, my reading is changing from the grey literature to begin to include exemplar texts around mental health, ethnography, and autoethnography. My explorations in post modernism are beginning to take shape and I start to understand, slowly, that “Our bodies don't lurk in isolation behind the five peepholes of perception.” (Gendlin, 1992, page 2).

I decide to look at the published literature around qualitative research and the postmodernist turn a bit more closely, and see if any part of it will suit me better than the modernist approaches (Habermas, 1990; Glesne and Peshkin, 1992; Denzin and Lincoln, 1994; Janesick, 1994; Cahoone, 1996; Charmaz and Mitchell, 1997; Grbich, 1999). I have already attended a statistics course to supplement my learning from my Masters studies, and am wondering how that would fit in with my current work. Now I begin to attend other courses to do with qualitative research and writing. The impact of all these readings is to engender in me a yearning to revisit my Masters degree and rework it in a more holistic and humanistic way so as to draw out the extra information I just know is hidden in the qualitative data with which I had been presented. This is impractical during the course of this study.

Kemmis (1980) asserts that the true value of non-experimental research lies in its connection to the real world, its ability to describe actions in their social and historical contexts, and its ability to rationally critique these descriptions.

Case study, as defined at great length by Peter Swanborn (2010, page 13), appears to me to be a useful approach. I like the idea of using a single case example to shed light on a phenomenon, but realise that finding such an exemplar case, event, group or institution might be problematic given the complexity of mental health services in England and Wales. I look at Grounded Theory (Strauss and Corbin, 1990).

Although there are ‘probably as many versions of grounded theory as there were grounded theorists’ (Dey, 1999, page 2) I can see no way that a theory could derive from my collected material. Indeed, I am not looking for a theory, and grounded theory also embraces the positivist and objectivist foundations whereby data are subject to modernist rules of generalisability, testability and verification, a way of thinking from which I am pulling away. Even with Charmaz’s (2006) constructivist grounded theory model moving some way towards a Blumerian (Blumer, 1969)

stance of naturalistic observation and in-depth participant observation, the emphasis on researcher and researched moves me away from this method of data collection for all the reasons given above. I am led to consider Action Research (Kemmis and McTaggart, 2005), but I feel that I am not positioned correctly to influence the actions of commissioners, providers or users of mental health services in order to run this type of programme successfully. As I feel I am studying phenomena, I take a close look at the various Phenomenological traditions including hermeneutics (Husserl, 1964; Giorgi, 1970; Colaizzi, 1978; Polkinghorn, 1989; Crotty, 1996; Lawler, 1998; Garrett and Hodkinson, 1999; Geanellos, 1999; Caelli, 2001; Laverty, 2003; Galvin and Todres, 2007), and narrative (Josselson, 1993), and language use, and the way these interact with nursing mentally ill patients (Koivisto *et al.*, 2002). I am much taken by the way they are used to describe structures of experience as they present themselves to one's consciousness without recourse to any theories or assumptions from other disciplines. However, it is the very idea of studying phenomena not as they appear to "my" consciousness, but to any consciousness whatsoever that puts me off this discipline. I am more interested in how the model would look through my own eyes, by this time, than through the eyes of an 'Other'. Ethnography (Van Maanen, 1988; Coffey, 1999) seems closer to my ideal, focusing as it does on the sociology of meaning through close field observation of sociocultural phenomena. But again, as in Case Study, finding such an exemplar, or even study-friendly group that could, ethically, be studied, seems improbable.

So I discard pure Ethnography. Not long after this abortive search for a methodology, I have a conversation with my supervisory team, Fran and Carol. We are mulling over "where to go next" and questions like that, and I mention that I have been looking at various aspects of qualitative research but have not fixed on any one discipline but that I just know I am wrong-headed in the way I am doing things so far, as nothing is really coming together for me. It is then that Fran asks whether I have taken an in-depth look at *Autoethnography* and I said I had not. So I look into it in really quite a lot of detail (Ellis, 1995; Reed-Danahay, 1997; Ellis and Bochner, 2000; Sparkes, 2000; Sparkes, 2002; Holt, 2003; Ellis, 2004; Holman Jones, 2005; Chang, 2008; Ellis, 2009) and continue to do so (Ellis *et al.*, 2011). My first port of call is Caroline Ellis and her book, *The Ethnographic I* (Ellis 2004), which I skim read to see if I am on the right track or not: it seems that I am so I read

it more thoroughly. The language she uses and the techniques she describes are, I feel, all accessible to my working style and situation in that I am comfortable with research that focuses on myself and to draw lessons from that. I am also comfortable with the style of analysis she undertakes, but I will modify it slightly so that the analyses are in a separate part of the chapter, yet remain intimately related to it. In this way, I wish to retain both the evocative and the analytical parts of the autoethnography. I then look to Denzin and Lincoln's (2005) *Handbook of Qualitative Research*, third edition, and the Section by Stacy Holman Jones: 'Autoethnography: Making the personal political' (pp 763-791). Liking the idea of autoethnography working 'to hold self and culture together, albeit not in equilibrium or stasis [. . .] It creates charged moments of clarity, connection, and change' (Holman Jones 2005, page 764), I decide to think hard about what I am experiencing, what it is that is shifting within me that makes this method and methodology look so promising as a way forward. I need to seek out the answers to my unformed questions. As Holman Jones asks, 'How much of my self do I put in and leave out?' (2005 page 764) I, too, ask how much will be needed of my 'self'? Will I, a mental health service user, have the necessary wherewithal to follow through such an invasive process? Like removing my own appendix using a grubby mirror and penknife: will I need to be anaesthetised, either locally or generally? In the vernacular, '*will I be able to hack it?*'

The autoethnography method is not for everybody or for every situation. It is not an easy route as it is a difficult method to master. It requires particular writing skills not always found in people who conduct research, skills more often associated with people who write fiction. It is a method that focuses on the author him- or herself, and the author's relationship with and reaction to situations that occur in his or her life with particular reference to that part of the author's life that is being studied – in this case, service user representation in the mental health world. As with other methods of research, autoethnography throws up some ethical issues peculiar to itself, as well as others more general in their scope. The ethics of the study are discussed below. Writing autoethnography means you are writing at the level of emotions, you are writing evocatively, and the whole reason for writing in that way is to access areas within your reader that language does not always reach, to evoke reactions, thus offering lessons from your research, lessons that can be tweaked out

through an analysis of the vignettes.

Holman Jones (2005) reports on her performance of a poem to illustrate ekphrastic texts (page 769) and I am transported back to my 14th year, rebellious at school, in an art class where the teacher is trying to explain how a performance could encompass a performance itself. I understand quite clearly what is being said but require the release of disruption so state that I do not. I bathe in this young teacher's attempts to explain what she means and continue my obstruction to everyone else's dismay. This flashback engendered by a simple story in a text book surprises me with its clarity. Such, I consider, was the stuff of autobiography, but where does it become autoethnography? I read about Holman Jones's grandfather (page 771) and am transported back to the future. A friend of mine had taken her own life and today is the day of her cremation, a day of deep reflection in those who knew her. She died in a loving bosom of friends who all saw her as she could not and yet were powerless to prevent the act. It has been bothering me, whether to go to her memorial service or not. Reading how Holman Jones was affected by not attending her grandfather's funeral convinces me to attend hers. And my mind flits back to how I felt when I heard that an acquaintance's daughter had not been allowed to attend the funeral service of her young friend because, at age 9 years, she was considered too young, and how this affected her even years afterwards. This is the power of autoethnography, to force reflective thinking on how you react to the ways society in general and people in particular act.

My version of autoethnographic study is based around the researcher's (my) detailed memories and contemporaneous field notes generating evocative stories, that I term vignettes, which are then more formally analysed in a separate following section of the chapter. These analyses are then drawn on to inform the discussion area of the thesis and will be used to create an overarching concluding chapter. It might be argued that to create an autoethnography in this way risks losing or diluting the evocative nature of the method, an evocativeness that is at the core of autoethnography. I believe that this is not necessarily the case and that the resultant greater clarity of analysis in the whole will make up for any potential shortfall.

There remains the question of collection and examination of data. There are three

main methods of data collection. The first is through interactive interviewing, whereby the researcher asks people to describe their experiences verbally, and this will be achieved by using field notes to record memories and situations and then reflect on the way those situations impacted on me and my interactions with other service users and SURs, my practice. Next is written descriptions of a phenomenon by participants, in this case 'participants' means me, and my field notes will be expanded into evocative vignettes. And finally there is observation, whereby verbal and non-verbal behaviour is descriptively described by the researcher in the form of vignettes written evocatively, drawing from comprehensive contemporaneous and memory-driven field notes. As Holman Jones (2005) explains, autoethnography falls between stools in that one is interviewing oneself interactively, and one is describing one's own experiences of a phenomenon in writing about what one observes one is doing at any given moment. Similar in some respects to Grounded Theory, analysis begins when the data is first collected and is used to guide decisions related to further data collection. It is an iterative process. However, the great divide between the two methods is that autoethnography focuses on the researcher's own experiences and reflections on experiences that have happened to him or her, while with Grounded Theory, the researcher engages with other participants. This whole process seems to me to be so clearly preferable, in both data collection and data examination terms within my chosen field of research, to other quantitative or qualitative ways of working that I decide that autoethnography is my methodology of choice.

Thus, the end of academic year 2009 sees further evidence of practice development, another change to the title of my study, to: '*Solace: Relationships in Care*', and a redefined focus onto the autoethnographic route. Initially I designed the route with an ultimate aim that was to describe a particular model of service user representation and that has not changed. I seek to describe a model of peer representation that can be used by mental health services providers to save them time and money, and to enhance and enliven the lives of my peers. I began with a study to look at service user representation in general in the world, and end with a study to look at the world inside me and my place in it. This progress in my original research was informed in no small part by my doctoral studies showing practice development and the reading of relevant documents and books generating research relevant references.

Autoethnography as a method of research works because it is evocative. In other words, it impacts on readers by working on their emotions. It reaches the parts that language can't reach. Even if the reader takes nothing away from it, it will have evoked a response within them. It is this evocation that autoethnography aims for. It is this evocation that I am looking for when I offer my vignettes throughout this thesis. Each vignette or story is accompanied with a reflection on what the story has given us. This is written to aid understanding, to focus on reader's mind on the lessons learnt. This method of using an autoethnography to explore the various by-ways in service user/survivor peer representation is powerful because it engages people's emotions and, particularly, because it focuses down on often overlooked minute aspects of the subject. By being appointed to various panels and posts, as well as having evidence from other service users, carers and staff at all levels, I will be able to pick a route through the hidden and murky world of mental health services. The resultant model I describe will offer staff and service users a way of maximising recovery whilst minimising costs and bureaucracy to the benefit of all.

*

This latest part of the thesis has to do with my reflections leading up to the choosing of autoethnography as a methodology. It charts my epistemological journey from a quantitative/modernist position to one of a qualitative/postmodern stance and the considerations that went on in my mind while such a transformation was taking place. Of particular note, emergent from my review of relevant literature, is the realisation that to study mental health service users and their representatives in the field I would need to find suitable candidates and nurture them, gaining informed consent and ethical clearances before even starting my study, and this was just not practicable as the target group is not homogenous in any way and is rather shy of research being done *to* them – in contrast with research being done *by* them. To proceed without this informed consent from all involved would be unethical. The choice of autoethnography and its methods meant I would be examining myself embedded in the world of the service user, and also as a developing SUR as the study moved forwards in time and as the project developed. The resultant data promises to be much richer and more abundant than any achieved by more statistical or other quantitative/positivistic methods and, ethically, there would be a much

reduced risk to the health and well-being of myself and others from my work. Not all risk, however, would be removed by focusing on one's self because, necessarily, others would become associated with me in my work and so become identifiable. To negate this, where ever such danger would exist I would employ *nom de plume* composites of anonymised people. I would also be putting myself at risk.

What Caroline Ellis describes is a form of autoethnography that does not sit entirely comfortably with me, with its analyses set within the sometimes rather novelistic text rather than, as I prefer and have presented in this thesis, in separate sections to the descriptive vignettes. This might be seen as the difference between the evocative and analytical autoethnographic methods, but not totally removed from it. The purpose of the use of vignettes is to set the scene for the following analysis as well as to evoke responses at a deep level within the reader, to reach those parts that other writings fail to reach. As described above, I shall write field notes of both my memories of specific events and of events as they happen to me. From these field notes, I will draw on writing skills to generate vignettes that are aimed at evoking emotional responses in the reader. This will be followed by a more formal analysis of the vignette in its own light, in the light of foregoing research, and referring back to other sections of the thesis. These analyses and vignettes will generate a conclusions chapter and inform discussion. In this way, I aim to present my experiences and my reflections on experiences within an analytical yet evocative framework.

The next part of the narrative report deals with ethical considerations. It might seem on first consideration ethics play a small part in autoethnographic studies. This is not true as will be seen.

The Only Way is Ethics

We are three once again. We sit with hot drinks in Fran's small office, all snuggled around with books and papers and the other accumulations that academics have in their offices. Carol is by the door, Fran is on the swivel chair by his desk and I am cuddled up in the corner under the open window. It is an unseasonably warm

October midday and the city outside the open window is in full and gloriously noisy swing, drowning out half our conversation. I have come to a sticky patch in my studies, a wall, and have asked for guidance, for a few tufts of grass to grasp to pull me from the mire. It is all about ethics and autoethnographic studies. We have been chatting for a little while. Carol is speaking.

Carol: Ethics? Openness, transparency, not using other people's words, doing no harm. The main ethical point is that when you are doing an AE and you are the subject of the research and your encounters are the subject of the research, how much does that change how - there's a question for me - how that changes how you respond to people, react to people. Does it or doesn't it? What does being a researcher do, either enhancing or reducing your ethical viewpoint?

Fran: It's not a governance issue, it's more of a philosophical issue.

Carol: It's more to do with your methodological stance and why you decided on AE, and what particular ethical dilemmas did that present you with? That particular method and that particular philosophy? And you have had those. You have had times when you've thought: "That was a prime conversation that I could use for my thesis, but how do I use it ethically when they didn't know when I was talking to them that I would use it in research?" Telling them would have had an influence on the conversation. You can reflect on a conversation you've had and you can, if you like ... but you are reflecting on it, were reflecting on it as Richard the Service User Representative, or in whatever other role, whatever part of Richard was engaging with that other person.

Fran: You're forgetting the central focus of your study which is yourself. And of course you live in context with others, but primarily it's you in a context - it's not the context that's at issue.

Carol: There are ethical dilemmas arising from using this methodology because under normal circumstances anybody that you report on and any conversation that you report on, you have to get prior permission. Now, with Autoethnography you

can't. And in a way it changes the whole perspective if you then have to get people to sign things that say "I am currently doing an autoethnographical study, so anything you say may be taken down and used in evidence ..." But that's a real issue with AE, isn't it? And it must have created some dilemmas for you. And that is what I would like to see reflected in it. And I know that there've been times when you have come into supervision and you've said you wanted to use a conversation you've had, and we've said, no, you can't use it in the way you want to use it. You use it to reflect on you, on the effect it had on you, rather than quoting the conversation you had with another person.

And so the conversation went on, but I was musing and mulling over my scant knowledge of ethics. This is an issue that hasn't come up for me since my basic nurse training in the early 1990s and I feel myself a bit at sea with it. Evidently, there is a need for some research through the relevant literature. I'll start at the beginning and go back to my roots.

The first book that leaps to my mind is Alasdair MacIntyre's 'A Short History of Ethics' (MacIntyre, 2002). He takes his readers from the prephilosophical 'Good', through the transition to and history of the philosophers, ending in modern moral philosophy. Quite a survey. Tellingly, he begins his book with the observation that: 'Moral philosophy is often written as though the history of the subject were only of secondary and incidental importance. This attitude seems to be the outcome of a belief that moral concepts can be examined and understood apart from their history [. . .] and so [historians] end up by suggesting that although what is held to be right and good is not always the same, roughly the same concepts of right and good are universal' (page 1), and ends with the view that to 'absolutize' moralities 'could only succeed if moral concepts were indeed timeless and unhistorical, and if there were only one available set of moral concepts. One virtue of the history of moral philosophy is that it shows us that this is not true and that moral concepts themselves have a history. To understand this is to be liberated from any false absolutist claims.' (pages 260-1). The main message I get is that the concept of what is 'good' is very slippery; it is one scattered through time and place; it is different things to different people; and, it is not at all well decided in philosophical circles. So, I opt for Carol's

suggestion rather that one should ‘do no harm’, but I wonder whether doing no harm can be divorced from doing good?

What is ‘harm’ and what does ‘do no harm’ mean, anyway? How does the concept of harm fit in with an autoethnography of this sort? The way I recognise harm is by the effect it has on another person, the subject. If we imagine a subject in repose, in a position of rest, content with life and just ‘ticking over’, then harm would be a disturbance of this sense of peace in a way that the subject would not enjoy. I suppose this sort of harm is less the physical and more the psychological type whereby people might find themselves in levels of distress through reading my words, as well as finding myself in distress after writing and reflecting on my own words. Not harming people is different to having a general duty to help them. Much of the harm we do is an unwanted consequence of what we do anyway: ‘Often it is the cumulative effects of many individual acts that cause the harm’ (Dower, 2000, page 280). So how much should we care about doing no harm? I suppose the answer might be that we should care just so much as we can, but this is to beg the question. We can care about doing no harm, yet do it anyway, either consciously or as an unwanted consequence of our actions (such as not giving our excess wealth to charity). The fact that we care about it doesn’t stop it happening. Another view might be the utilitarian one of always promoting the greatest balance of good over bad – but there we are again! What is ‘good’? I feel myself back in the mire and grasping for tufts to pull myself to a better understanding.

The main lesson I take from Alastair MacIntyre’s book, is that no single approach holds the key to what is ‘good’ and ‘bad’, but that to have a view one must adopt a position. I like the concept offered by the utilitarian view that there is a balance in things, and this sits well with my beliefs built up during a lifetime in a Western Christian democracy. This does not mean that I will blindly follow the precepts of utilitarianism, to allow the principle of utility (the promotion of a general happiness) to over-ride my existing principles of good and bad. This is because utilitarianism ‘is a revisionary analysis of our attitudes and concepts; and it is relevant to ask whether it would preserve what we value in those attitudes and concepts.’ (MacIntyre, 2002, page 232). I seem to possess an innate sense of right and wrong built up over the years, and this sense is what I will rely on when deciding what is ‘good’. This

reliance will also allow for the attainment of the utilitarian concept of happiness, as following my heart, as it were, will ensure the least amount of unhappiness for me while I believe it will offer the greatest chance of happiness for others. In this way I hope to minimise the harm I might do with my writings.

So, how much should I care that my deeds or omissions will do the least harm? The utilitarian concept of beneficence holds that ‘we ought to promote the greatest balance of good over bad’ (Dower, 2000, page 281), which leads me to a consideration of a general duty of caring. However, this is not an all-encompassing duty. Rather, I inhabit a degree of moral space between what I should do and what I should not. This leeway allows me to decide for myself what to do. Perhaps a more sensible stance to take would be that I care for others as much as I can consistent with a reasonable concern for the quality of my study.

And here we come to my study. I have rejected a positivist approach because I believe it is unethical to ignore all the qualitative data one is presented with in research, but what do I mean by unethical? That is the question I have tried to answer in this part of the thesis. My study is an autoethnographic study, and, as such, my experiences are not the story but I must discover the story within my experiences (Ellis, 2009, page 148). It is interesting, in this case, when considering care, who stands to be harmed by my studies beyond myself? Chang offers one view when she writes: ‘As you play a multifaceted role as researcher, informant, and author, you should be reminded that your story is never made in a vacuum and others are always visible or invisible participants in your story’ (Chang, 2008, page 69). In doing so, I must recognise that ‘ethics is a continually negotiable set of responsibilities between the author and the story and the author and the reader (Muncey, 2010, page 108). Ellis, again, states that she does not feel she is responsible to tell her participants a particular version of her story, but that once she has decided to tell them, then she is ‘responsible for telling them a truthful story [. . .] one that is lifelike’ (Ellis, 2004, page 147). She proposes that researchers, me, should work ‘from an ethic of care, and treating people with an ethic of care’ (page 149) and so we are back once more to caring about what I will do, as discussed above. I am comfortable with that, for, as Grant writes, ‘in order to make coherent who we are, we have to have a notion of how we are and where we are going’ (Grant, 2010, page 113). Also, the concept of

audience harm is of real concern to me, and not only for the harm they might do back to me, for as Adams writes: ‘As members of an audience, we bring with us our own set of preconceived ethical and moral demands to impose on the author. Such, were it not subject to continual vigilance against concepts such as being unfair, would quickly raise the potential for “ethical violence” against the author’ (Adams, 2008, page 185: Note). Taking narratives back to those written about needs to be handled with care (Ellis, 2009, page 314), care that I should write to understand how other people put their worlds together and how they influence mine, and, in so doing, how I can survive and find meaning in the chaos (Ibid., page 316)

Frank (1997) describes two other facets of ethics: that of *narrative ethics* and that of *clinical ethics*. He holds that clinical ethics is all about writing about a sick person and narrative ethics is about thinking with stories rather than about them and that sick people have lives beyond their illnesses. ‘Further, Frank argues that the moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one’s story is shaping one into. This entails the requirement to possibly change that self-story if it feels that the wrong self is being shaped’ (Grant, 2010, page 115). I think I should recognise that I can never know how others will respond to my story or interpret it. This endless questioning of whom I might hurt or help with my story forms a basis of narrative ethics and needs to inform my story. It is an iterative process, ‘never knowing whether our decisions are “right” or “wrong”’ (Adams, 2008, page 179). Of course, I might just hurt myself. Ellis (2009) says that she has ‘come to believe that the well-being of the researcher is not always less important than the well-being of the other, especially others who have behaved badly’ (page 317). I tend to agree with her.

I think that, when I am engaged in ‘doing autoethnography’, I don’t necessarily know initially where the sources for my reflective pieces will come from, nor necessarily on how my reflections on those lived experiences might impact on myself and others. Often, this could be in a much deeper way than if I were ‘collecting data and reflecting on it’ in a traditional Positivist way, as I used to. Sometimes, the views of other people ran counter to my own. Do I ‘report’ these directly within the study? Of course not. After all, the study is about me, the researcher/writer, not these other people. What I report on and reflect on, and must

be ethically aware about, is primarily the effect such interactions have on me and my practice, and to illustrate this process there may be times where others' views are seen in the study, but only as shadows, as a means of illustrating to the reader the process of reflection and modification going on within the researcher/writer, going on within me. I believe that my ethics are necessarily based in a white male Christian perspective, because that is what I am, are formed from utilitarian principles, and that I must work from specific cases back to those guiding principles and back again, time after time, in order to decide what to do; and that it is easier to talk about ethics than it is to do ethics.

I feel easier in myself, having made the decisions around the ethics I will use in this study. However, does that go any way towards answering Carol's first question? I would like to think that I act ethically at every turn, even when not researching, but I also understand that this is probably not humanly possible. Doing research, though, does have the salutary effect of focusing my mind on the ethics of what I am doing. In this sense I believe that my Christian utilitarian principles stand me in good stead by doing no harm, at least as little harm as possible, to myself and all the people around me. Also, I am dealing with institutions that I do not wish to harm, so that has to be a consideration, too. I do not feel that I am in the game of attacking institutions for the things that they try to do to the best of their abilities. If they fall by the wayside, then who am I to kick them rather than try to help them get up again? I would much rather see myself in the role of Critical Friend, a phrase attributed to Desmond Nuttall (Heller, 1988). As a critical friend I believe one is tasked to be careful with one's relationship and this includes observing keenly the ethics of what one is doing. And as Carol has said, I am the subject of my own original research and so must apply these ethical principles to myself and become my own critical friend. So to answer her question, "what does being a researcher do, either enhancing or reducing your ethical viewpoint", I believe that being a researcher enhances my ethical viewpoint, that merely writing this paper has informed my work as a Service User Representative working within the voluntary sector thus adding to my practice development, and that this insight into the ethics of research will inform my study. It is my belief that if you keep your ethical stance clear in your mind whilst performing your study and writing up your research, research and ethics can be bedfellows.

How has the journey affected me? There can be no doubt that my journey from becoming a mental health service user to that of a SUR, and concurrently passing through my doctoral studies with its insights and opportunities, have had an impact on me and on my self-image. I have become more reflexive and much less self-critical, more understanding and tolerant of others and a much improved advocate with a deeper and broader knowledge of the mental health world in general. These improvements to my working self as well as generally to my own self-perception and skills has come in a large part through the reflexivity part of my doctoral course, leading to reflexivity in my life in general. By looking deeply at why I did things as I did, I understood more about the mechanisms underlying my work and life. On the deficit side of the equation, I can often foresee the sorts of problems into which people get themselves and tend to shy a little from the consequences as a self-protective mechanism, which results in my becoming slightly more removed from the world of the mental health service user purely through my greater understanding of the issues affecting it. Did I see these changes coming? Absolutely not. Do I regret passing through this process? Again, no. However, I think that these potential changes should be viewed as an ethical consideration for anyone else thinking of pursuing this or a similar course of study. This is because historically we researchers have been very careful about how our studies affect others, whether they might be harmful or hurtful or whether they would tend to make a difference and whether that difference is acceptable, whether the risks are outweighed by the benefits. We have been less careful about the effects our researches will have on ourselves, and without such consideration, we researchers might become almost inadvertently wounded by our discoveries.

The following part of this evocative narrative report takes us on a journey of reflection as to the similarities and, importantly, differences between mental health service users or survivors and mental health SURs or Peer Specialists. That there is a difference goes to the core of this thesis as without there being a difference, the role of SUR would not exist independently of the mass of unrepresented service users. Many unitary authority departments and NHS Trusts utilise users of their services as 'representative' of service users as a whole, but this begs the question of who these representatives are actually representing. Goffman (1963) argued that a service user

(or other marginalised person) cannot be a representative of a group, as to be so destroyed the representativeness of that person by lifting him or her from the group to be represented. It is argued here that such representation is indeed possible, given a few simple safeguards. This leads to a consideration of the model I am working towards, a model of SUR supported remuneration whereby peers are educated into the vagaries of committee work and influencing people while at the same time practising a skill, initially under the tutelage of other peer specialists or SURs. It will be seen that there is a difference between mental health service users and mental health services representatives, and that this difference is based very largely upon the SURs own drive to make a difference in his or her life and the lives of others. From this, education and training can develop a useful peer specialist who can go some way to manipulating the system so that the system itself becomes fairer, more equitable, more even-handed and less powerful, thus acting for the benefit of all service users.

Becoming a service user and then a Service User Representative

‘For I will restore health unto thee, and I will heal thee of thy wounds, saith the LORD; because they called thee an Outcast’ (Holy Bible. Jeremiah.30:17)

What’s the Difference?

“What is the difference between a service user and a Service User Representative?”
I was asked, recently. “Can you explain it?”

I find myself sitting at home considering this latest question with Chopin’s *Nocturnes* playing from one corner and the fish across the room looking at me through the glass front of their aquarium. I have just fed Jack-the-dog and he is snoozing at my feet. All is peaceful and ideal for considering such questions.

As I write in an email to my supervisors at the university: “It’s been suggested I look at the similarities and differences to be found in and between the two groups, service users and SURs, so I am writing around that a bit at the moment.”

I am minded of the original focus of my study in 2005, in that I wrote about investigating the difference between the mental health service user and the mental health Service User Representative, or SUR. This has survived during the practice development of the project. This difference is at the heart of this thesis and needs to be explored through research of relevant references before we advance any further. So, the question is not a new one and also the questions arising from a simple and straightforward request are complex and central to this thesis.

Of what does “*service user involvement*” actually consist? Well, let us refer to the relevant documentation once again. Involvement can mean a great number of things. We are discussing mental health service users and this would tend to reduce the scope, but not by much. However, Government rhetoric on the subject tends to remain just that, with stated aspirations failing to come to fruition time and again. Almost the last time the policy makers specifically mention mental health service user and carer involvement is in their 1999 National Service Framework paper that states that the NHS needs to arrange things so that the involvement of service users and carers happens as a part of the process itself – “And specific arrangements should be in place to ensure:

- service user and carer involvement”. (DoH, 1999, page 10).

There was some movement in 2007 with the development of a national user involvement network, although it seems to be struggling to find its way. NSUN is based in London and has ambitions to be representative of the whole of England. The trouble is getting people to sign up to it is an uphill struggle. So far, only a few service user led organisations in the mental health field are members. The result is that NSUN is less representative that it would like to think it is. Mind you, it was a big ask for them to try to cover the whole national scene. The intention was good, being to unite the mental health service user voice across the country, but I think the problem is that mental health service users are not an homogenous group and tend to

resist being 'organised' in any meaningful way. So the government looked to offering disabled people in general are more locally based model by giving the commitment that:

"By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user - led organisation, modelled on existing CILs (Centres for Independent Living)."

(DoH, 2005, page 91).

CILs were established in fewer locations than was hoped but those that have been established help, for example, to support people to self assess their needs, to support people to use Direct Payments, to offer advocacy services, to offer peer support, and to offer an advice and information hub. CIL's have also offered services to meet people's needs such as assistance in recruiting and employing personal assistants, employment support projects, supported housing services and peer support services (Morris 2007, page 6).

Here in Dorset we have a new umbrella organisation called Access Dorset which is developing CILs across the county. We are calling them Access Centres to differentiate them from Independent Living Centres already set up to offer physically disabled people access to enablement tools and equipment. Access Dorset are themselves a pan disability project with mental health service users as one small part of their focus. That they recognise that mental health service users are an important part of their focus is demonstrated by one of the seats on the governing board of Access Dorset is held by a representative from Dorset Mental Health Forum. Currently that person is me, though the seats can be taken by another Peer Specialist if needs be.

Although service user involvement in their own care is a key aspect of the new Recovery paradigm, many mental health service users do not see themselves as "disabled" and so have trouble identifying with the needs of service users who have physical disabilities. As Jenny Weinstein says:

"It may be that the different groups of people who need support in their daily

lives use different terms to describe themselves and what they want even though they may be in agreement with each other that the most important thing is to have choice and control over the support needed. It is suggested here that there may be some contradictions between introducing personalisation, so that people can live their own independent lives integrated within the community while at the same time legislating from above for user - led organisations."

(Weinstein 2010, page 210)

The use of different terms is widespread in the mental health service user community. Indeed, the very term 'service user' comes in for a lot of criticism. Peter Beresford, in his book, *A Straight Talking Introduction to Being a Mental Health Service User*, addresses this question in chapter 3. He recognises that "language... is a field of conflict. It is almost impossible to escape this." He recognises that there is no agreement within the service user movement as to which terms to use when referring to people who use mental health services in one way or another (Beresford, 2010, page 24). With this recognition in mind, it is not surprising to find that there are people within the mental health services user/survivor movement who would discard the disabled label anyway. The reason for this, in my opinion, is that to hold a view about disability is to hold a view about the disability being rooted in society as a whole, not in the person him- or herself. What do I mean by that? Well, it is my view and the view of many others that society should be so organised as to be able to embrace less able members of society. At the moment, society is largely organised for the majority of able-bodied able-minded people. An experience I will never forget is being consigned to a wheelchair whilst going around a department store as I could not walk properly for a while. Access to various departments was difficult, adult people looked at me differently to what I was used to and wouldn't meet my eyes, and children stared at me and joked. When it became difficult for my carer to have me accompany her, I was left holding a large plastic water butt to one side of the corridor while she went off to investigate other goods. So, I can understand why people don't wish to be labelled as disabled - but sometimes a label is useful. As Peter Beresford explains, "many service users find their diagnosis reassuring. They feel it helps them explain and make sense of their feelings and situations. Others reject the labels attached to them." (Ibid., page 21).

I will digress a little from considering service users to try to explain myself a bit better. My wife is my carer and, in the beginning, she had very strong views about being called a Carer as she felt that she was “merely carrying out her wifely duties”, duties she would normally carry out as a loving wife. I tried to explain to her that Carer is just a label, a title that can be used or abused. For example, to allow her to get the social support available to her as a carer, she had to have a Carers Assessment, done by the Carers’ Officer from the local NHS foundation trust. After having had the assessment, she was entitled access to the trust’s Carers’ Allowance, a sum of money set aside to help carers in their lives. Her portion of the carers’ allowance allowed her to buy time in a massage parlour, helping her to relax and taking her away from being a carer and the other pressures of life. She found this to be extremely beneficial. The Carers Assessment also allowed her to join the Carers’ Forum, which meets every month on a Wednesday evening and empowers carers to offer support and encouragement to each other, as well as discounted trips to events such as the Dorset Steam Fair. This forum is funded by the local borough council. These meetings have become a regular aspect of her life now and she has made several new friends through it, but without her accepting the title (or label) ‘Carer’, then she would never have known about these extra supports available to her.

There is a body of opinion that Service User Representatives are not a representational sample of the service user subgroup as a whole – assuming, of course, that mental health service users *are* a subgroup. This concept of “*representation*” needs to be explored. There is the issue of the differences between being ‘representative of’ a group and ‘representing’ a group. The SUR works towards straddling both camps. Firstly, he or she is deemed a representative member of a sub-group by dint of ‘lived experience’ - even though the physical existence of such an homogeneous group is far from certain, as well as there being active resistance for such a view from some workers because of their Goffman-based training. SURs are also seen by many as ‘Experts by Experience’ and their views on pertinent subjects are valued as stemming from such. Lindow (1999) reports on the answer to questions being put about representatives being too articulate or too well to be truly representative of service users as a whole. She turns the question around and asks whether “workers send their least articulate colleague to represent their views, or the least confident nurse to negotiate for a change in conditions?” (Lindow,

1999: page 166). I think this question of service users being a subgroup of society needs to be carefully considered when talking about representation. It is plain, using such statistics as one in four of people suffering from mental health problem in their lives, as quoted by Mind, Rethink Mental Illness and other organisations, that were mental health service users a subgroup then they would be a subgroup of up to a quarter of the population. This would indeed be a subgroup of the population as a whole, but would hardly be able to be considered homogenous. Acting as SURs, we try to be a 'representative' of a 'constituency' of other service users in much the same way as a local Councillor does, relaying their group views to service providers and bringing news back, as well as representing their group's interests on decision-making bodies. So, to be a representative of views from the subgroup would be to represent those views from one's constituents, those people who are or have suffered mental distress who are within your ken. To be able to represent views on a more national level one needs to include local SURs and their views into one's studies. This way of grouping the ungroupable is what democratic parliaments do.

Services officers often ask the question "Why won't our users get involved?" A better question might be "Why on earth would our users want to get involved?" (SCMH, 2001). Why would people who have been at the painful and life-threatening end of mental distress want to risk being labelled as 'unrepresentative' or 'not ill enough', or seemingly waste their time and money attending committees and training sessions, not to mention staff selection boards and facility inspections, when they could as easily spend their time at home watching daytime TV or pottering in the garden or in a little job somewhere? Why would you? Why do I? Well, I can only speak for myself: It gives me a 'good feeling'. But is that sufficient, as Shaun asked?

"It has to be about more than people feeling good about themselves - or does it?"

Shaun Byatt, West Dorset Mental Health Forum, 2005

Shaun's question goes to the heart of the matter. Is it sufficient that to be a service user representative is to feel good about yourself? Or is there a deeper more complex reason for representing people? I hope that, as you read, answers to this core question will become apparent.

There's always an aspect of professionalization to everything. This does not mean that you have become a professional in the sense of being an employee of the National Health Service or the county council but that you have developed a professional attitude to your work as a service user representative, an attitude that will enhance your effectiveness when dealing with those others who are services professionals. For example, conduct in meetings or means of addressing the Chair or dressing appropriately for the situation. All these things can be learned but until they are, they do not come naturally to people. This learning might be seen by some to divorce them from their constituents and thus make them less representative of that constituent body, but I would argue that this viewpoint is erroneous: Merely teaching people skills of communication and presentation does not turn them into card carrying employees of an organ of the State.

Many of the tasks I am asked to do are with Dorset County Council as many of the solutions to mental health problems lie with social, rather than medical responses (Fryer, 1999; WHO, 2001). I am also aware that 'involvement is often a conditional invitation to join someone else's ball game where rules and goal posts are already set. You can join the team as long as you play ball. We are expected to always be on our best behaviour and not to upset anyone. It relies on the premise that as responsible partners we are all of us good obedient citizens who will learn the inclusion game, stick to the rules and play fair. Naughty citizens don't get to join in.' (Gosling 2010, page 34).

As with encouraging people with mental health challenges back into employment, payments for services from, and even voluntary contributions of time made by mental health service users are beset with difficulty, not the least clashes with the State Benefits system (NIHME, undated draft). In England, over 900,000 adults are in receipt of sickness and disability benefits for mental health reasons (cited ODPM, 2004, page 3) and the fear that even voluntary activities will trigger a benefits review

keeps many people from becoming more involved.

What exactly does "*Service User*" mean? Maybe we need to go back to the literature. Perhaps we should ask the Social Service Research Unit of the University of London, who state:

"We define 'service users' broadly to include patients; unpaid carers; parents/guardians; users of health services; disabled people; members of the public who are the potential recipients of health promotion/public health programmes; groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services; groups asking for research because they believe they have been denied products or services from which they believe they could have benefited; organisations that represent service users and carers".

(Oliver, *et al.*, 2006, page iii)

Tait and Lester (2005) focus down a bit more, erring a little on the side of the medical model at times: "Users are most frequently portrayed as patients – as objects of the clinical gaze of mental health professionals (Pilgrim and Rogers, 1999) – and therefore in terms of their illness." They go on to redeem the position a little by shining a light on other aspects of being a service user: "users can also be seen as consumers, survivors and providers, all of which imply different notions of the roles and responsibilities of people with mental health problems and the relationship between them and mental health services." The Dorset Mental Health Forum definition of "Service User" is as follows: "Any person experiencing mental health problems, accessing any form of relevant service" (DMHF, 2009, para. 3)

Service users being seen as 'consumers' or 'clients' – although the terms at different both politically and semantically, they fall under the same overall heading in this case – of services reflects the 1980s concept of patient as customer in the NHS, with the ability to take their custom elsewhere if dissatisfied. This ideal, however, does not extend to mental health services as it may to, say, surgery, as mental health services do not offer the same levels of choice to their service users that other branches of the NHS might – in fact, it offers one choice, that of 'take it or leave it'.

The idea of the user as 'survivor' comes from a 1970s (in other words, very early in service user representation history) consideration of strength in unity, where people grouped themselves for mutual support against a mental health system that they had survived (Hughes, 2006). User as 'provider' is based in voluntary and charitable organisations that provide services of one sort or another to other service users and society as a whole, such as safe houses and drop-in centres, and the development of advocacy and other services, as well as statutory services utilising their 'experts by experience' (Davidson, 2005) in roles centred around delivery of a service to the statutory body such as training packages or participation in recruitment initiatives and interviews, as two examples.

"Experts by experience" has become one of the concepts of the moment in mental health. It refers to the knowledge that patients, service users and carers have acquired through either the very experience of distress, or caring for someone with mental health problems.

(James, 2007, page 1)

'Experts by experience' is an important reclassification of the social worker - service user relationship, as it, unlike 'service user', 'client', 'consumer' or 'customer' before it, makes a claim for a specialist knowledge base rooted in an individual's experience of using services. The social worker working with the expert by experience is suggestive of a relationship of equals whereby one expert's expertise has been accrued through their training and practice and the other through their experience. This suggests that the social worker needs to acknowledge and affirm the expertise of the other—the expert by experience—in assessing and agreeing a way forward.

(McLaughlin, 2009, page 1111)

If social work is concerned with empowerment, liberation and

promoting social justice, it then becomes essential to develop a continuous critical dialogue concerning the language we use, deconstructing it and unearthing the assumptions behind its usage.

This is not to suggest that there is another term out there that should be championed to replace 'service users'. It may be possible to consider such terms as 'people', 'active consumers', 'responsible consumer - customers' or even 'citizens', but all these contain their own assumptive worlds and fail to effectively and accurately reflect the nature of the social work relationship

(McLaughlin, 2009, page 1114)

Broadly, a mental health service user is anyone who uses the services laid on to help with their mental health, but this is not quite what we are looking for, as critiqued in McLaughlin, 2009, as it is much too broad and could include everyone. But then, if one in six adults will have a mental health problem at any given time, and the problem will last longer than a year for half of these people (ONS, 2001; DoH, 2009), should we *not* be including everyone in this term? Does the very act of exclusion of certain people create a stigma around those included? Irving Goffman writes about these sub-groups in his classic work, '*Stigma: Notes on the management of spoiled identity*' (Goffman, 1963).

Goffman writes about stigma in general and holds that: "Persons who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self – a similar 'moral career' that is both cause and effect of commitment to a similar sequence of personal adjustments." (Ibid., page 45) This would seem to open the path to people becoming representatives of their groups, once those groups are recognised as such, and is core to the move from service user to SUR. After all, is that not what politicians do? So why can not mental health service users do it, too? But Goffman seems to argue against this, labelling those people as 'professionals'.

Goffman again: "A comment here is required about those who come to serve as

representatives of a stigmatised category. Starting out as someone who is a little more vocal, a little better known, or a little better connected than his fellow-sufferers, a stigmatised person may find that the ‘movement’ has absorbed his whole day, and that he has become a professional.” (Ibid., page 38) But are those professionals a subgroup of the stigmatised group or a separate group in themselves?

He goes on to outline what he sees as two points regarding this: that the stigmatised person who becomes a spokesperson for their group will mix with other representatives from other groups, thus making them less representative of their own group; and, second, he suggests that the act of writing about a stigma gives the writer a privileged position and one that excludes him from the ranks of the purely stigmatised, thus rendering him as no representative of the group as to be representative you need to be as the rest of the group and so, perhaps, inarticulate.

I have to say that these standpoints, though recognisable to me, do not resonate with my experiences. I have been both a professional representative and a writer on the subject of my particular stigma for some time yet still consider myself an expert by my experiences and able to represent the other members of the group to ‘normals’, as Goffman will have it (Ibid., page 15).

People who have experienced mental distress, and the services rolled out to help them with it, are often cited as experts in their own care, for example in an inspection and oversight role with the Patient and Public Involvement Forums (PPIF) and now with their successors, the Local Involvement Networks (LINKs), or being trained and used as tutors to deliver the Expert Patients Programme’s chronic disease self-management courses (CMO, 2001). Strangely, though, the very use of the term ‘Experts by Experience’ seems to offer legs to Rupert Sheldrake’s (1981) notion of *Morphic Resonance*. What the rest of the scientific world terms lawfulness, Sheldrake calls morphic resonance, which he describes it as a kind of memory in things determined by repetition and not by their inherent natures, transmitted via "morphogenetic fields" wherein information is transmitted without loss or change of content, though Carroll, in his *The Skeptic’s Dictionary*, would argue hard against it all (Carroll, 2009). We, at the then West Dorset Mental Health Forum, coined the phrase in 2004 at the inception of our Service User Representative programme, but

we soon noticed the term being used elsewhere in the literature. Which came first? Who knows? I certainly don't.

We see, then, a difference between service users and SURs, but what is it that makes them different? The first thing is a personal drive to 'make a difference' and to be representative, as Goffman pointed out above. There is as well and aspects of 'making meaning' for the SUR as an internal process whereby the SUR him or herself can answer questions they might have about the meaning of their mental distress on a more philosophical level. After that, I believe the fledgling representatives require the support of some form of organisation behind them. Without this support, the will to represent may well falter and die when faced with the implacably dull greyness of many service meetings (for example, see Gosling, 2010, page 30). It is true that people do act as representatives of their groups, often of themselves alone, without independent support, but they will be receiving support from the service organisation in some way. This, however, can become a little incestuous with the representative being too close to the services and thus truly becoming one of the Goffman 'professionals' (Goffman, 1963). A much better system is like the one run by the Dorset Mental Health Forum, whereby SURs are employed by the charity as Peer Representatives and Peer Specialists to garner and then represent those views both from and to their service user constituencies. The project is funded by a *Big Lotto* grant and so is truly independent of the service commissioners and providers, and all the more valued by them for it. Thirdly, SURs require training in their roles in order to successfully carry out their SUR duties, to be more 'professional' in their approaches to the Professionals, to be more comfortable in their interactions with statutory services' representatives. This training is, as is the case in Dorset Healthcare University NHS Foundation Trust, Dorset County Council, and Dorset Primary Care Trust, provided free of charge to those wishing to become representatives from the community, or it can be accessed in-house from the support organisations, for example *Help and Care of Bournemouth*, or Dorset Mental Health Forum.

So, me pondering here to the sounds of the night, being stared at by my now hungry fish, my feet being warmed by Jack-the-Dog, have I come to a conclusion as to the difference between service users and Service User Representatives? I think we see a

similarity and a difference, as in many walks of life where people stand up to speak on behalf of their groups. But mainly, I feel, the differences are slight. Perhaps what the question should be is not what the differences between service users and SURs are, but what makes a Service User Representative more or less effective without turning him or her into a professional and so negating his or her representativeness?

*

So there we have it, a rather unanswered question in many ways but one that is in line with my experience of the work. I think what is necessary now is to engage in some original research and examine the route I took to becoming first a mental health service user, a patient, mentally ill, or sick in the head – whichever label you prefer. This is because an understanding of how I entered the world of mental health service users offers an insight into my particular circumstances. These base circumstances are fundamental to understanding my drive to become a SUR, to put myself forward as representative of a stigmatised group. I begin with my latest diagnosis, and there are many people who would argue that diagnoses in mental health are just so much paternalistic eye wash (Bentall, 2009, page 269). However, there are others who find comfort in having some reason for feeling so strange and separate from others. The challenge of engaging with the concept of diagnoses is that they are embedded in the medical model and many people have a problem with that, ‘which many service users find damaging and unhelpful’ (Beresford, 2010, page 4). The reality is that we have them at present and need to work with them in order to make progress in this medical model-controlled world (Ibid., page 56). Beresford goes on to describe the difference between a medical model describing mental distress as "mental illness" and a social model that takes the fact of mental distress (sometimes labelled with a diagnosis) as one factor in an array of difficulties that society, as it is currently organised, puts in the way of people suffering from mental health issues. He explains that ‘the social model of disability has demonstrated its revolutionary potential for disabled people's lives, so we can expect that a comparable social model of madness and distress could have the same potential for service users/survivors. It offers a basis for a completely different way of coming at mental health issues – one which prioritises service users’ perspectives and puts them and their lives in a wider context. It points to different ways for people to

understand themselves and each other and different ways of addressing their experience and circumstances' (Ibid., Page 61). Until such time as this some might say somewhat utopian ideal is reached society-wide in the Western world, we are stuck to a great extent with the medical model of disability and mental distress offering diagnosis as a starting point. My diagnosis is: "Complex Post-Traumatic Stress Disorder" or C-PTSD for short.

The review of the literature offers unsystematized but extensive empirical support for the concept of a complex post-traumatic syndrome in survivors of prolonged, repeated victimization. This previously undefined syndrome may coexist with simple PTSD, but extends beyond it. The syndrome is characterized by a pleomorphic symptom picture, enduring personality changes, and high risk for repeated harm, either self inflicted or at the hands of others.

(Herman, 1992, page 387)

It is fortunate that I have not acquired the label schizophrenic as, 'importantly, many patients with a diagnosis of schizophrenia also meet the diagnostic criteria for *post-traumatic stress disorder*: that is, they exhibit a cluster of emotional symptoms often seen in the victims of traumatic events. Because they are rarely questioned about these kinds of symptoms, that is hardly ever recognised.'(Bentall, 2009, page 131). The C-PTSD attacks my mental equilibrium in several ways, which are enlarged on in the original stories below, and the symptoms of this diagnosis are held in check with a combination of psychiatric drugs, rounded diet, loving companionship, lessons learned during Cognitive Behavioural Therapy (CBT), and exercising the mind and body.

The first story describes an event that lived deep in my unconscious mind as a distant memory, only rearing its ugly head during a Max van Manen Masterclass when he asked us to construct stories around an aspect of our hands as an exercise to illustrate his teachings around his concept of '*Punctum*', or forceful meaning, in targeted story telling (Max van Manen, 2008, personal conversation). His idea is that for a story to have social impact, to influence the social, it must have hooks that grab into people's

perceptions and make them understand at a more visceral level what the story is all about, what lessons are being offered, so that they can take that story and internalise it thereby hopefully altering their perceptions of perhaps a previously held view of disability or illness. Subsequently, I gave Max and Fran a copy each of the story for them to use in their teaching practices. The event itself occurred in 1982 but the memory of it surfaced on 15th May 2008. It has now submerged again and the only details I have are this story. Thus begins my journey into darkness.

Hands and a Grenade

It is half-way through the Falklands War in springtime 1982. It is cold. It is dark. I am very tired. As I walk back to my lines, I pass a Forward Medical Aid Post. The internal light slashes across the pitch black between us and blinds me. I stop dead as it falls on me. The armed guard recognises me: “Sarge! Hold up! Have you got any of those spare grenade pins on you?”

I feel inside my windproof smock’s pockets among the boiled sweets and pens, and pull out two or three: “Yes. Why?”

“MO needs you inside at the double!” I run into the tent and halt in shock. Facing me, under fizzing glaring white lights, is a medical team with a body on a Gurney between them. The blood-spattered tall man on the left has a silver ‘thing’ in one hand, and is wrist-deep inside a young man’s chest, holding the edges of the wound open with his silver retractor.

“Felix?” I nod at the doctor. He looks instantly relieved. “Get over here. This patient was shot in the back as he was about to throw a WP grenade, and he rammed it into the hole. Problem is, he’s only able to hold the lever down because I am, too.”

“Shit, sir!” White phosphorous (aka ‘WP’) is horrible. If it goes off, sticky lumps of phosphorous will eject across a space about twenty metres in diameter and as high. The phosphorous would then react with the oxygen in the air and would burst into

almost uncontrollable piercing destructive flame and burn deep into any soft surface – like the doctor’s and nurses’ bodies.

I look into the brightly lit chest cavity and see the grenade with its distinctive shape and colours. I also see the doctor’s long, thin fingers slippery with blood as they wrap tightly around the young man’s hand, holding those younger fingers around the grenade. Near the hand I see the edge of a young heart, beating rapidly, pumping blood around this dying body. Shit, indeed.

“Don’t move, Boss.” I reach forward with my naked dry left hand and take up the pressure from him. “Now, gently slip out of there and clear the tent. Fast.” I look at the deep brown eyes of the patient, dopey with morphine. The letter ‘M’ is on his forehead, and tears are running down his chubby child cheeks. His lip and chin are too young to grow bristle - he is just a baby. So, what the fuck is he doing here? I keep my left hand around the grenade and reach for one of the pins in my jacket pocket with the other. I smile at him and nod gently.

“You’re not alone; I’m here with you, son,” my eyes say as my right hand moves into the chest cavity next to my left. I glance down and see the grenade needs twisting slightly to the left to expose the pinholes. I rotate my left hand and his fingers come off the body of the bomb with a juicy splashing “plop”. I now have the fly-off lever safely under my control.

I gently line up the pin with the holes. The blood is getting deep in there, seeping from somewhere faster and faster. I have to be quicker or the grenade will be hidden under the blood. I automatically check my breathing and heart rate – both calm and normal, as usual during ‘the job’. I carefully twist and pull, and line up the holes and the tips of the split pin. I gently push and twist it through, and caress the ends apart with my fingertips. This secures the fly-off lever and renders the grenade as dangerous as a tin of beans. I smile at the young, very young, baby-young man and sink into his great big brown doe-eyes, pleading at me from behind the drugs and pain and fear not to be left alone, to be left to die alone. I look and look and can’t look away. I lift the grenade out and his arm drops down the side of the Gurney to dangle, dripping blood on the muddy floor. There is a slopping sucking sound as the

bomb comes free, the boy's wet damaged flesh holding on to its shiny tin-plate friend until the last.

I am suddenly hyper-aware: the smell of blood and chemicals and piss and shit and vomit coming off the boy on the Gurney; the sounds of people milling about outside; the feel of warm blood thickly squirting up my left forearm; the dampness inside my boots; the raw taste of blood in my mouth; the feel of the filth and grime on my skin; the roughness of my shirt; the throbbing ache inside my head; the hunger in my centre, not for food but for someone, anyone, to tell me everything would be alright, that this brown-eyed olive-skinned baby boy would be alright, that I would be alright. It all rushes at me at once and I feel sick, the taste of bile sharply stinging the back of my throat. I need a drink.

I lift the grenade clear and show it to him. I am soul deep in his eyes now, and his life leaves his body. There is no shuddering or gasping or shaking; he just leaves me. One second he is looking back at me, and the next he isn't; but nothing else changes, I just know he is gone. His isn't my first dead body, nor even my third, but his troubles me. The trouble is hiding deep in his eyes: I am still emotionally locked inside them, fascinated, staring at the sudden blankness, emptiness so different from the drug-filled pain-filled worry-filled fear-filled eyes of a second before. Was it that long ago? I am in there and he is not - and I realise with a tide of guilt that I should have left the bomb there; that I have just murdered him.

I place the grenade onto the medical tray and wipe my hands on the sheet beneath him, then turn and walk out into the cold windy muddy noisy dark among the medics and Marines and squaddies. I nod at them and close the tent flap, and then melt myself into the surrounding gloom, making my escape quickly and quietly. Looking back I can see the silhouetted guard looking for me but I walk on.

I do not cry. I do not grieve for him. I do not talk about it again for twenty-five years.

Loss

24th May 1999

There was a time; I felt it time; I knew the time was ripe
To move from life; to leave this life; to quit this life of mine.
But other people linked by feelings held me tight against my will,
Held me tight and held me closely, held me warmly close to life.

I tried as hard; I pushed as hard; I lived as hard as bone.
But try as I might to win the fight, I would see the sight alone.
Of rigid flesh, of secret flesh, of stinking flesh of war,
Of dead men's gizzards, blind men's eyes, emptied heart and soul.

I watched the blood ooze thick as mud; ooze thick as night away.
I saw the life, I saw the soul, I saw the young men die.
No thought for them at home again, for them alone at home,
Of them left all alone at home, waiting till they come.

They do not come, they cannot come, they will not come again;
I've seen them fall like forest tall, obscenely felled by me.
I've plunged knife and took a life, I saw the life ooze out.
I heard them cry to the blue sky, I heard their frightened shout.

And from one I saw an orb, a misty ball of light,
Float from his chest, float to sky, to fly his soul on high.
But this was maybe all a dream, a fantasy of mine,
And soon I will wake up, wake up, and live my life of crime.

The restlessness, the restless soul, the hopeless wasted cause;
The pain, the prison, and the strife; the major feelings lost;
The feelings formerly were mine, but now they are all lost.
All gone, all gone, flown without soul - all gone, flown with his
soul.

Richard L Peacocke

*

Professionalism pervades it, but inevitably, when reading the above original narrative, one is drawn into a consideration of *Self* and *Other* (Canales,2000). It is

often seen that human beings develop a concept of differences between ‘them’ and ‘us’ so as to protect themselves from feelings of fear and to order their world view. Beyond an obvious nod to brotherhood, the concept of otherness allows for the development of criteria for others (Chang, 2008, page 26), for existentially different human beings. Chang lays out three criteria of other-ness: ‘others of similarity; others of difference; and others of opposition’. The young soldier lying on the gurney in the story moved conceptually from an other-opposition (as an enemy to be killed on sight) to that of an other-of-similarity (as an injured soldier, brotherhood, a brother-in-arms) as his needs became apparent. In my experience, it is recognised by soldiers that enemy soldiers are probably very much like them, doing a job of work, but who are others-of-opposition as well, which tends to set up emotional dissonances – one reason why the opposition are deliberately dehumanized, turned into targets. It is when one is confronted by someone who has finished hostilities and now needs help that one moves him to the category of other-of-similarity alone. When this almost automatic reaction to somebody in need is suppressed, then the consequences for the soldier can be emotionally dire – such as is said to have happened on Mt Longdon with 3 Para, members of whom are alleged to have executed Argentine prisoners of war (Shirley, 1992). This move engendered my own emotional dissonance, the difficulty I faced dealing with him. As an enemy soldier, killing him would have held no worries for me; but as someone similar to me, that he died was of huge significance and had the detrimental effects that later surfaced as part of my post-traumatic stress disorder years later.

"The silence spreads. I talk and must talk. So I speak to him and say to him: "Comrade, I did not want to kill you. If you jumped in here again, I would not do it, if you would be sensible too. But you were only an idea to me before, an abstraction that lived in my mind and called forth its appropriate response. It was that abstraction I stabbed. But now, for the first time, I see you are a man like me. I thought of your hand-grenades, of your bayonet, of your rifle; now I see your wife and your face and our fellowship. Forgive me, comrade. We always see it too late. Why do they never tell us that you are poor devils like us, that your mothers are just as anxious as ours, and that we have the same fear of death, and the same

dying and the same agony — forgive me, comrade; how could you be my enemy? If we threw away these rifles and this uniform you could be my brother, just like Kat and Albert. Take twenty years of my life, comrade, and stand up — take more, for I do not know what I can even attempt to do with it now."

Paul Bäumer in *All Quiet on the Western Front*

Another aspect of this journey into madness is the moment a world crumbles and leaves one high and dry, alone in the madness of the moment, a prey to the past and all the bottled up, battened down emotions of a lifetime of abuse. Most people associate PTSD with battle-scarred soldiers but any overwhelming life experience can trigger PTSD, especially if the event feels unpredictable and uncontrollable. The next part of the narrative describes just such a moment, when the car I was driving to work one uneventful morning came into an unavoidable high-speed collision with a truck coming the other way. It was the end of one state of mind and the beginning of a far darker time, one that showed it still had the power to terrorise me years later when, in 2010, I was witness to a road traffic collision that left me shaking. I had been travelling along behind a white panel van at about 50mph (80kph), when this van seemed to silently detonate in front of me. Small bits of van, a lot of dust, and naked bodies were strewn across the road. Before I could stop, I had rolled over one which reared up and ‘looked’ at me through my side window. What I had initially seen as an explosion, I soon realised was the result of an articulated lorry ripping out the side of the van with a sharp corner of its trailer and the ‘naked bodies’ were pigs’ carcasses being taken to market. These reflections only came later, after I had panicked and fled the scene in a cold sweat and shaking, the victim of my PTSD now reinforced.

The final straw

I know that, on a World scale at least, I am extremely fortunate compared to other people. I am a free man in a free country. I live in a modern and war-free zone with

sufficient income. I have all my limbs and sense organs. I even have friends, family and children. I am very lucky. But there are times when none of it means anything at all. It all seems a load of crap. It would mean more if I could free my mind of this interminable turmoil, this cycle of light and dark; if I could just determine the critical angle of incidence of my thoughts and begin to defeat the total internal refraction of my thought beams, stop them feeding on themselves and on me. Until I can get outside of myself, I shall be locked within.

I know deep inside that there is nothing I can do to stop it as my life slowly - so painfully slowly - unravels before my eyes like a cartoon character's woolly jumper. I had hoped against hope that if I worked harder and longer, and shoved it deep beneath the surface, that all would be well in the end (because doesn't everything always turn out for the best in the end?), but that just made things worse. As I piled layer upon layer of new life-skin across the pustulating boil of the hurt-unresolved, it did not decrease but grew more compressed and concentrated. There began a competition between the outward pressure of the boil and the containment strength of the life-skins. This competition had, in the end, to be resolved: but then who thinks of the future when the present is going so well?

And hasn't my faith in the inherent goodness and rightness of my life and the way I have lived it - except for those parts that I hide even from myself - always been upheld by the way I have always been fit enough and strong enough to be able to drag myself and my slowly growing burden from one shell scrape to the next? Fate's little pieces of shrapnel have always whizzed passed just above my head.

I am now a 57 years old white Anglo Saxon male of no fixed religion. I have filled many roles, as I have said before. Such is my burden. It is what has made me. It is what I am, but I am also more than this. I am me, and I know what I know. Sometimes, this knowledge seems to be out of step with the reality around me, and then I am labelled '*depressed*' or '*at risk of self-harm*' or some such and all is inner conflict. At other times, me and the world are in harmony - then all is well.

Most of my past had been tucked safely away - or so I believed. It took three road traffic accidents in less than twelve months to shake my world view and send me

over the edge of sanity and into a crazy egocentric world of self-hatred and suicidal ideation.

They called it '*Clinical Depression*', but I called it '*Hell*'. They said I was suffering from '*Post Traumatic Stress Disorder*', or '*PTSD*', but I thought that if I was suffering from anything, then it was from an upsurge of memories better forgotten and dreams better not dreamt. They said I was suicidal, but I just wanted it all to end - one way or another. I suppose in a way we were all correct. They said I was arrogant and unbending, but I just wanted them to go away and play their mind games on someone else. Many influences were boiling up and competing for primacy inside me; so what was the straw that broke the camel's back?

It was 1998. I had just completed an honours degree in psychology and a diploma in mental health nursing and become a registered mental health nurse. I had been the health care manager of a medium-sized prison for the past year and was relishing the challenges this brought. And I had just emerged from a painful and difficult divorce. It was then that I decided to touch my brakes at about 45 mph (72 kph) on the way to work one dank morning.

I had great confidence in my car. It had recently been fully serviced and new tyres had been fitted, so the crash came as something of a surprise. I was in a long fast straight skid on a wet and diesel-polluted road – and, on reflection, it seemed that my brakes did not work at all. In front of me was a large red van. Either side were low grass banks into fields beyond hedgerows. Cows grazed quietly, only vaguely aware of the world beyond their electric fences. A magpie swooped low across my front. March drizzle sprayed gently, covering everything with a pearlescent sheen. All was countryside-peaceful – and everything held its breath and waited.

The other driver was desperately trying to get his vehicle out of the way, desperately trying to avoid the collision. I saw his face as he stared at me and watched as he struggled to control his vehicle. He came closer and closer. The reality and inevitability of the coming impact forced itself upon me. I wished it would not happen. Like a child, I wished that something magical would end this flight into oblivion. There was no doubt but that I would now die. And there was no doubt but

that I was looking forward to this final release.

I knew that I would have to hit straight on because a car's greatest strength lies in its front crumple zones, but I had no control whatever over my flight towards the van. And flight it was. There was no sensation of contact with the road at all. The engine came off-line when the automatic transmission disengaged, and was very quiet. The rev. counter showed 900 rpm, tick over, so I reached down and switched off the ignition. I didn't mind dying, but I was not going to roast to death in an avoidable fire. The engine died. *'Finished with engines'*, the Naval final order went through my mind. Then, from gentle peace the world went mad around me.

Everything was in slow-slow time. I watched the wipers swish-swash slowly across my windscreen. I saw small droplets of rain coalesce into rivulets running sideways across the maroon expanse of my gleaming bonnet, shattering the mirror image of the red van as if in gloating anticipation. I smelt the damp and earthy air of rural Dorset, of rotting woodland and new growth, of life and death and life. I felt the solid weight of the brake pedal under my foot and the death-shudder of the wheel as the car struggled to avoid eternity. The gentle hum of the engine just ticking over and the swish of the rain-soaked road passing under me would be the last things I would hear, but I was wrong. I thought of Marion and Samantha, of Richard and Kevin, of all my family, and thought how I would miss them. There had been so much I had wanted to say and now it was all too late. I felt the warm glow of my veins and arteries dilating, feeding my muscles with sugars released by the adrenaline surge of excitement and fear that year-long millisecond ago. I felt comfortable and ready for the end. I hoped it would be reasonably swift and painless, but that was out of my hands now. As I watched, the two bonnets rippled gently together. I relaxed and let life go.

Even though expected, the crash was sudden, violent, unremitting. It was bone-crushing and nerve-jangling in its violence and ferocity. Subjective and objective times met with a thud as the car fed itself into the front of the van. The apparent stretching of time came to an abrupt end as contact with the van smashed us back into this world. Now everything was very fast and very loud. In the space of one shattering heartbeat, a proud *Rover 2000*, nurtured and loved and polished through

many years, newly serviced and with brand-new tyres, turned itself into so much scrap metal. The bonnet crumpled, the engine slid beneath the cab, the steering column came back and broke in two as it smashed into my chest. Crumple zones crumpled; the rear seat flew forward and its steel-reinforced arm-rest folded in two. And through it all my seat belt locked me firmly to my seat.

My brain bounced about as my head ricocheted off the head rest and steering wheel. My ribs creaked and bent and cracked under the crush of the safety belt holding me down and saved me from flying headfirst through the windscreen. My sternum buckled under the whack of the steering column. My hips and legs bruised as I flew forward against the restraints. My eyeballs juddered. My teeth chattered. My hands and feet seemed to bulge as blood flew forwards. My ears rang to the cacophony of a dying car. My eyes grew dim as I began to lose consciousness.

PRISON HOME

It's strange, but sometimes when I think of past and now and soon
I feel a fire within my brain, a pressure from within.
These feelings never had occurred as day by day went by
But now I know the heaping price of youth days spent in sin.
Father always tortured me but never raised a hand,
And mother smothered me in love and coated 'gainst the storm
Her first-born only son and heir whom she knew sought her help,
Who revelled in her warm embrace; truth a burrowing worm
Within a heart protected from frost and sun alike;
Held captive and lost and alone while others move along
To rhythms he could never match and dance steps far too hard;
To native drumbeats of the heart and wild free Gypsy song.
And so he grew and grew and grew within his home-made jail
'Til now he is all fizzled out and trapped and unaware
Of how the song is sung, the dance is stepped, the tom-tom beat,
Until a brick, a stone is moved, and people show they care.

Richard Peacocke, 1999

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Posttraumatic Stress Disorder is the development of symptoms following one's exposure to an extreme event of some sort, such as this car crash. This event (or these events, because this event acted as a catalyst to a whole gamut of stressors as will be seen later) will have either involved actual or threatened death or serious injury, or the person might have witnessed an event that involves death, injury, or a threat to the physical integrity of another person (DSM IV™, 309.81, Posttraumatic Stress Disorder). They may even have learned about an unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate. One's response must involve intense fear, helplessness, or horror – or all of the above.

The symptoms one has resulting from this include constantly re-experiencing the traumatic event, often called 'Flashbacks', avoiding situations that are associated with the event, a general numbing of feelings and emotions, and an increased arousal state. Rarely, a dissociative state can result that may last from a few seconds to several hours, or even days. During these dissociations, one might behave as though living through the event again. I have suffered from such dissociation.

Objects and situations that remind one of the events that caused the trauma are avoided because they cause psychic pain. This also means making deliberate efforts to avoid thoughts, feelings, or conversations about the event and to avoid activities, situations, or people who remind one of it. This may go so far as to include amnesia for an important aspect of the event. "Psychic numbing" or "emotional anaesthesia" also usually begins soon after the event. Enjoyment of previously enjoyed activities is reduced or extinguished, and one can feel detached or estranged from other people, or of not being able to feel emotions (especially those associated with intimacy, tenderness, and sexuality). One may even not expect to have a career, marriage, children, or a normal life span and this can turn into a self-fulfilling prophesy through dangerous or suicidal actions (RCPsych, 2011).

I suffer from these symptoms. Specifically, I re-experience traumatic situations – though I have learned how to avoid these by not thinking about the past (another symptom) and avoid memorials and getting together with people who remind me of the traumatic situations (more symptoms). An example from this story might be the

feeling that, on the way to the impact, I actually looked forward to death, embraced it as a friend, and generally exhibited a will to death that subsequently shocked me to recall, to the point of these thoughts being buried and hidden beneath more so-called acceptable memories. People often ask me to attend Remembrance Day functions or ex-military gatherings or parades, all of which I avoid like the plague – which is what PTSD is, a sickness of the soul.

Post-traumatic stress disorder: A common anxiety disorder that develops after exposure to a terrifying event or ordeal in which grave physical harm occurred or was threatened. Family members of victims also can develop the disorder. PTSD can occur in people of any age, including children and adolescents. More than twice as many women as men experience PTSD following exposure to trauma. Depression, alcohol or other substance abuse, or other anxiety disorders frequently co-occur with PTSD.

<http://www.medterms.com/script/main/art.asp?articlekey=187>
79 (Accessed 30MAR11)

I am definitely always psychically numb and this extends into all areas of my life. In fact, whenever I begin to feel emotions, my mind automatically dampens them down and tries to resume that grey flatness that is safe and comfortable for me, if not for others, and this has in the past led onto dissociative behaviour. My illness has arguably resulted in my losing two wives and two girlfriends, two families, two houses, two successful careers, and so on. I was hospitalised for three weeks and have been actively suicidal several times, and self-harmed at others. There are still many days when I wish not to be here any more, but nowadays I find it easier than before to apply lessons learnt in the past to keeping myself safe until the feelings pass or are ameliorated in some way. This is no way for a grown man to live. I worry about my mental health as my post-traumatic stress disorder, my PTSD, means I fall into the remit of the Mental Health Act 1983 as revised in the 2007 Act:

"mental disorder" means any disorder or disability of the mind

(Mental Health Act 1983/2007, Ch.12, Pt 1 Ch 1. 1 (2))

So how can I write about my PTSD experiences? As the sage said: “With extreme difficulty”. I find it hard to recollect my PTSD experiences fully because my mind tries to shy away from them into that comfortable flatness again every time I approach them. The way through this for me is to write a bit at a time and edit at the end. This is how I have written this next part of the now to which follow, and I hope it offers some more insight into my life. This story has been published in Grant *et al.*, 2011, page 26).

Where are the sirens?

Mallorca in the sun. It is the end of September 2010 and I am sitting in the hotel grounds beside a cool blue pool, drinking OJ and sucking OP smoke (other people’s smoke). People are all around me enjoying the warmth and sunshine, and music pumps continuously from a large black loudspeaker on the other side of the pool. I have been people watching for the past hour or so, trying to avoid staring at the best examples of the finest England can offer, and soaking up some rays. Everything is mellow and melodious. I am relaxed. Calm. Collected. As I say, mellow.

The loud grey cloudy peppery thump in the distance draws my attention away from the cloying dampness of my swimming shorts and the stinging sun threatening my reddening body. Seconds earlier, I had been sitting here trying not to think about the on-shore breeze cooling me beneath the blue-white Mediterranean sun, but now I am alert to all the small intrusions around me as I try to analyse the thump in the distance.

Visions of a colder greyer damper place wheedle their way unbidden across my mind. I hear the thump as the bomb goes off and the sky falls in. ‘*Felix is down*’ says the Battalion net radio and I feel fear hit my legs and shiver up my back. What do I do now? We are a bomb disposal unit creeping towards a bomb scene in a planned and ordered manner designed to minimise risk. The Boss, a 29-year old Sergeant, went ahead to organise the rendezvous, the RV, and now he is down which leaves

me in charge, a 22-year old Corporal. What do I do? Sasquatch, the Royal Engineers Search Advisor, runs down the convoy. ‘*What do we do, Dick?*’ The shock sinks in and the brain takes over. Could this be a come-on attack designed to hit the convoy as we over-react to the situation? ‘*Carry on the sweep as planned until we get to the RV.*’ Sasquatch is happy with that. ‘*Okay. I’ll organise it.*’ He runs away, a camouflaged flurry of arms and legs and maroon beret among many others, all intent on getting this convoy of soldiers and policemen to the scene safely. A helicopter chases low overhead, rotor disc glistening in the winter sunlight, as the Brass react . . . I jerk myself back to the present day. This is not a sunny winter’s day in 1970s Northern Ireland, this is a sunny autumn day in Mallorca in 2010. Get a grip!

The loud thump in the distance had sounded like an explosion, a powdery-grey cloud of an explosion, but where are the sirens? One would expect the constant music and the hum and buzz of the air conditioning to be drowned out by the Banshee howl of sirens, had it been an explosion. Another thump interrupts the *Beatles* music droning out of the poolside speaker and now I am really alert, but still no sirens.

Were they “two maroons for the lifeboat?” I don’t know, but I don’t think the Spanish use maroons. I remember destroying hundreds of maroons in Hereford, after they fell out of their *Use By* dates. We fired them off across waste ground and the thumps were very similar to those I have just heard. They flew well and exploded just above the ground the required distance away in a thump-flash and cloud of grey-white smoke. Maybe there will be a third thump? Still no sirens.

The two thumps might have been aircraft breaking the sound barrier – a sonic boom or two? Perhaps, but it would have to be military aircraft, members of the *Ejército del Aire*, as there are no more supersonic passenger planes that I know of, now *Concorde* and *Concordski* are no more, or does that show my age? But that might soon change. The music changes to *Rod Stewart* singing about going back to school, Maggie, and still no sirens. No one else has reacted either. I glance around. Bodies continue to broil about the place. Adrenaline continues to surge around inside my body, released by the thumps.

As no further thump is heard, and there are no sirens or flashing blue lights, my

heartbeat lessens and I notice that the sun carries on burning me. My hormones are working overtime but I relax as the adrenaline and noradrenaline wear off. I sit up and wrap my beach towel about me, blocking off the rays and the breeze. I sip my orange juice and ice and look around me. My left foot itches across the instep so I scratch it with my right. My shorts are still cool and damp and continue to cling to my thighs. 'Night Fever' by the *Bee Gees* thumps and squeaks across the pool. And still there are no sirens. Relax! But I can't. My body wants to fight or flee or freeze but I do not allow any of these to happen. What about fright?

I sit and soak up the sun while sipping my OJ. I pull my towel up onto my head to ward off the sun and dampen down some of the cackling coming from several fat women wreathed in smoke on the other side of the pool as well as trying to block any more image-inducing input. *Barry and Kim's* 1969 *Archies* hit 'Sugar Sugar' comes over to me, cooled by water and breeze, and I consider going for a swim.

Maybe the thumps were made by Spanish naval gunfire out in the bay, similar to the gunfire heard in the Falklands? But why would the *Armada Española* be firing guns in Palma Bay? Of course, they wouldn't! The problem with PTSD is that one's attention, one's alertness, once switched on takes a while to switch off again. What is needed is distraction but even *Dean Martin's* tones fail to soothe me. It doesn't help that the thumps are reinforced by other input jangling my memory strings. A jet liner takes off from Palma de Mallorca airport and crawls through the blue sky in front of me. The roar of the engines echoes off the hills across the bay and I see an Argentinean *Douglas A-4C Skyhawk* attack jet flying low over the steel blue-grey San Carlos Water in the Falklands. It is 1982 and I imagine the pilot's face as he is chased by tracer and rocket. The mottled grey and white jet skims the calm sea towards the ships parked in rows as they unload. A *Westland Sea King HAR3* helicopter flies above the aircraft as it whips towards the warships and suddenly rises to the attack. Before it can loose it's bomb onto HMS . . . who knows which, as they all look alike to me . . . an anti-aircraft rocket flies up it's exhaust and the neat little plane turns into a blossoming black, red, gold, and grey cloud thrusting forward between shining debris. The pilot, a small solid figure, is thrown away from the mess and drifts down under his parachute to splash into the chill waters of San Carlos. We cheer and whoop, and I switch back to the present.

Steve Harley and Cockney Rebel are singing their song about making him smile, and cooking smells and cigarette smoke waft across me. Sometimes it is like sunbathing in an ashtray. I still haven't figured out what the two thumps were, but their significance is diminished as I relax a bit more and lean back into my plastic chair. I sip my OJ with its melting ice. "Why do fools fall in love . . . ?" Sigh.

Still no sirens?

Good.

POST TRAUMATIC STRESS

You stood behind me; I was lost, alone within my head.
You stood there with me - deep with fear to see the thing
you dread.
You stood alone up on the cliff, I walked towards the
Bill;
The Pulpit Rock was dark to you, my mind to me was still.

The waters crash and shatter light to splash their shadows
high,
Then plunge grotesquely 'tween the slabs and suck down
with a sigh.
The keenest edges call me down to dive among their stands
. . .
And then the breeze brought perfumed air from well-known
far-off lands.

The sun shone brightly (in the glow of moonlight on the
rocks);
The corals of a far-flung sea; the fishy smell of docks;
The jungle boiling green and foul, with venom streams
entwined,
All glowing with the promised note a youthfulness had
signed.

The pictures change: the scene slips back, the waters
chuckle in;

And suddenly, as quick as thought, I am immersed in sin.
The Belfast docks, the concrete streets, the verdant
valleys round.

The hills and bogs and downs and lakes. The goodness that
abounds.

The soda bread. The severed leg. The fingers in the glove.
The fear. The ache. The quietude. The losing in her love.
The guilt. The sin. The sin. The sin. The sin. The sin.
The shame.

I stand and watch the waters fall. And rise. And fall
again.

The ships were grey and dark and huge: we rolled across
the sea

To ask the Argentines to leave - and then perhaps take
tea.

The waters grey. And white. And green. And black. And red.
And blue.

And still as still. And loud as loud. And calling me to
you.

I saw them fly, those sons of sky. I saw them burn. I saw
them die.

I saw the foolishness of life. I saw at once my child, my
wife.

I saw the evil in my heart. I saw how I enjoyed my part.
And at the end, in Stanley town, I found the time to
settle down.

I checked the guns and knives and tanks, and made them
safe to store.

I cleared the bombs from frozen shit behind the wall or
door.

I found the letters from their moms, the drawings from
their young;

I felt the sadness in their lives, the hopes to which
they'd clung.

The letters from these lost souls found a place deep in my
heart;

I recognised that we had all been closer than apart.
I saw the photos of their wives, their sweethearts; read
their fears;
I touched the drawings from their kids and felt their
bitter tears.

I smelt the perfume on pink cloth well hidden in his hand.
I saw his stomach opened out and blown across the sand.
I felt his rising pulse of fear as Death strolled slowly
nigh.
I saw the longing in his eyes as last he saw the sky.

I also felt my pulse of fear and firmly pushed it down;
I caught the wetness of a tear and called myself a clown;
I drew a breath, shoved in the pin and - man and bomb both
dead -
I closed my heart and closed my love and turned my aching
head.

I close my eyes, my tear-filled eyes, and see again the
scenes

As clear as day but altered - to allow their use as
dreams.

I feel the pressure on my back of someone standing there
And turn to look at you as you turn off your stare.

Now back at Portland's Pulpit Rock, the message clear and
clean:

Without you there behind my back, I would no more be seen.
I owe you much in love and time, and thank you from my
heart.

You are my pal. My friend. My love: you are my other part.

Richard Peacocke
Dorset 2000

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So, there you are. This occurred some years after the crash that kicked it all off

afresh, but PTSD is often like that and comes up on a sufferer quietly, a silent attacker approaching a sentry. PTSD develops differently from person to person. While the symptoms of PTSD most commonly develop in the hours or days following the traumatic event, it can sometimes take weeks, months, or even years before they appear. In my case, a bit of both. It is also instructive to reflect that I was away from home, in a strange land, away from my usual grounding cues. Thus are barriers between then and now, there and here thinned and become porous, and allow bleeding between the universes.

Medication is sometimes prescribed to people with PTSD to relieve the often secondary symptoms of depression or anxiety. Antidepressants such as the Fluoxetine (*Prozac*) and Sertraline (*Lustral*) are the medications most commonly used for PTSD, though Pregabalin is favoured by the doctors of Combat Stress. There has been a lot of literature against the use of antidepressants, which is sometimes strange given that the observable ‘difference is still minimal and usually attributable to discursive effects, other drug-induced effects, or amplified placebo effects.’ (Moncrieff, 2009, page 61), and other views to that effect. I agree with Dr Kramer, who writes: ‘My own beliefs aside, it is dangerous for the press to hammer away at the theme that antidepressants are placebos. They’re not. To give the impression that they are is to cause needless suffering.’ (Kramer, 2011). While antidepressants help me feel less sad, worried, or on edge, they do not treat the causes of my PTSD. Some doctors have tried using drugs like sodium valproate and carbamazepine, usually reserved for treating epilepsy, as a treatment for posttraumatic stress disorder, but this treatment is still experimental. There's no good-quality research yet to be found to say whether drugs for epilepsy can help with PTSD.

The trouble with medications is that they come with many toxic side effects, one of which can be a lowering of one’s libido, noted as ‘sexual dysfunction’ listed with galactorrhoea (spontaneous milk flow in the absence of childbirth and nursing), urinary retention, sweating, hypomania or mania. (BNF 59, 2010, page 233). So, not such a problem then? However, this loss of sex drive feeds into the anger firing up in my soul as if I have eaten too much pepper. So is a psychic emergency transformed into a somatic effect.

The following vignette is something of a rant against the unfairness, or perceived at least to be unfair by me, of side-effects from medication, especially in regards to sexual dysfunction and the way this seems to be pushed to one side by the staff one encounters in one's travels around the mental health world. I recognise that it is not their fault, but that of society as a whole that it is difficult to talk about such things, but they must be talked about. One result of this reticence to talk about sexual dysfunction with a client or service user is a build up of resentment against the very staff who are trying to help you. This creates further distance between the service user and the "normal" and helps to strengthen perceived stigma and alienation, because it is often assumed that "normal people" are sexually active. It is also an assault against one's self perception of manliness. One has to get to grips with these feelings of inferiority before one becomes an effective SUR because an SUR needs to interact with people in particular ways, in ways that do not expose the SUR to further psychic damage. The reluctance of staff to address this situation, this lack of libido due to medication side-effects, does not help in the development of an SUR. Thus, a rant – which has also been published in Grant, Biley, and Walker, 2011, page 145).

Sex

Counsellors and doctors know loads about everything, but sometimes because of that they feel they should know everything about everything else, too. On the subject of sex, they seem to have one tune. Sometimes I feel completely *robotised*, but at other times I could do with a damn good fuck to take the world away for a few shattered moments and make me feel lovely and loved again. However, when I broach the subject on the side (as it were) I am told that my sex drive is knackered - and, of course, I believe them so don't even try to make contact. And anyway, who should I try to connect with? Nobody wants to be near an ugly fat smelly wart of a loser like me - and a shag would certainly be well out of the question! But I still feel that grinding ache in my organs . . .

"You know, one of the first things which disappears is the sex drive, so don't worry - it's only temporary. It'll come back." But this sage piece of bollocks misses the mark almost completely. The sex drive does not go; it is sublimated beneath a vast ocean of undeservedness. You don't deserve a cuddle, so you don't ask for one. As you have not been cuddled, you cannot be worthy of one. But of course you know that already, so what's new? You are obviously unlovable, otherwise someone would love you. You know that you are *fat-or-thin-or-ugly-or-unspeakable-or-dirty-or-smelly-or-untouchable-or-not.fit.to.be.seen.out.of.the.house-or-a.total.disgrace.in.every.department*, or some or all of these, and so anything which seems in the very least to agree with your view of yourself is grabbed and held on to - because you have to believe in some-damn-thing and you have to be right about some-bloody-thing! Even if it is about how utterly fucking disgusting and fucked up you are!

"You know, one of the first things which disappears is the sex drive, so don't worry - it's only temporary. It'll come back." It never went anywhere! It has always been there. I am a man and I enjoy looking at women, and I'm sure you ladies enjoy the sight of a man. And then there are you who prefer the sight of another man or woman. Whatever, and I don't really give a toss what you like, it does not go away. But I just clearly knew that I was too ugly and disgusting, that my clothes were too shabby and that I smelt too bad, for even the remotest chance of the other party feeling the way I did. I knew that, so I repressed my feelings. It might have been nice to have been proved wrong once in a while, instead of having my belief reinforced!

"You know, one of the first things which disappears is the sex drive, so don't worry - it's only temporary. It'll come back." But you get into a habit of not bothering anyone else for sex. If the feelings get too much then you take yourself in hand and relieve them - but, of course, that is selfish and dirty as well! You know your partner is suffering in silence - and probably doing the same as you - because you are poorly, so you feel guilty. I mean, I should have waited until she came home and then stretched her out and given her a good seeing to instead of partaking of autoerotic

fruit. But she would not want me; she only stays here out of charity: you can't desert a sick man because that would make you look a right bastard - and we can't have that. Nope, must stay and see it through. Anyway, that is how I think she thinks.

"You know, one of the first things which disappears is the sex drive, so don't worry - it's only temporary. It'll come back." Yes, but whose? Some partners are so distressed about this illness, this invisible ailment that they lose all sex drive themselves. They never try to be sexy or excite that lump of crying meat who used to be their partner in bed next to them - I mean, why should they? There is no sex drive, is there? It's the first thing to go. And there I lie, wide awake and thinking, thinking, thinking. No one cares a shit for me. The person I love the most, my bestest pal in the whole world, doesn't fancy me anymore. Mind you, that's no surprise, is it? And I have seen how people glance at me in the street, glance and look away. They also obviously wonder at how I have been let out alone. Everybody knows I'm a nutcase. They all know that I am mad - if not yet raving, it won't be long! This stands out clearly in the way I walk - the *"Nut-house Shuffle"* - even though I try very hard to walk properly, it's the drugs they give you. It is obvious in the places I go - the surgery, and always hanging out with a nurse. And everyone at work knows as well, and are laughing at me behind my back: *"Couldn't hack it!" "Fucked up, big time!" "That's the end of a promising career!" "Not see his face around here again! And good riddance to bad rubbish - he was crap at his job anyway. We'll all be better off without him!"* And my family - it is better not to talk about my family! I have never been so patronised in my whole life. For crying out loud, can't I get treated a bit more like a human being?

Do you know, sex might well initially be a very low priority on the agenda, but human contact is all about sex. And contact is high on the agenda. Without contact, we're lost. So, okay, I can't raise a smile because I have been coshed by all the bloody tablets I take. That does not mean I don't feel the need. That does not mean I don't want you. That does not mean that I don't love you - even if I find it hard (very bloody hard) to understand what you see in me.

Maybe a massage? Or some encouragement? Don't just piss off to bed and leave me downstairs, night after night. Don't imagine that is what I want to do. Perhaps I am frightened to come upstairs before you are asleep, in case you laugh at me. Perhaps that would be just that little bit too much for me to bear.

*

I am angry at the world and frustrated with myself. I am irritated that I still need such contact, especially considering the effects of the psychic numbing of my PTSD. My self-image has taken a battering and this leads to lowered self-esteem and a lowering of my defences against depression and anxiety, those two pretenders who act erroneously to try to control the PTSD. Apart from being chronically poisoned by the prescriptions said to help me sustain a reasonably level-headed life-style, the condition itself, including the stress and depression associated with it, have serious effects on my functioning. The stigmatisation of such mental health challenges pushes one further away from mainstream society and into the arms of nurses and other service users, safe havens in a confusing time. One of the more dangerous of those effects is dissociation.

An SUR needs to be in control to some extent at least of the symptoms from which he or she is suffering, as otherwise he or she would be ineffective in the role. This is another aspect of the differences between service users and an SUR. Sometimes – and I have seen it done – service users who are obviously unwell have been asked to undertake work which makes them feel worse because they cannot complete the work satisfactorily, at least in their own minds, leading them to a sense of failure. This is not a helpful or healthy position to be in. The wellness or otherwise of service users needs to be carefully assessed before they are asked to undertake the responsibilities of an SUR. This is why training and effective managerial supervision are so necessary. If a service user is actively dissociating, is actually "not with us" some of the time, how can he or she be said to be an effective representative of other service users?

Dissociation is a common symptom both of PTSD and depression-and-anxiety. Many people have sought therapy for a depressive- or anxiety-related disorder only to find that therapy and medication are not enough. Often, the problem is because the

client's dissociation is ignored or unrecognised by a clinician. Dissociation, like self harm, is sometimes understood to be a crucial survival mechanism that protects one during a crisis and afterwards. If you are able to function without fully experiencing the emotional impact of an event, you can accomplish tasks until it is safer to deal with your emotions.

For example, let's say you are a bomb disposal officer with the Army in 1970s Northern Ireland. Before you even get near a suspect device, you know that the perpetrators may very well have had it in mind to protect their device with either sniper fire or booby traps, either on the device or on the approach route. This has been common practice for so long that it is routine to plan for it. If you were to feel the terror of having your life threatened, you might not be able to deal with the detail of such a planning meeting nor when you get to dealing with the device would you be able to separate yourself from the situation sufficiently to risk being blown to smithereens at the slightest slip up or bit of bad timing. I have knowledge of one Warrant Officer Ammunition Technician who suffered in this way, and over the course of a weekend he was sent home to Germany without having completed his tour of duty in Northern Ireland. In another example, if you are a child who is being physically, sexually or emotionally abused, dissociation allows you to endure the experience without having to *fully* experience it (tell me about it). Sometimes dissociation is so deep that all memory of the abusive situation is lost or forgotten. It is a critical part of people's survival responses to be able to dissociate.

That is dissociation in the past. That is when, arguably, it is useful to get by, but what about in the less-threatening present? With PTSD, what is non-threatening about the present, when memories can become so powerful that your body shuts down into a dissociative state rather than relive the full force of a traumatic event from the past? The next story in my narrative examines dissociation.

Dissociation

In the real world again - or as real as I can get it - I have been walking for three hours. My town clothes are warm and comfortable. It is summer and hot and dusty in the tracks and fields of Dorset. Skilfully outfitted ramblers look at me with curiosity, and then turn back to their maps. I am reading Sylvia Plath's, *The Bell Jar*.

All is deserted. Ripe crop and chemical tang, crushed Comfrey and dry Nettle, an abundance of different grasses in seed. Blackthorn hedges rise impermeably above a rock-strewn bank to my right and Barley falls in great tablecloth folds into the valley to my left, to rise in breeze-shimmered sheets to a headboard of dark and brooding woodland. The noon sun beats down on my uncovered head and draws out my moisture in great gobletfuls, rinsing dust and seed in rivulets off my sore face. A pheasant calls from the edges of a dark wood.

My nose, over laden with toxic dust and no longer able to filter, allows further loads to deposit on my bronchial tubes, soft palette and tongue. I have no handkerchiefs, and the small numbers of nose tissues I find crumpled in my black winter jacket's pockets are already soaked with mucus and capillary blood from nasal passages raped by constant evacuation. My energy levels are rapidly failing, as is my aim - I had determined that I would die here among the fields of Dorset beneath blue summer skies.

I find a crossroads - a right place, a meeting and parting place, a place of rest. An ancient place populated by streams of insects moving through hard-edged shadows thrown across sun-bleached path. Large bees thump past my ears and smaller creatures covertly buzz and zip about me. I place myself central, a traffic island for airborne insect life, and sit cross-legged with my head in my hands.

All is heat and dark and noise. I sit. Heat reduces but noise increases. The etymological rush-hour approaches. I sit. The World melts around me and symbolic representations upon which I have relied for my whole life are brought into question. I sit. I am no longer in a heliocentric orbit on a spinning rock; the World is orbiting

me, my still form, and it is entirely noise and breeze-kissed cheeks and pain and eternal temporal pause-time - dreamtime.

Precious liquid, salt and warm, flows from my eyes. My cheek muscles jerk and my lungs stop their unnoticed slow rhythm, to suck air and blow waste in a jerky uncontrolled manner. My nose, so dry before, runs freely and my lips shake, and quieten, and dribble.

Sweat in my hair, neck, and forehead forced, I wipe the stinging liqueur from my eyes as I open them. Sunlight streams blinding into my World, and much time has passed. Much much time has passed.

Dusk, and the insect traffic has given way to rabbits nibbling the few green shoots to survive the farmer's chemical holocaust. Unconcerned at my slowly unravelling presence beyond the odd cocked ear, they continue to hop and feed, hop and feed. Birds fly home across dusk-purpling skies. Sparkling, an as yet finite number of stars peek through gaps in the curtain at tonight's audience.

I have been sobbing for some considerable time - though time has no meaning, and I have not realised that I am sobbing. My reality-symbols drift and sink into a symbiosis with the quiet nature-land about me. I feel drained. Degaussed. Unmanned. Energy less. Spirit-free. Shamanic. I spread my arms above my still-crossed form and tickle beneath God's beard. I give myself to nature. I have nothing left to live for and want to be taken there and then, there and then. I wish for it and plead for it. I pray for it and beg for it. I plead, grovel and cajole for it. But Death eludes me, laughs in my face. I cross my arms and cry. My mind is clear and blank, black and empty. I have no thought beyond me. I am me am I. There is no other. I sob.

Then I stop. Everything stops. It all stops at once. All is silent and calm. I feel a gentle hand, a gentle enfolding warmth in the cold breeze still blowing against my cheek. I am lifted to my feet, yet not lifted. I am made to breathe my breath blown on the breeze into my upturned face. My tears dry. My pains recede. My eyes clear.

Bats fly about me harvesting an airborne crop of late commuting insects. An owl calls. I look to see if there is anybody near, but I am alone. I feel her but she is not here. I do not feel loss. I take a deep breath and the spell is broken.

I begin my long walk home.

*

My literature search has shown that there are varying levels of dissociation (Bernstein and Putnam, 1986; Carlson and Putnam, 1988; Kihlstrom, 2005; Angiulo and Kihlstrom, 2008). At its mildest, *Everyday Dissociation* is what we all experience and it is healthy in general. This encompasses states such as day-dreaming, ‘spacing out’ during the drive home from work, time dilation, and fantasy. The next level is the *Traumatic Dissociation* that comes from experiencing a trauma. The more dangerous the trauma, generally, the more serious or severe traumatic dissociation becomes. Here we find numbness, deadened emotions, and, sometimes, out of body experiences (OBEs – leaving one’s body). These states are common in PTSD and can include symptoms such as derealisation, which is the constant experience of dissociation; and depersonalisation, i.e. not feeling the sense of “*Me*” or not feeling your body as belonging to you. Also, in its most extreme form, and rather controversially, dissociation can cause a sense of fragmentation, of various self-identities within one, now diagnosed as Dissociative Identity Disorder (DID) and found more in women than men (Scott, 1999).

Sometimes to try to gain some level of control over this sensation of sinking into dissociation, I will enter a state of otherness and self-harm. This brings me back to reality by the sharp pain, taking the internal pain and externalising it; and the knowledge that I have marked myself as a person in distress adds to that distress, as I begin to fear the stigma associated with my self-harming, such as social sidelining and exclusionism. The last thing I want is to be pushed out of my social milieu into a world of mental ill health sufferers, treated with kid gloves and pushed to one side with words like “Bless him.” Perhaps this is why my major forms of self-harming are invisible to the naked eye, like overdosing or sleep or food deprivation, although I *have* cut myself in the past when things got a little too worrisome, but it is

important to understand that this behaviour is totally separate from, and does not reflect an internal will to death, suicidal ideation.

The next part of my narrative, explores this development in more depth. I look at the subject of self harm in the light of my own self harming in the past and muse on the origins, benefits and results that may obtain from such actions.

Self-harming

“Like a thief in the night.” (*1 Thessalonians 5:1-5*) That’s what they say when something happens unnoticed. In the case of Paul’s letter, it is the Second Coming of Jesus Christ at the end of days, but it can be used for more personal things. In my case, it was the departure of my phlegmatic demeanour, which has stood me in good stead over years of bomb disposal, prison nursing duties, court appearances, and dealing with my ex-wife: A numbness has been inserted in its place.

The dulled numbed emotions developed over several years and have maintained their dominance ever since, taking any raised emotion and damping it down to the same porridge stodge pool as the rest.

Occasionally, when my guard is dropped because of tiredness or emotional overload or feeling safe for some reason such as in the bosom of my family and friends, hidden away from the dangers of the world, a musical interlude or a memory or a piece of art will spring out at me and start my eyes to tears. These moments are ruthlessly suppressed by the porridge pool and normality returns. I cannot afford the luxury of these feelings, allowing them free rein (or reign) over my alertness. *That way there be dragons*. Thus, people have to work hard at being my friend and not so many want to do that and so drift away. I am sure that some see it as a challenge and do make the effort, but they have their own problems. However, when I find one such, I value that person greatly and am utterly aware of how fragile is the relationship.

So, when someone or something looks to be threatening it, the pain often becomes unbearable and I have to do something about it for my own sake. I have to bring myself back from the self-destruct panel. I have to protect myself. In such circumstances, the emotions well up fiercely and the porridge pool is not strong enough to pull them back down to it. The logical mind says: “Wake up, old man! You’ve got to do summat here or you’ll be stuffed, and no mistake!” or words to that effect. In fact, it doesn’t come as words in a cod Northern accent like that, but as a realisation that things are getting out of control. I need to do something fast and drastically. I cut myself. I take an overdose. I switch off entirely and become, for a time, someone else – who knows who, just someone else – for longer or shorter periods, responding to the situation to hand, wandering off, putting myself in harm’s way as a means of ending the pain, dissociating.

I suppose that the rarest thing I do is to cut myself. It is much more common for me to take an overdose of my tablets. I do not know why this is but it seems to be the way I have of avoiding the pain. Some time ago, the way I dealt with things was to pull out my beard hairs one at a time with a pair of eye tweezers, or sit myself in a scaldingly hot bath and watch my lower body go scarlet. In the beard case, my reasoning was that I was saving myself having to shave but in reality it took a long-time to achieve a hairless chin and the pain, for what it was, was acting as a distraction for me. I don’t know what I was thinking of in the bath; I was too young and it was too long ago, or maybe I do not want to remember. Such is dissociation.

Another time I was tempted to self-harm was when I was of the opinion that my fiancée and carer, Stephanie, was talking about me behind my back to my care coordinator, David. On this occasion, I felt the need to cut the back of my hand with a rusty modelling knife blade. I made four superficial cuts to the back of my left hand in straight lines and almost immediately regretted having done so. It was so patently obvious that I had cut my hand on purpose that other people joked about it. My care co-ordinator was not fazed at all. He took it all in his stride and noted it down in his file. But then, he was trained in self-harm matters.

By far the most common method I use to self-harm is to take a non-fatal overdose of

my tablets, my medication. I have no idea why I do this, but perhaps the very act of doing it gives me back some control over my life. Obviously, having taken the tablets, I feel quite shame-faced. However, as far as I know these overdoses have caused me no harm. The worst that has happened was when I took too many Haloperidol capsules and slept solidly all through the night, waking in the morning with a headache. Of late, these self-destructive urges have been waning and I have felt more stable on my medications and in my living conditions.

Often people talk about crying for help, but I do not think that is it in my case as I never ask for help after self-harming. There are times when the prospect of dying is almost welcome. I think, rather than being actively suicidal, I am being devious. For example, if I die it might be seen as an accidental overdose and not suicide. I do not know why this is important to me, but obviously it is. After all, should I die, who will be able to chastise me? I will be well beyond anyone's reach, but it will be a black mark against my name even though I would not know about it. But *Sod's Law* says that there is an afterlife and I would be left staring down at all the upset I have caused, and of course the thought of causing all that upset is a strong reason not to take things too far. The reason for self-harm remains, however, in having control over areas of my life when I feel that control is slipping, that I am losing control, and my ability to inflict damage on myself under controlled circumstances is a very important part of my life.

CASTLE MUD

The world becomes too much to bear
With eyes or ears or taste or touch,
And so I close myself away
From eyes or ears or taste or touch.

It's easier in the warm confines
Of this old castle made of mud,
With my enemies there with me,
Away from the cold sight of God.

What need I for security
When I'm locked in from the outside?

Walk through the gate while it's ajar?
It's always been locked from outside.

Richard L Peacocke, 2000. Dorset

*

Thus is my vulnerability laid bare. The Freudian death drive is strong within, but only under certain circumstances and at a time of my own choosing, which allows a little free will – does this make me a metaphysical libertarian working within the concept of a free will that requires the individual to be able to take more than one possible course of action under a given set of circumstances? It also gives me comfort for my old age, as there is no way I would allow myself to become totally dependent on someone else and live just for the lack of dying. The seeming lack of long term hope is merely realism to my mind – and am I now a determinist, a compatibilist? I do not think so.

The phenomenon of hope, which also lies at the root of any meaningful recovery, can best be understood in the context of my experiences of being in the world. If all understanding is self-understanding based on pre-understanding then “Understanding is projection and what it projects are expectations that precede the text” (Weinsheimer, 1985, page 166). In the case of the disruption and fear engendered by suffering dissociative states, including depersonalisation, and the self-harming practises that creep up on me, only hope for a better and more settled future keeps me going along my personal recovery path. In this sense, the self-harming is fulfilling a self-protective role, albeit suppressed.

A shift towards a fuller understanding takes place not from a neutral observer's position, one who is detached or removed from the immediacy of the experience, but via the intimacy of understanding that comes as a part and parcel of the hermeneutic circle. This is my aim in this writing, to help you, the reader, to experience from first hand, or as close as you can get, my emotions and the reasons for my actions, and in experiencing this, to more fully understand me. Within this context, understanding is emergent when we circle from the whole to the parts and back to the whole again, constantly forming and continually revising our understandings about the whole as

more parts of it come into view. As I do this, I help you to form and reform prejudices. It is important to remember that prejudices are not false judgements, they are conditions of understanding. Thus, instead of getting rid of our prejudices, we should choose from amongst them; we must be constantly questioning our beliefs and our understandings as we become prepared for the text we are exploring to say something new to us.

There can be no doubt but that the experience of self harming focuses one on the living that is to be done. I think the lessons learned are sparse from this story. I was in a sorry place and one way of dealing with it was to self harm. That self harm fell well short of suicidal intention and was used more as a method to pull myself up short and focus myself on my shortcomings is evident from the text above. It is also evident from the text that most of my self harming was done privately, without the knowledge of others, except for when I scratched my hand with a rusty modelling knife and regretted it almost immediately because it had the effect of advertising to the world that I had self harmed. This was not something that I required the world to know. I felt ashamed that I failed to keep private that which should have been kept private, that others knew of my weakness. There is prejudice and stigma attached to mental ill health and evidence of self harming is often seen as a badge of that same mental ill health, thus attracting the stigma. I did not want this stigma to reflect on my fiancée to her detriment. Therefore, I kept my self harming invisible to the world. For example, it was mortifying for me to admit to the doctor that I had taken all my Haloperidol capsules and required a renewal of the prescription. This mostly strictly controlled privacy worked against my receiving any help, which meant that I was left out in the cold.

The next vignette looks to the first stage of many a psychiatric/medical model intervention – medications. That I am already on a large prescription when the story begins is understood, as very few of us (being the ‘us’ in the stigmatised group, users-of-mental-health-services) gets away without being placed on one medication regime or another. It is when medication ‘fails’ us, is ‘no longer therapeutic’, that the medics look to change things. This change over time can be a fraught one, with danger ever present of relapse or something worse and as yet unknown.

An interesting aside is the staff's use of language. The modern word used to describe whether a person is taking medications as prescribed is 'concordance' – the similarity or agreement between two or more things, as in 'concordance with medication'. This implies that the person expected to be taking the medication has a choice – and one might argue that where there is free will there is choice, also.

Philosophers who distinguish freedom of action and freedom of will do so because our success in carrying out our ends depends in part on factors wholly beyond our control. Furthermore, there are always external constraints on the range of options we can meaningfully try to undertake. As the presence or absence of these conditions and constraints are not (usually) our responsibility, it is plausible that the central loci of our responsibility are our choices, or "willings".

(O'Connor, 2011)

I wish to argue that, yes, there is free will, but that choices are constrained and mediated by perceived consequences, either explicit or implied by the staff members, most often by the medics. The most serious sanction still being used is hospitalisation under a treatment section of the Mental Health Act 1983 (revised 2007) whereby a person can be restrained and forcibly medicated because of some deviation in his or her social behaviour that is deemed by a Responsible Clinician (RC) acting in partnership with an Approved Mental Health Professional (AMHP), who is a non-medical staff member who has had specialist training for the role, and a second opinion doctor, to have occurred due to some treatable mental disorder. Not that the staff see this as a punitive issue but as a caring one, but this is where viewpoints often differ. A more honest word for staff to use in such circumstances might be 'compliance' - the state or act of conforming with or agreeing to do something. This word still appears in reports where the RC or, less often, the AMHP is discussing a case and wants that 'patient' to be 'compliant' with the medication regime else they may be 'recalled into hospital' to 'stabilise them' or to 'ensure adherence'. What the patient - the user of mental health services - sees is something different. Things might start as 'concordance' during an acute phase of the illness where any help offered is often readily accepted; but as side effects and other consequences of medication come to the fore, this changes in the mind to

‘compliance’, implying that a level of coercion exists. Only the medical side of these bargains expects ‘adherence’ to the regime where the more acceptable definition might be ‘support’, to hold firmly to a belief, idea or opinion. The recipient of the care often views adherence as ‘obey’, to be conscientious in supporting or following someone or something, to adhere to the rules.

What is emergent from all this is the imbalance in power between the care giver, the medic, and the receiver, me. This power imbalance can cause a range of abuses to occur, the least of which might be a change in medication to try to combat the effects of my ‘illness’. After all, does the medic have to be seen to be doing something to help, even if it is only in his own mind? And it is that same sense of imbalance that draws for me a picture of a doctor picking up the phone to the AMHP to initiate a Mental Health Review with a view to perhaps incarceration and forcible medication. This perhaps unreasonable fear prompts me to ‘take my medicine like a good boy.’ I, thus, adhere to the regime and comply with the doctor’s orders, but does this all add up to my being in concord with what is happening to me, my loss of sex drive, periods of vomiting, constipation, weight gain, tiredness, loss of concentration, and so on? I will let you decide.

Medication Changes

You sit quietly at home upstairs in the bathroom doing nobody any harm and strangers whom you feel sure you know but can't quite place come in and start to ask prying and personal questions for about ten minutes which you feel is alright because just lately you haven't given a damn anyway and then they go and you look at the clock and see that over two hours have passed in the ten minutes they were there but at least they have not locked you away as you feared so you can't be a complete loon so you go back to the bathroom and carry on reading your book for the rest of the day.

(Peacocke, 2000a).

To the question *"Is there anybody in there? Just nod if you can here me. Is there*

anybody home?" comes the reply, "I have become comfortably numb." Pink Floyd's music dances brittle as a sugar Christmas icicle across my consciousness, as I sit alone in a house full of ghosts and giggling demons. It holds out the hope of eventual salvation, and I snort. I know that is all nonsense, and that soon I will die - but not yet. As of today, the time is not right. It is not yet convenient. But soon ...

Convenience

December 1999

Written while an inpatient.

One day there will come a day, with the skies all turned
grey,
And the winds in the trees all a-cry;
When feelings run shallow, like fields long left fallow
Have flooded now winter's gone by.
And the nurses and doctors have washed themselves of us,
And sent us all home with a sigh.
The windows are empty, the doors stand ajar,
And the cupboards are washed down and dry.
The cats have long gone to wherever cats go to,
And the plants have been left there to die.
You know, sometimes constraints of the heart and the
tongue
Are more powerful yet than steel chain;
But once those old hawsers are let free and slipped, then
The answer returns to the brain.
Why live in a mortal fear of a bomb? Why wait
For just one more of her smiles?
Why live and struggle when you know 'tis done -
Isn't it better to die?
They've got you by the balls when you're stuck behind
their walls
And must agree to abide by their rules.
But once you're free of them and a free man once again,
Then the ice-hot razor once more calls.
Now, the secret - I have found - is never to expound
Too deeply on the subject 'Suicide'.
The staff don't like it, see! And the Doctor? Nor would

he.

And they have no way to understand it's me:

It's me who's ever in such pain; in my never-ending Hell
of self-blame;

In a place where Demons prick you when you're down.

It's me who'd crawled the slippery wall, and me who'd
slipped back, thinking I would fall,

Until I reached the crumbly edge again.

But having reached the rim and seen all my dreams fall in,

I find life still the awful lie it always was.

My GP had prescribed Prozac, which did nothing, and Melleril, which made me sick and knocked me out for the night. That was *nice* of her. So began my struggle to survive psychiatric care.

In the beginning there was the iatrogenic error:

Prozac

Generic name: *Fluoxetine hydrochloride*

Brand names: *Sarafem, Prozac Weekly, Prozac*

Prozac is prescribed for the treatment of depression—that is, a continuing depression that interferes with daily functioning. The symptoms of major depression often include changes in appetite, sleep habits, and mind/body coordination; decreased sex drive; increased fatigue; feelings of guilt or worthlessness; difficulty concentrating; slowed thinking; and suicidal thoughts.

<http://www.drugs.com/pdr/prozac.html> accessed 24/02/10

Melleril (discontinued in the UK - June 2005)

Melleril contains the active ingredient thioridazine, which belongs to a group of medicines known as the phenothiazine antipsychotics. (NB. Thioridazine is also available without a brand name, i.e. as the **generic medicine**.) It acts by blocking a variety of receptors in the brain, particularly dopamine receptors. Dopamine is involved in transmitting signals between brain cells. When there is an excess amount of dopamine in the brain it causes over-stimulation of dopamine receptors. These receptors normally act to modify behaviour and over-stimulation may result in psychotic illness. Thioridazine blocks these receptors and stops them becoming over-stimulated, thereby helping to control psychotic illness. This medicine is used to treat schizophrenia, only as a second line treatment if other medicines have failed.

<http://www.netdoctor.co.uk/medicines/100001603.html> accessed 24/02/10

BUT:

Prozac should never be combined with thioridazine due to the risk of life-threatening drug interactions; and a minimum of 5 weeks should be allowed between stopping Prozac and starting Mellaril (*sic*).

<http://www.drugs.com/pdr/prozac.html> accessed 24/02/10

“The undesirable side-effects of approved, mistaken, callous, or contra-indicated technical contacts with the medical system represents just the first level of pathogenic medicine.”

My particular form of depression was intermixed with anxiety, keeping me on the move for 23 out of 24 hours a day. I also suffered posttraumatic stress from the Army and elsewhere. I was in a bit of a state by the time the psychiatrist got to me.

He arrived at my house. I had worked with him in my role as mental health nurse and held him in high regard, but now I was really embarrassed. He brought a woman

with him, someone I did not know, to help him keep his assessment objective. Of course, I thought they had come to 'nut me off' to the local psychiatric unit. I knew that they would not waste their valuable time visiting me if they did not feel there was something seriously wrong. Yet, here they were. Sitting in my front room and looking at me.

I believed I spoke with them for about ten minutes, but it was for over two hours. He prodded at my mind and life. He asked me things I had never asked myself. He queried my very existence, and I had to agree with him. He asked me about the past, present, and future - what future was that, Doc?

When the chat was obviously at an end, he asked if I had any questions. I asked him when I would be 'admitted'. He said he felt that would be a retrograde step and was not recommending it. It was an utter relief to hear, and I must have shown it in my face: I thanked him. He went on to say that they felt I was very poorly and needed help, and that the nurse with him would offer it in the first instance: I thanked him again. He said good-bye at the door: I thanked him yet again. The nurse said good-bye as well, and that she would be in touch: I thanked her. Marion asked if I were okay: I thanked her. I went upstairs and felt like crying. I was so relieved.

We spend our professional lives telling people there is no stigma attached to being admitted as a patient to the wards. We tell them that it is like having a broken bone that needs mending, and that they would not think twice about going into hospital to have that done, would they? So why should they worry about going in for a 'rest' when their mind is a little damaged? But of course, we know that is all bullshit. There is a stigma attached to mental health hospitals that is totally undeserved but is there all the same, and the embarrassment level is multiplied a hundred- or a thousand-fold if you work in one as well, and especially so in the late 1990s.

Although there is agreement on what 'stigma' is (a mark of disgrace or discredit that sets a person aside from others), definitions differ in the breadth of experiences they describe. Stigmatisation is the process wherein one condition or aspect of an individual is attributionally linked to some pervasive dimension of the target person's identity (Mansouri and

Dowell, 1989). It is the negative effect of a label (Hayward and Bright, 1997), or the process of establishing deviant identities (Schlosberg, 1993). For Corrigan and Penn (1999), stigma is another term for prejudice based on negative stereotyping. The clear inference is that the 'negative' aspect reflects not only unfavourable stereotypes, but also the negative attitudes and adverse behaviour of the stigmatiser. Clausen (1981) saw stigma as 'a buzz word, arousing more emotional reaction than words like devaluation and discrimination'.

(Byrne, 2001)

The shrink's decision would have been either to leave me in peace, doctor me in the 'community' (at home), or admit me to a mental health institution 'out of area' - which in my case would mean somewhere like Exeter or Bristol, such is the effect of centralised training and institutionalised stigmatisation. He decided to treat me at home. In my mind, this was a mistake. And so began my career as a mental health patient, and you know what my definition of a career is, don't you? It's an uncontrolled downhill rush to disaster.

As before, like the witches in the Scottish play we three meet again in the Forum offices. The detritus of previous work lies all around us, distracting mind and eye. Carol, Fran and I are discussing the next steps. Fran is laid back, his lithe frame almost supine across the metal framed chair, his crossed legs partially beneath the corner table. Carol sits upright across the wooden expanse from me. I have a migraine coming on and am finding it hard to focus.

Fran: I think so. You know, you write evocative prose and perhaps draw in a number of pictures and the describing what those . . . what those pictures are all about - but, hey-ho, that's analysis. We've already got the interview one. The nature of . . . I can't remember in precise detail how long it is and that kind of thing. There were a number of issues but the key one was the way the committee changed. Fascinating! And you pick up on that and then go off and do your supportive literature review and describe it in a

particular way. I think the medication one will be an interesting one.

By this remark, Fran initiates a writing spree around the changes to my medication. And timescales come a little later on, at precisely 47 minutes into the meeting:

Fran: *Could we have a typed, well-defined goal? For our next meeting? Would that help you? Could you achieve that?*

Me: *I'm not sure what you mean?*

Fran: *Writing about the medication change, just for example?*

Me: *Oh yeah. I can do that.*

Emerson, *et al.* (1995) comment on writing fieldnotes that: “In writing fieldnotes, ethnographers have as their primary goal description rather than analysis” (page105). My own experiences of note taking are echoed out by Alvesson (2002, page 7), writing: “Even when researchers have been ambitious, systematic and detailed in note-taking, they sometimes feel that the notes fail to capture what really went on. Some people rely more on their ‘head notes’ (memory) than field notes (written down impressions), as the former may appear to contain richer and less sterile material”. This is borne out by Ellis (2004, page 116): “. . . all autoethnographic writing occurs after experience. The question is how long after?” Tessa Muncey calls on several writers to discuss the pros and cons of memory research, ending with the conclusion that it “is quite clear that accurate and permanent retention are not features of human memory” (Muncey, 2010, page 104).

So, bearing in mind always that my retention will be neither “accurate” nor “permanent”, what really was the issue that caused the change in medications? I think I need to go back to just before my last but one visit to my GP. Already taking a wide range of medicines for arthritic pain and cardiac problems, I am also seeing things and imagining that people are out to get me. I think it is important to realise that these feelings aren’t merely passing fancies – I have been having that sort for as

many years as I can remember - but true fears, activating adrenaline surges whenever I feel under threat. Such is the problem that when they occur I do not realise the feelings are illogical. It is only afterwards, on reflection, that the strangeness of the situation becomes apparent. These feelings have been coming on for some time, but not as strongly as this. Things are coming to a head and I need help.

I visit the GP one sunny blustery morning in November, a visit like countless others by other people so that I feel part of the herd once again. The doctor's surgery is made-to-measure in this brand new building and he sits slim and dapper at his desk, note pads and pens all around and a computer in front of him. He is dressed in a white stripy shirt and matched tie and grey trousers, and looks every inch the professional GP. I find this reassuring. He is a kindly man and I took to his manner right away on meeting him some three years prior.

This is likely to be my final visit as I am moving house soon. I speak slowly and quietly mainly because I am embarrassed and anyway can't be bothered to speak up. More than half of me would rather be lying on a railway line at this very moment and it has taken a massive amount of will and all the cognitive skills I learnt in Cognitive Behavioural Therapy years ago to get me here. I almost don't wait to be seen, taking the hump because I have to wait 15 minutes or so, but hold my ground and stare at a large picture of some poppies waving in the breeze. When I have sat for a moment I decide to explain in detail what the symptoms are. He listens gravely.

Me: I feel insects on my skin all the time, irritating me when there are none there. I hear women's voices very quietly taunting me; so quietly that my heartbeat in my ears can drown them out, but still definitely there - like the voices of ghosts in my room. I also feel under threat all the time and think someone is going to shoot me through the curtains by using my shadow as a reference point for their shots. I even am beginning to believe that creatures can come into the house through the shower's drain and have to have the shower door shut or I lie awake for hours. I am afraid these feelings are getting worse and not going away.

I drivel on for what seems an hour but is actually only a few minutes, explaining in detail the thoughts and feelings swelling my head to bursting point and making me jump at the slightest of shadows. He sees me drawing to a juddering close and draws in his breath.

GP: You appear very depressed. You are more depressed than I have ever seen you. Have you experienced these distressing feelings before? Is there a history of them? What about some tablets?

The GP turns to his computer screen and taps a few keys to scroll through my medical record. I can't see what is displayed there but whatever it is makes him frown.

Me: Yes, a number of times in the past, which is how I know to come to you now. What do you think, doctor, should I take tablets?

My mind wanders back to a diary entry I wrote about such things.

It has been two weeks now, between visits, and I can see this in the notes I have been keeping. My mood was elevating nicely at the start of the period but took a downward turn after raking over the Falklands' coals once again. The notes show I bounced down and then recoiled up and too far. It is this almost uncontrollable wave of moods that I find so hard to deal with.

When this happened before, I was put on Lithium until things settled down and maybe I need that again. I have made an appointment with my psychiatrist to discuss this in a week's time. I have not been feeling safe of late, what with the moving walls and floors again, and the whispers from the corners. Re-reading my notes from 9 years ago, it is astonishing that I had the same symptoms then as I do now, with hardly any change. The severity comes and goes, and the hallucinations and fears and suicidal thoughts are much the same, but what was very interesting was a piece of writing describing my struggles not to self-harm from 1998. I had forgotten about that.

I drag myself back to the present and the words coming from the GP, much of which I have just missed.

GP: Would you like that?

Me: What?

GP: Change the medication to Risperidone twice a day to go with some Sertraline?

My mind wanders again.

RISPERIDONE

Indications: acute and chronic psychosis.

(BNF42 (2001) page182)

Side effects: of the atypical antipsychotics include weight gain, dizziness . . .

(Ibid. page180)

SERTRALINE

Indications: depressive illness, obsessive-compulsive disorder. (Ibid. page 195)

Side-Effects. SSRIs are less sedating and have fewer antimuscarinic and cardiotoxic effects than tricyclic antidepressants. (Ibid. page 193)

Doesn't that make you feel better! 'Fewer' side-effects than something else, but still toxic. So, more poisons to ingest. There seemed to be no point in discussing the ins and outs of medication *per se* (Bentall, 2009; Moncrieff, 2009). The GP is making faces that tell me he is on the point of calling an Approved Mental Health Professional or AMHP, to discuss a Section of the Mental Health Act 1983/2007 if I don't agree to take the tablets. I agree then disagree three times, by which time he is getting visibly cheesed off with me and is reaching for the telephone. I agree, finally.

Me: Yes.

GP: Okay. We'll start the Risperidone on 2mg twice a day and the Sertraline on 200mg once a day, and see where we go from there.

Me: Okay.

I shrug inwardly. To be honest, I don't really care if he poisons me or not. I am beyond caring now. I only know I don't want to go to hospital. That would be so very destructive of my lifestyle and freedoms that it frightens me. He writes a prescription and I am vaguely aware that he is telling me about side effects and so on but I am not listening. I think I am going beyond listening as well. I take the prescription to the pharmacy around the corner and leave with my new tablets. This is November, and by February my dose has been raised to 6mg a day, divided morning 4mg and evening 2mg and 150mg in the morning; my symptoms are now back under control. Currently, the 'script stands at 2½mg twice a day and 200mg of Sertraline in the evening. The symptoms are still under control to some extent, but slip sometimes. The new psychiatrist wants to 're-diagnose' me, but it is all change again soon when she goes on maternity leave and no doubt the next shrink will have different ideas. More modern evidence suggests that even my self harming might be catered for by taking tablets prescribed by well-meaning doctors, thus obviating the need to self harm at all.

Growing evidence suggests that though psychotropic medications do not necessarily correct putative chemical imbalances, they do pose substantial iatrogenic hazards. For example, the increasingly popular neuroleptic (antipsychotic) medications, though helpful for many people in the short term, pose the long-term risks of obesity, diabetes, movement disorders, cognitive decline, worsening of psychotic symptoms, reduction in brain volume, and shortened lifespan (Ho *et al.*, 2011; Whitaker, 2002, 2010). Indeed, though neurobiology may not fully explain the etiology of DSM-defined disorders, mounting longitudinal evidence suggests that the brain

is dramatically altered over the course of psychiatric treatment.

(BPS, 2012)

So, here I am now, on this new medication and suffering some of the side effects but also feeling decidedly thick in the head and lethargic. The trouble is in the unpicking. Which parts of the symptoms are medication induced and which parts are produced by my illness, my dysfunction? It is important for me to know which is which as, by that measure, I can decide whether to continue to take the medication or not. Life is complicated by continuous thoughts of self-harm and suicide for no apparent reasons that I can see, as everything else is under control one way or another. Maybe it's just me reaching for the control back? I remember the feelings from last time.

Convenient

Why can't you see?
Why can't you hear
The voices
And faces
Screaming within me?
Shit! Surely everyone can hear them
Calling from my eyes!
What the bloody
Hell do I have to do
To have people believe me
When I say I can't keep on keeping on?
Oh God! How I hate it all,
And hate me most of all.
Trapped inside a rotten carcass
Waiting for a stinking death;
Imprisoned and helpless
And spinning alone
To what?
I wish it were
Convenient
Now.

R Peacocke, Dorchester, 2000

I am back in the room in the Forum, with pieces of work lying all around and the two tutors looking at me. The air is thicker after nearly an hour of conversation and I feel it is getting close to the time to draw things to a close. There is one more facet of the situation that I want to explore, and it is in this exploration that I gain my greatest insight into how I am behaving towards others – a measure of my madness.

Carol: And we're not saying how long it has to be; and don't judge it as you're writing it, 'cos as with that 'Quantum of Solace' thing [*she means just 'Solace' but has it confused with the James Bond film*], you wrote it and started to judge it at the end and we kept saying, "No. Don't change it. It's fine. Just leave it because it speaks." And my worry is that you're in . . . the transfer and the process you had to get in to . . . stepping out of this world of writing and of being where the thesis was, stepping out of that to get into the sort of administrative process was actually very disruptive – not just for you but for several people because it took them out of the flow, and people are still stuck in a way in this very analytical looking at themselves bit instead of being . . . they're beating themselves. And this might enable you to get back there and be more comfortable. And I don't think any of that has to do with your medication. There's nothing wrong with your thinking processes.

I feel somewhat reassured by this. My noggin might be throbbing but at least it is still on the right way round! I try to explain myself a bit but have the feeling that I am making a hash of things, rather muddled and not clearly articulated.

Me: It's very difficult to know that without anybody else saying that because I don't change inside myself. So without someone saying "there's nothing wrong with your brain", I think to myself: "Is there something wrong with my brain?" And I wouldn't know really, as I have no insight into it at all. So
...

Carol: That's not right. You do have an awful lot of insight.

Me: No. It's the mechanics of what's going on, you know ...

Carol: Right. Yeah.

Fran: Well, let's have a look at your writing.

Thus assured, I feel much better about my cognitive abilities and go home ready to write again, but it is not easy to get started and I have some false starts before I can write this.

*

Such an impressionist tale as this - the form of which is “dramatic recall” (Van Maanen, 1988, page 103) - is a useful way to cover a lot of ground in a small space. It is clearly original and shows some research of relevant references within the narrative, but what is emergent? I think the main points covered are:

- Self-other issues, as noted above (Canales, 2000; Chang, 2008), raise their respective heads again with the experience of waiting rooms at surgeries and psychiatric clinics. In this sense, the reader finds me feeling comfortably anonymous in the general practitioner's surgery waiting room among others waiting to see the doctor or nurse for issues presumably not connected with mental health. The only person who knows why I am attending is me, and this suits me down to the ground. I can hide in this anonymity and feel safe. The assumption the reader is allowed to draw is that waiting rooms in psychiatric clinics are not as psychologically comfortable, as they steep one in the stigma of being a ‘mental patient’. This, in my experience, is indeed the case.
- The reassurance given me by others wearing appropriate dress. The doctor wears smart casual clothes of a standard appropriate to his social station, and this is also reassuring to me as it sets the scene for the doctor-patient

relationship, a relationship that I understand. There is a dress code to be followed after all.

Standards of dress and personal presentation are relevant to most employers and having a policy on dress code can be important.

Where the employees meet customers and are effectively the shop window for the company, the benefits of presentable appearance are obvious. But even where the employee's work is internal, there are less tangible benefits such as:

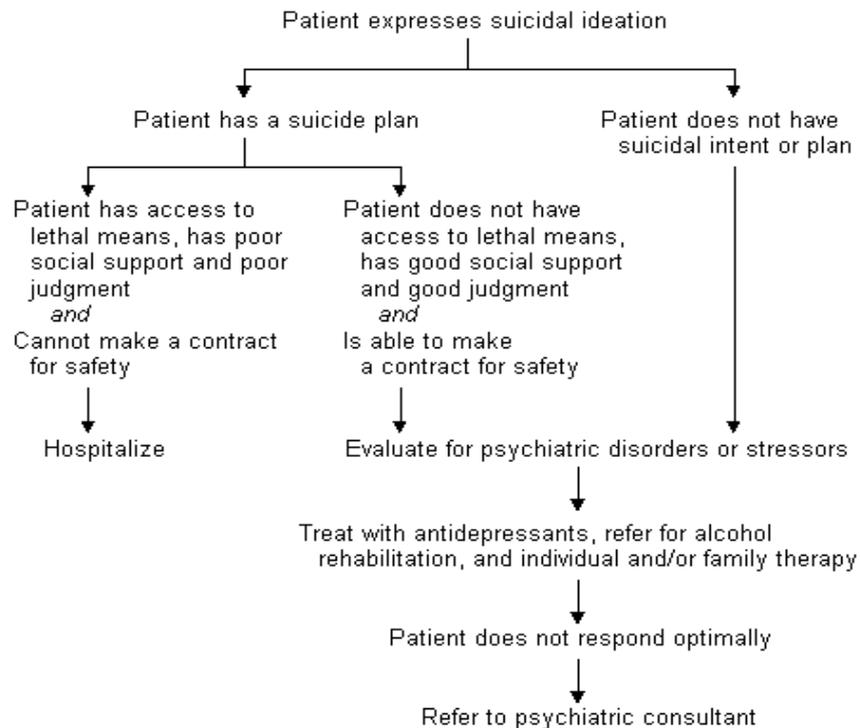
- creating a team atmosphere,
- engendering standards of professionalism, and
- creating a corporate image.

Bain (2008)

Understanding where I stand in any given social occasion, such as visiting a doctor, demands a visual clue for me to orientate to. This is the role of dress codes in my life, one that I observe for myself as well. If I want to be a part of a decision-making elite (as happened to me a couple of years ago with Dorset County Council) I wear my suit; if I wish to be a part of a group meeting, I observe the dress that others in that group wear and follow suit; if I am beyond caring or do not care what people think of me – as happens when I become depressed – then I slob about in my very-un-smart casual and do not shave, or wash, or sleep ... but that is a sign of my mood slipping that requires remedial action.

- Suicidal ideation unaffected by medication emerges as a distinct problem in this case. I begin in a deeply suicidal state and end still suffering suicidal ideation, so the medication, whatever else it has done, has not made much difference and I have to fall back on tools learnt many years before during extended Cognitive Behavioural Therapy and so remain by and large un-

helped by this visit to the doctor.



Taken from Gliatto and Rai (1999).

Personally, I find my response to be sub-optimal and my suicidal thoughts troubling, especially when accompanied by depression and plans for suicide. The medics tell me that these thoughts may indicate the presence of a serious psychological disorder. Who are they kidding? Of course there is a disorder. The critical distinction is between my thoughts regarding death and suicide and actually feeling suicidal. Suicidal ideation can be divided into two categories:

- a. It can be *active*, and involve a current desire and plan to die.
- b. It can be *passive*, involving a desire to die but without a plan to bring about one's death.

At the moment, I am *passive*.

About social power differentials in general between the medics and the patient:

“What about some tablets?” Asking this while consulting a hidden-to-me computer

screen apparently displaying data that is all about me, the doctor exercises his social power to insist on my accepting medication; but it is also evident that different doctors have different ideas on medication, that they all rely on trial and error, and that all medication has unwanted effects and side effects on me, such as nausea, weight gain and sexual dysfunction.

Because the doctor - in most cases the GP or psychiatrist - has medical knowledge and credentials, it may seem as if they are superior to the service user. This relationship is complicated by the service user's suffering, often resulting in dependency on the doctor. However, a doctor should at least be aware of these challenges so as to optimise communication with the patient.

There may be differences of opinion between a doctor and a user of services in how formal or casual the relationship should be. For instance, according to a 1990 study, patients want to be addressed by their first name more often than is found to be the case, but most patients seemingly do not want to call their doctor by his or her first name (McKinstry, 1990).

Following on from this series of original narratives around the development of my mental health, it is time to look at the development of my Service User Representative work during which I will reflect on how my mental health problems affected my effectiveness as an SUR and how my effectiveness as an SUR may be affecting my mental health problems. This forms part of my practice development project and of the narrative report that connects the three strands of the professional doctorate. Relevant references will be supplied throughout.

and then becoming a Service User Representative

Widening the net

Tutoring on behalf of Dorset PCT on the Expert Patient Programme (EPP) allows me to get the general views of service users beyond those of mental health people, as the participants are mixed in age, race, sex, and disability - somewhat similar to the DCC Direct Payment Consultation Group I chaired for a while, but less focused.

EPP groups are arranged by NHS area office and are attended by up to twelve participants. The only criteria are that they must be suffering from a long-term condition such as diabetes, heart problems, arthritis, or mental health issues - it is not specified what this should be; that they are willing to attend for the six weeks of the course, for two and a half hours on the same day each week; and that they agree to participate as fully as they can in the course. These prescriptions carry no sanctions and so we find people attending for one or two weeks and then dropping out for a whole variety of reasons.

Course tutors are people who have attended the classes and have volunteered for further training to enable them to deliver the course to others. I attended the EPP course in Weymouth in a church hall. My long-term conditions were depression and arthritis, and I found myself not really taking part for the first three weeks. The two tutor volunteers were very understanding and persevered with me, bringing me forward almost inch by inch, until in week four I felt a part of the group and able to contribute albeit very warily at first. By the end of the course, I had volunteered for tutor training. I felt, along with my Care Coordinator, that this would be a good way to aid in my recovery. I suppose in this way I was following in the steps of Gadamer's hermeneutic circle as described above, where I had to 'understand the whole in terms of the detail and the detail in terms of the whole' (Gadamer, 1989, page 291). But of course, I did not frame it in those terms at the time, just that it seemed a good idea. It is only after reflecting on the situation as a whole that I began to understand.

Tutor training took place over a four-day weekend in a hotel in Plymouth. We were a group of ten volunteers and two tutors, all having passed through the EPP course as participants and all keen to learn. The course itself consisted of modules on how to teach, what to teach, and practice teaching it. The way we did this was to break up into groups after having been taught as a large group, develop our own wall charts under direction from the tutors and by copying example charts in the handbook that we had been given, and undertaking teaching practices around set lesson plans. The tutors adjudicated on these teaching practices and graded us, pointing out where we were deficient. It was a concentrated course and no doddle, but I passed it and so found myself as a tutor helping others take advantage of the advice in the course on how to best deal with many of the more common effects of having a long term condition.

On week one, we would sit in a semicircle around two flip charts and two tutors. One chart would hold pre-prepared charts of various parts of the course content, the other was for writing on at particular times throughout the course. Almost the first thing we do is introduce ourselves to each other and examine everybody's presenting long term condition and, crucially, how that condition affects the person's well-being and ability to live life to the full. These conditions often ranged across the physical spectrum. Cardiac and diabetic problems were common, as was Multiple Sclerosis or MS. Less common were the mental illnesses though, by midway through the course many of these would have become apparent, especially the common ones of depression and anxiety, often brought about by the person's physical infirmities. Thus, we would start to meld the group into a self-help team where each member would help and be helped along a recovery path. Now, I understand that this concept of recovery is sometimes a little obscure. We were not after medical recovery, the reversal of the condition, the removal of symptoms because it would be miraculous, if we could achieve that. Clinical approaches tend to focus on improvement, in particular symptoms and functions, and on the role of treatments, and we do cover such areas on the course. However, here we are speaking more of recovering a life style, of getting back as much of one's life as is possible by reminding people of the things they can still do for themselves, and also encouraging them to take full advantage of the various help systems that surround them. Recovery in this sense is much more a consumer/survivor model tending to put emphasis on peer support,

empowerment and real-world personal experience (Secker *et al*, 2002). Thus, rather than a clinical model of recovery, we followed a social model; instead of trying to deal with the physical realities of living with a long term condition, we tried to deal with the lived social realities and alleviate them a little. It was all common sense really, but people tend to forget what they know, and we helped them remember how best to cope in their individual circumstances.

At the EPP, I winnow the flow of conversation between us tutors and the participants for anything of interest to my role as SUR. Often, none are given but once in a while a mental health angle becomes apparent and I take on board the message. The following exchange between a participant (P) and me illustrates this:

P: I feel like I've done enough for others (*in her voluntary capacity elsewhere*) and would like to concentrate a bit on my own needs. I think sometimes you can do too long in the service of someone else and need time to yourself for a bit.

ME: What sort of things do you think you would enjoy doing it, then? What are you looking to do?

P: I would like to focus on my mental health. You can find support groups all over the place for other things, like arthritis, but there don't seem to be any out there for my mental health. I mean, a group for support - self-support - you know, users together - that would be nice for once. If I can get in touch with something like that ...

ME: I can put you in touch with the local mental health forum, you like? If you hang on afterwards, I'll drive round and we can say hello and pick up some magazines you might find interesting.

P: That would be very kind of you. I feel left out a bit.

ME: Well, we'll pop over and see what's happening over there. I have to pack all this stuff away first, though.

We go out to my car and pack away the EPP charts and so on before proceeding to the Forum. On the way there, we chat about how she feels she had been let down by her services and really feels “very much left out of the loop”, just because she has no secondary care contact. What I mean by that is that she has been seen on a regular basis by her GP but feels she needs the import of a psychiatrist or member of the psychiatric team, the secondary services.

When we enter the Forum’s offices, she is obviously surprised that such a resource exists and avidly gathers up any leaflets and magazine back-copies she can. I introduce her around and leave her there to explore our services on her own. My SUR job is done and I feel satisfied that have done my best to help in her search for information.

Of course, I recognise that her search is equally my search, and that in helping her I have helped myself in some measure. I can vividly recall my anger at not being able to access information about self-help groups and the like when I was in the acute stages of my mental distress. This distress was compounded by a feeling of being alone and the only sufferer in the area. As soon as I had accessed support groups I felt decidedly better but it had annoyed me that I had to find these groups myself, that nobody pointed them out to me. I feel that it is the responsibility of the care coordinator to seek out and establish links for his or her service user with local self-help groups and the like. That they don't do this is a measure, to my mind, of idleness and unprofessionalism. In this world of direct payments and personalisation, this linking with other groups or individuals is more important as the day centres that heretofore existed are no longer around. This places the care coordinator into the position of helpmeet when somebody first enters the world of mental health distress. I was first introduced into the expert patient programme world by my second care coordinator, the first having never mentioned it.

*

Reflecting on my own path to acceptance by the wider mental health community and the benefits I have gained from it over the years allows me to help guide ‘P’ towards

that same source of help. It is up to her to do the next bit, which is to approach the Forum and put herself forward as a volunteer. I can not do that for her and can only encourage her to take the next step.

The us-them dichotomy rears its head yet again here with participants – no matter the urging not to – seeing the Expert Patients’ Programme (EPP) facilitators as tutors in charge of their learning, whereas we tutor-positioned people, even though we are known as ‘tutors’, would rather be seen as knowledgeable helpers among equals. My particular emphasis is always on the urging of our participants down the path of recovery. Patricia Deegan writes that there are helpful and unhelpful staff attitudes. A particularly unhelpful one is to see their task as somehow getting the people in the “abnormal world” to fit into the “normal world” (Deegan, 1988).

Let us unpick recovery a little (Jacobson and Greenley, 2001, page 485). I am not writing about clinical recovery or rehabilitation from an illness – the people who come to EPP all suffer from various and sometimes multiple chronic conditions – but the owned lived experience of someone as he or she accepts and overcomes the challenges of a disability (Gosling, 2010, page 31). Patricia Deegan sees recovery as not the same thing at all to a television getting repaired or a car being tuned up. Rather, that people with disabilities ‘are not passive recipients of rehabilitation services. Rather, they experience themselves as *recovering* a new sense of self and of purpose within and beyond the limits of the disability.’ (Deegan, 1988, page 11 – emphasis in original). She goes on to write that ‘recovery is an important and fundamental phenomenon upon which rehabilitation efforts depend.’ Recovery depends on hope, and hope is the turning point that must quickly be followed by action, or at least the willingness to act. One must learn to say ‘I am hopeful’; I am willing to try’; and ‘I discover that I can do.’ (Knowles, 1986). It was the instilling and nurturing of hope in our participants that was at the core of my work for the EPP. It was that hope that I saw on P’s face as she gathered up the magazines and leaflets for further study. What became of her, I do not know. However, I do know what happens all too often when hope is extinguished - as demonstrated by my next vignette.

Death of a Service User Representative

Beep.

My mobile phone tells me that a message has arrived.

Sue: Hi Rich. Did you know that L passed away yesterday?

I didn't. It was news to me. I text back.

Me: Hi Sue. What happened?

Beep.

Sue: She died by her own hand yesterday. At home. Alone.

Beep.

Sue: Are you okay?

Me: Yes. Just shocked. I am at home now. Are you okay? Thanks for telling me.

Beep.

Sue: Let me know if you need me. Sue x

Me: Will do. Rx

It is early evening on Wednesday 16th September 2009. Another beep. I read it with a sense of doom.

Alex: Can I come round for coffee tomorrow morning? Alex

I feel a bit numb with shock or sadness. L was a lovely woman, a well-liked SUR, and respected by service management. I phone Sue and chat with her for a little while but she does not feel much like talking. I just assure myself that she is okay and then leave her in peace. I get the impression that she has the same thought of me and my feelings.

It is late and Steph is away in London, so I have no one to talk it all through with. I go to bed and read Alex's text, only remembering it then, and answer it at 10 o'clock.

Me: *Yes. Of course you can. Steph will be away, though, if that's still OK?*

Beep.

Alex: *That sounds good. I will come round at about 10 am and bring the chocolate biscuits. See you then. Are you okay?*

Me: *Yes. Fine. Ta. See you tomorrow. Rx*

She has not said why she wants to chat and I have not asked – if a friend wants a chat, then chat we will. I tune the radio onto BBC's Radio 4 and leave it on quite loudly, then go to sleep not noticing the switch-over to the World Service. Thank goodness for Zopiclone.

The next day. I wake up at 5:30am and lie listening to the still blaring radio and feel the cats as they play across the bed covers. Minnie eventually tries to get me up earlier than her usual 7am and I stomp downstairs to feed them all, then I go back to bed for an hour.

Alex comes round at exactly 10 am, ringing the front door bell. She is somewhat shorter than me and is dressed to the hilt in a lovely beige suit, but that is nothing new for her as she always dresses beautifully. She has her usual broad smile under dark, watchful eyes.

It is a strange moment as we sit and drink coffee and eat chocolate biscuits. The Zopiclone has left a sour metallic taste and this is distracting me. My head hurts a little. The cats are asleep on the bed and all is quiet in the house. Alex settles down into the settee with her coffee. We chat about this and that, and then about L.

Alex: Have you heard? L killed herself on Monday. You knew her, didn't you?

Me: Yes. She was lovely. Don't know the reason why or any details, though.

Alex: Yes. I knew her well, too. It has left me all down and shocked.

And so the chat goes on, each of us expressing our shock and wondering why she would have done such a thing. We agree that she had been very well thought of and loved by many. She must have been very lonely, but we do not know and are just conjecturing to try to ease our own hurt. I still feel numb, and it is an odd thing but my teeth feel strange too. I am out of sorts but cheered by Alex coming round. I hope that she feels a little bit better, too, so I ask her.

Me: I feel better after our chat, you know. It was lovely of you to pop round.

Alex: That's okay, honey. I felt really quite shocked and depressed when I heard the news that L had gone and just needed someone to chat with for a while. I feel a little better now having talked it through with you. You know, sometimes that's all that you need to do, chat it through.

Me: Yes. I felt shocked last night. Sue had only just texted me and then you did, but I wasn't sure if I wanted to chat. I don't know if I would've agreed to meet if I'd known that it was about L, because I didn't feel ready to talk about it at all. At least we have put the world to rights as well today!

Alex: Do you feel any less down, then? I always think it is important to talk things through. I'm glad we met today. I needed to talk and I think you did,

too?

Me: Yes. I did. I'm glad you came round. It's always lovely to see you, you know.
It's just that it is such a sad reason.

I am glad. We hug at the front door, my nostrils fill with her perfume and my cheek is tickled by her hair. She hugs hard and I realise a little more just how upset she has been. I hug back. Two hours have passed since she arrived but it seems like only one – a measure of my own distress?

It is nice to have supportive friends, and to be a supportive friend. I reflect that this is an important part of life anyway, but much more important when one deals with other people who suffer from mental ill health. Alex understands this as well.

Steph phones and says goodnight – she sounds tired, so I do not tell her of L's death – and I go to bed with the radio on as last night but this time with the curtains open to let in the night sky and air a little, allowing me to breathe.

When Steph comes back, it takes me quite a time to broach the subject of L, not until late that evening. Steph remembers L and is very supportive. She says she felt there was something wrong when she called last night but could not put her finger on what it was. Now that she knows, she feels easier.

So how do I feel? I don't know really. It still hasn't sunk in properly but that doesn't seem unusual in the least, I suppose. The way I feel is numb and stirred up at the same time. I keep thinking about dying and the reactions of everyone around me should I do the same as L, which seems very attractive at the moment. Her death has had a massive effect on Sue and Alex and me and others. I keep concentrating on the hurt my dying would have on all about me, and this will keep me on the straight and narrow. I hope. The last thing I want is to upset anyone.

PAIN

 Leaden
 Dark shadows;
 Endless corridors of pain
Screaming silently through time
 To fall on ears deafened
 And buffeted
 By life.
 To fall,
 Quietly and unnoticed,
 To smile,
 To vanish into the past
 And be forgotten
 At last.

*

I think it is always difficult to deal with the death of someone one knows, but it is especially painful if that person takes his or her own life, as L had done. Having known L, it is especially difficult to divorce myself from the subject a little in order to write about it at all. For example, this is my third attempt in as many days to address this issue. I hope it will be worth the pain.

Suicide can have a very upsetting effect on those who are left behind. As in L's case, often the person who has committed suicide thought that no-one cared about them. Not only grief and shock, but those who remain have many other feelings and emotions to work through, such as feelings of hurt, confusion, guilt, anger and remorse. (Survive, 2008; Raptopoulos, 2010, page 78).

Suicide has such ramifications beyond the usual grieving that it should be unpicked a little here. There are innumerable sites on the Internet, and so many articles and books on the subject, that any try at a literature review would be way beyond the scope of this paper, indeed of this thesis. The route I have chosen is one of selection using a commonsense criteria to avoid all those sites dedicated to showing how best 'it' is done and those evangelical sites calling on the mercy of one god or another

and promising hellfire and brimstone, or forgiveness. I have also left out commercial sites. I have only selected sites written in the English language. Yet there are still a plethora of sites to choose from. So, I search with credibility in mind and come to the NHS website as a start. Here we learn that:

Suicide is a leading cause of death, particularly in young people, both in England and worldwide. It is estimated that around 1 million people will die by suicide worldwide each year. During 2008, there were 4,282 suicides in England.

Attempted suicides are much more common than actual suicides. There are at least 140,000 attempted suicides each year in England and Wales.

(NHS, 2011)

They write, further on, of gender differences, but L was a gay woman so where does that leave us? Women, we are told, “are more likely to attempt suicide or engage in other types of self-harming behaviour. However, men are more likely to succeed and die by suicide. Suicide rates are three times higher in men than in women” (NHS, 2011).

The NHS site lists various theories as to why people die by their own hands. At the end, they offer a ‘newer theory’:

A newer theory about suicide, devised by an American psychologist called Charles Joiner, states that three main factors can cause someone to turn to suicide. They are:

- a perception (usually mistaken) that they are alone in the world and that no one really cares about them
- a feeling (again usually mistaken) that they are a burden on others and that people would be better off if they were dead
- fearlessness towards pain and death

The last factor poses the biggest risk that someone will go through with a successful suicide attempt.

The theory argues that fearlessness towards pain and self-harm may be learnt over time, which could explain the strong association between self-harming behaviour and suicide.

People who are regularly exposed to the suffering and pain of others may develop this fearlessness over time. This could help explain why suicide rates are higher in occupations that are linked to such exposure, such as soldiers, nurses and doctors.

(NHS, 2011)

There is also the thought that SSRIs and suicide can be linked, ‘that SSRI antidepressants can cause suicidal thoughts or even drive some people to attempt to commit suicide’ (Moncrieff, 2009, page 63). Although there is no clear evidence that L was being medicated with SSRIs, the thought is there that having spent time in the acute ward of our local mental health hospital it would be unusual for a service user to leave there unmedicated and that the medication of choice is usually one SSRI or another.

This just about summed up L’s life. Her close relationship with her partner had not long broken down and she was now living alone – she bought a dog to keep her company. She was a lonely soul though others did often try to reach out to her, especially her friends in the Christian movement of which she was a part. It is difficult. How far does one go before one is being intrusive? The final time I saw L was as an inpatient on the acute admissions ward of our local mental health facility. This was a month or two before I heard that she had died. She was very depressed and clearly distressed. Without speaking, I walked up to her and we had a long hug, then I told her to call me if ever she needed anything. She said she would. I never saw her again. Joiner’s theory (NHS, 2011), above, would seem to indicate that this was a part of her feeling she did not want to be a burden on others. His final point,

that a suicide loses the fear of pain and death, would also fit with L. She was a highly-regarded national and local activist for mental health rights and had made many friends. Inevitably, some had killed themselves, but that is the reality of working in the field of mental distress as we do.

Of the causes of suicide listed, the NHS site offers that ‘having a mental health condition is the most significant risk factor for suicide. It is estimated that 90% of people who attempt or die by suicide have one or more mental health conditions.’ Severe depression is listed as the top cause of suicide in the mentally ill (NHS, 2011a).

Elsewhere on the same NHS site, it states that a history of self-harm can often indicate a risk of suicide in a person. This would fit with Joiner’s third statement, too. L certainly had such a history but she was private about it to me, so I never knew the details as to what she had done to herself. Self-harming is where a person injures their body on purpose. It must also be remembered, though, that many people who self-harm do not want to kill themselves. Self-harming can be seen in this context as a kind of “survival strategy”, providing a person with a way of coping with overwhelming emotions (NHS, 2011b). This is why I self-harm on occasions and I suspect why L did too, though, as I have said, she did not discuss such things with me.

So, how does one survive a loved one’s suicide? There are considerations to be addressed. Firstly, you need to stop what you are doing and take time to think through the issues. What you are going to say to people? Who do you want to talk to? And, what will you do of a practical nature in the next few days to help yourself over this time? You must be cautious, as many people will have comments, either in an attempt to explain the inexplicable, or to comfort you. Also, be aware that some will have words of blame and others may be critical of the deceased or of you and your family. You must try to find a trusted family member, friend, clergy, or the funeral director - someone who will not be judgmental or critical. Perhaps seek out professional help, such as a grief counsellor. Then use your chosen person to help you decide what to do first, who and how to tell, and how to take care of yourself. Many of life’s details can be taken care of by someone else, or delayed, and being in

shock is not a good place from which to make important decisions (Grisham, 2011).

Sue, Alex and I began along this path by using mobile phones to text message each other. There are other ways. I also used the Internet social media called Facebook to chat to one of my supervisors as a way of grounding myself. This is the subject of the next vignette.

Facebook Support Session 12/11/09

12:50 **Francis** *OK, back... u OK?*

It is relatively unusual for me to contact my supervisor, Francis, outside of our prearranged meetings, so he was naturally curious.

12:50 **Richard** *Hi Fran. Depressed at not being productive usual thing*

I am not being honest. I am still reeling from L's death, and the effects it has had on me are sometimes almost overwhelming, so I need to 'ground' myself (Simmons and Griffiths, 2009). So I use an opening gambit.

12:51 **Francis** *have you had invite from Dorset Trust to their user involvement day?*

This was the last thing on my mind, but the grounding techniques had begun.

12:51 **Richard** *No When is it?*

12:51 **Francis** *hang on I'll check who was on mailing list 10Dec*

I check my own diary for an entry on that date.

12:52 **Richard** *I'm up for hospital visits for DHFT that
afternoon*

12:53 **Francis** *hm...could be important event... L was going to
chair, I guessed that was yr friend....who passed*

We had reached the subject of my worries. I hesitated a little before moving on the subject more fully. I sandwich the painfulness between two more commonplace considerations.

12:54 **Richard** *Has it been passed to Dorset Mental Health Forum.
Yes, L was the one. Foolish girl. If only she could have seen
herself as others did. These Hospital visits are unriggle-out-able
in the normal course. You have to be at death's door*

Francis picks up on the subject of the chat as soon as he reads this last and, ignoring my other comments, addresses the core subject of L's death and its effect on all of us.

12:56 **Francis** *I know, she was great....*

12:56 **Richard** *But I guess we none of us see ourselves as others see us, no matter the evidence?*

12:56 **Francis** *yr right, I think we are both guilty...*

Francis has explained that he now understands why I contacted him and gently eases the conversation on. I am satisfied that he has understood and am busy grounding myself in the light of his knowledge. He helps me along.

12:56 **Richard** *Had a bit of a triumph yesterday. Conducted some training for Poole BC and got 100% positive feedback.*

12:58 **Francis** *excellent, but that doesn't surprise me at all....*

12:58 **Richard** *You are sweet. It surprised me! I thought I was winging it ... is that the right phrase? Winging it?*

12:59 **Francis** *ah well, winging it is often best, as it's real and spontaneous...rather than stilted and boring. Yes, right phrase*

13:00 **Richard** *I guess it's true; they liked it. But I don't want to admit it! Typical.*

Here, I have linked back to a running comment on my dislike of compliments about my work. I then raise a gentle joke about Swine Flu and begin to end our session by offering thanks for Fran's help – we both know what the session was really all about, after all.

13:11 **Richard** *I have to go get a flu jab now - will be oinking later! Thanks for the chat and the energy. I feel better now.*

13:12 **Francis** *good, enjoy yr jab....lol....*

‘lol’ is an indication of humour. I reply with the same to say that I have understood he made a joke, and end the conversation by cutting the connection.

It is a sad thing, but Francis has since been taken from us by cancer and his loss is felt very keenly. Rest in peace, Fran.

*

This internet chat took up 22 minutes of our time, but the effect on me was worth it. I felt connected to the world again and could go and get my Swine Flu jab with a calm mind. It is strange when you see it written down, but that session was really rather valuable to me. But then, conversations often contain much more than the bare words would seem to indicate. To begin with, there is the participants’ prior knowledge of the subject and all that surrounds it. Then their implicit decisions as to what to disclose and where to lead the conversation based on their overt and unconscious needs at the time. Conversations can also be enriched by body language – something not available when viewing the written word alone, which is why the internet use of ‘smileys’ like ☺ or ☹ is so valuable as they indicate mood to a reader. Another indicator is commonly understood abbreviations such as ‘lol’ – ‘laughed out loud’, and so on. These seemed to have their genesis in dating magazines where acronyms such as ‘GSOH’ held sway (although I always thought it meant ‘good sense of humour’ rather than ‘good standard of health’. Perhaps I am just an innocent abroad.) A useful source of information regarding such terms and many others may be found at <http://www.internetslang.com> among many others.

Another type of chat is the interview. These can be structure or semi-structured (FAO, 1990). Interviews are often spoilt by a sloppy approach to truly understanding what the interviewee is trying to express. This is why I prefer the semi-structured approach: I like to indicate the general direction for the interview and then conduct it rather like a conversation, leading when it goes off track but otherwise letting it flow. When I observe some body language that I deem to be important to understanding, I intervene and try to elicit a fuller explanation of whatever triggered the behaviour. If

all else fails, I keep notes on the side of the interview record to be displayed when the transcript has been completed.

That is one reason why I called the interview I had with ‘Harry’ a conversation. This follows. When interviewing ‘Harry’, I allowed a great deal of leeway so that he could pursue any line of interest that he thought necessary. After having explained the reasons for the interview and how any results will be used, I obtained his consent to the interview and began. We were in the quiet front room of a small bungalow home, sitting on comfortable soft chairs. We began the interview at 15:20 hours and completed at 16:05 hours. This is an excerpt, the full interview script is at Appendix B below.

A CONVERSATION WITH HARRY

26 June 2008 1520-1605hrs

Dorchester, Dorset, UK

‘HARRY’	-	H	-	The Interviewee
RICHARD	-	R	-	The Interviewer

R What I was thinking of doing . . . if . . . if . . . if you don't mind, is . . . erm . . . talk about your *experience*, your *lived experience*, in whatever depth you want to go - I'm not going to dictate anything to you but your *experience of working with . . . erm . . . service users*, especially mental health service users.

H It's a big question . . . erm . . . just to take it as . . . I'm *Harry*. Umm . . . I've been a mental health nurse for 10 years, during which time I've nursed on an acute admissions ward; I've nursed in the Royal Air Force, as an air and medical evacuation

nurse, as well as ward-based; I've worked in eating disorders at the Priory in London; I've worked in a home treatment team, and also run a home treatment team; my current role is . . . is non-clinical.

R Are there different dynamics to having a meeting with a service user and without a service user?

H Definitely! Unquestionably. Yeah.

R Do you think it holds back on business, or does it just 'modulate' business; does it change things?

H Umm . . . 'modulate' is a good word. Yeah, I'd say 'modulate' because I think people are much more careful about what they say as well . . .

R Yeah . . .

H . . . and, certainly, how they say it. It's a . . . I've seen people, but . . . ah . . . ah . . . the trouble when you say that, is you . . . you put everybody into the same bracket, don't you? You're stereotyping people when I know there's . . . you know . . . people who *will* speak out . . .

R Yeah . . .

H No, but again this is a personal perception, I think that things are slightly different with a service user there because there is a degree of expectation - they *have* to do

something - so there's an element of fear. And also, you know, their professional pride, you know . . . erm . . . they know how to make their *colleagues* like them, but how do you make the service user think that they are doing a good job, too? But that's just a . . .

<PAUSE>

R Is it important to have the service user think you are doing a good job?

H Well, if a service user doesn't think you are doing a good job then you're *not* doing a good job. So . . .

R So, then, it matters, then?

H If you've got a conscience, then it matters.

R But is it necessarily so? I mean, would the service user necessarily be representative of all the service users?

H No. That's very true, actually, because everybody's very different . . . umm . . . That's a very good point . . . it *is* a good point, but I don't think it changes the dynamic. Whether that person represents . . . erm . . . themselves or a whole group of people, it's still that the dynamic would remain . . . y'know . . . umm . . . but it's like . . . it's . . . it's like . . . y'know . . . the Prime Minister . . . umm . . . a number of people wouldn't . . .

won't vote for him next time, but a number of people will. Everybody's different and it doesn't matter how good your self-values are, they're not going to meet with everybody.

R That's true.

H You know . . . and erm . . . but I don't think it changes the dynamic.

R Erm . . . So, put yourself in this position: There's this . . . erm . . . there's a committee you're on - usually just you and other service providers and commissioners on this committee . . . umm . . . Just put that in your mind. And you're going into it and, suddenly, you hear that a Service User Representative will be joining you, and it's the first time they've been on that committee. What would go through your mind, and how would you deal with other people's negative and positive comments? Or, positive and negative comments so as not to slant it in any way.

H I tell you what's frightening, and I think is almost indicative of our society, is that *nobody* in that room would say *anything* about it. If people were concerned about it, they'd keep it to themselves. If people were frightened of it, they'd keep it to themselves. If . . . *everybody* would keep it to themselves because they know they need to be 'PC'. But there'll be individuals in that room that'll be thinking: 'Oh shit!' And you can see it on their faces rather than you'll *ever* hear it - 'cos *I've* never heard it . . .

R Yeah . . .

H . . . but I know it happens, and I can see it, and . . . er . . . but it does, unquestionably, change the dynamic. But I think, actually, it's a very positive thing because it means, normally speaking, you get something from the meeting. In other words, it direct . . . it becomes directive rather than just . . . erm . . . reactive. It becomes directive; they're looking for a solution. Whatever it is that the agenda has brought up, they're more likely to actually . . . and *also*, as well, what a service user does is it makes it *real* because it's like anything, isn't it? You can *plan* something until you're blue in the face, but it's not until you *implement* it that it actually *means* anything.

And I think what happens in these meetings, often, people plan things and they over-plan them instead of just saying: 'Right, this is . . . we've done this element of planning but we're going to start it on this date, and we're going to go ahead, and we're going to do it.' And it's more likely to take it from the planning to an implementation stage if you've got a service user - that *wants that service* - in the room . . . because it makes it real. Otherwise, it's just four walls. That's a . . . that's kind'a how I see that.

*

I will end the transcript on that point as he goes around in circles to say much the same thing in different ways for the rest of the interview. The complete transcript can be found in Appendix B below. This much, however, brings up the main point that the mere presence of an SUR on a committee meeting has an influence on how that meeting is conducted and the results of the meeting are more likely to be action-specific.

The action-specific perception account proposes that people perceive the environment in terms of their ability to act in it. For example, softball players who are hitting better see the ball as bigger. Tennis players see the ball as moving slower when they successfully return the ball. Furthermore, the perceiver's intention to act is also critical. Only the perceiver's ability to perform the intended action influences perception, while the perceiver's abilities for

unintended actions do not influence perception.

(Witt, *et al.*, 2010)

What else is emergent? Well, what about the fact of the interview itself? Harry had some reason to agree to be interviewed, as I had a reason for wanting to interview him beyond informing this thesis. He (along with his reasons) is now gone, but I remain. When I query myself, I cross the bridge between fact and intuition and, crossing that bridge I naturally wonder what is below. Jung held that this is the realm of:

'the psychological image, lying between fact and idea. The psychological image is as real as you or I in this room. It is in between fact and idea. It is neither thing nor thought, matter nor mind. [...] We have direct experience of this realm - what is my experience? It is in the space between the reality and the thought, the body in relation to the world. To be embodied is to be also in the world. This relation is a subtle field and is in relationship to the posture of the body in the world.'

(Romanyshyn, 2009) .

I believe my posture was one of truly wanting to hear what Harry had to say, wherever that led. Thus, I was open to what he said and could follow him along the path and help him when he faltered or wandered off track. Therefore, the main driver to the act of arranging and conducting this interview was to elicit a viewpoint on the work of SURs from a member of the statutory services. Harry, no longer an NHS employee but an independent trainer, had worked at various nursing jobs at a number of levels, completing tasks as part of a team and alone. He has accumulated vast experience over many years of mental health nursing within the military and the NHS. The reason I asked to interview him in particular was to tap into this reserve of knowledge in how Service User Representatives are seen and welcomed by the statutory services. This information is usually difficult to access - and to believe, when it *is* accessed - because an SUR interviewer can never be sure that the interviewee is not just mouthing platitudes to placate the mental health patient before

him or her. Maybe this is a jaundiced viewpoint, but SURs are a suspicious lot. My psychological image below the bridge was one of the knowledgeable nurse-tutor giving his guidance to me, the student. This all seems to have resulted in a very informative interview, or ‘conversation’.

The interview resulted in my issuing a fact sheet to the other SURs outlining the main findings from the research and reassuring them that their work is worthwhile and very powerful when completed correctly, by taking the posture of critical friend to the services (Costa and Kallick, 1993). ‘Establishing and leading a network takes courage and resilience. A critical friend builds confidence in network leaders to help them to take risks and to experiment with new ways of working’ (NCSL, 2005). Being an effective critical friend requires trust and knowledge, a small part of which is offered by Harry’s insight.

Another role of the SUR is to be able to expound on various topics, to be to a greater or lesser extent a teacher, either to other SURs or to various external groups. Some of us focussed on this role and made it our own. I have delivered on such subjects as Risk Management, LUNSERS¹ (Lambert, *et al.*, 2003), Advance Directives, Meaningful Service User Representation, Raising Awareness and Introduction to and Building Knowledge and Skills in Mental Health Matters, Direct Payments and Personal Budgets, and Recovery, so I was an old hand by now. Sue and I held one such workshop for local statutory services front line workers. This was to offer views on the then new paradigm of Recovery (Jacobson and Greenley, 2001, page 485) as discussed above as part of our examination of the Expert Patient Programme role I held. We would also cover various ideas on how these workers could utilise the way of thinking in their work with vulnerable people. One such is shown in the next vignette.

The story takes place in a large council-owned property made up into lecture rooms. The delegates are sat around rectangular tables, scattered about the space to offer a clear view of the display screen on the wall behind us, as well as acting to divide them into three work groups of three people each. Within these constraints, the nine

¹ Liverpool University Neuroleptic Side Effects Rating Scale

delegates had a free hand as to where and with whom they would sit. As we enter the room, Sue is speaking ...

Aspects of Recovery

Sue: Recovery from the effects of a serious mental illness does NOT mean medical recovery, whereby the disease is quashed and the patient returns to normal functioning, though this might indeed be the case for a few service users. No. Recovery in mental health, rather, is a return to a place where the service user feels secure enough to lead as active a life as possible.

Sue pauses as she surveys the audience. Slight and pretty, Sue fills the room with her presence and the nine delegates on her course are rapt. We had been lecturing on this Introduction to Mental Health Matters course for two days, and now we were introducing the concept of recovery. Sue was taking the lead.

There is increasing national and international interest in the concept of 'recovery', particularly in the field of mental health and psychiatry. It is a concept that has attracted considerable enthusiasm and hope in an area often characterised by disillusionment and defeat. The present interest in recovery initially arose from the lived experiences of people with severe mental health problems. Since then professional bodies, health care agencies and governments have become increasingly interested in adopting recovery as the guiding principle for mental health policy, practice and services.

SCIE, (2007), Introduction.

Sue: Recovery can be thought of in many ways.

I ponder. I am sitting at the front left of the room in an overstuffed armchair. I feel tired and depressed and psychotic all at once, and must rest for a moment. Sue has read my thoughts – or did I read hers?

Sue: There are many ways you can think of recovery, but we'll take it in stages.

Sue pauses and gives the delegates time to absorb things. They are thinking that recovery is a simple concept and are surprised to learn that there are depths to plumb here.

Sue: Indeed, recovery can be thought of as the possibility of improvement in a person's condition and/or experience; the importance of the person assuming an active and responsible role life-style; and is based on successful experiences with 12 step programmes and self-help groups.

As she speaks, she pops up the next point on her *PowerPoint*TM display on the wall at the front of the room to my left. I resist the temptation to look up but nod sagely – my contribution to this bit (my head is still swimming a little with the effort of remaining focused). As Sue speaks I am thinking of the various types of recovery I have heard of, including the Medical Model, the Consumer or Survivor Model, the Social Model of Disability, Psychiatric Rehabilitation, and the Empowerment Model of Recovery, not to mention Procovery. Each of these has a different set of criteria that makes a definition a slippery thing. For example, the Medical Model is often equated with cure or return to how things were before the illness or injury occurred, but by this definition few who experience severe mental illness would be said to be in recovery or had recovered (Whitwell, 2005).

There is seen to be a difference between the Medical Model's concept of 'complete clinical recovery', with a total absence of symptoms, and the Social Model, or 'social recovery'. The Social Model sees recovery as the ability to live more or less independent lives, importantly, even if some or all of the symptoms remain in place.

There has been concern that the Recovery Model, as it was called, was being ‘hijacked’ by ‘the professionals’ to suit their own ends, offering only token interaction that includes tick-boxing and target-reaching rather than a focus on a service user’s chosen outcomes. This concept was termed ‘Procovery’ by one Dorset-based mental health service user, ignoring the fact that this term has already been used to describe self-determination in one’s own recovery – an irony not lost on me.

Since then, the current concept of recovery has moved from professional definitions towards self-definition (Gosling, 2010, page 31) pivoting around considerations of how to live well with a long-term mental health condition. An analogy often trotted out is that of a person suffering from diabetes, a somatic disturbance of the sugar-insulin systems, whereby they live well even with this long term condition, suggesting that you can *be* well even if you *have* a long-term illness, or as the Stanford University self-management course put it, ‘Living a healthy life with chronic conditions’ (Cooper and Clarke, 2005).

Social Recovery has been defined as, ‘a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’ (Anthony, 1993).

Sue: Based on her personal experience, Patricia Deegan (as early as 1988) defined recovery as, ‘a process, a way of life, an attitude, and a way of approaching the day’s challenges’. And if we look through the recovery literature, for example Allott, *et al.*, 2002 and Ralph and Corrigan, 2005, we find similar descriptions of being ‘in Recovery’, and of it being an ongoing process.

The delegates were starting to fidget a little and I hoped Sue would soon close this part of the session. The next bit was mine and I was now rested and sitting upright again.

Sue: Recovery from chronic mental health problems, even when acute and severe, in this view, involves many stages. Inevitably, therefore, there will be setbacks and uncertainty along the way and this has been described as, 'an uncharted, unpredictable, and personal journey' by Antony Sheehan in 2002 (NIMHE, 2002). The concept of recovery emphasizes a person's capacity importantly to have hope, and suggests that treatment can be guided by attention to life goals. The recovery approach focuses on wellness and resilience. Hope is the primary driver; give a person hope and the recovery path is not long in following. Thank you.

Sue turns and looks at me. Standing and speaking to the group has been stressful for her and she looks drawn. I stand up and take the front position while Sue sighs as she sits down in my chair. We are both currently in care for mental health issues and are pursuing our individual recovery paths, so I understand her feelings. I speak to cover her sighs:

Me: Okay. Thank you, Sue. Now we will go on to some group work.

*

Teaching, disseminating knowledge and skills, is one part of a Peer Specialist, or SUR's job. In carrying out this task, the SUR is opening himself or herself to potential criticism regarding their representativeness. Peter Beresford is a case in point. He is a long-term user of mental health services yet is also Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University in London, where he joined as a lecturer in social work in 1990, was made professor in 1998, and received an OBE for services to social work in 2007. He also chairs Shaping Our Lives, the national disabled people's and service users' organisation and network. For some people, if a mentally ill person is able to lecture or teach at such a high level, then for them that person is not as mentally ill as they make out, therefore, not representative of the sub-group "Mentally ill". This lack of representativeness in their minds dilutes the message being put across, and therefore they wonder why they are there listening in the first place. When this happens, we

lecturers observe the phenomenon of students, or delegates, going to sleep or becoming mildly disruptive. It is also reflected in the feedback forms we collect at the end of the sessions. And this is the problem, that those feedback sheets are the only window that their management have on our performance on the day. The feedback sheets form an important part of the management decision as to whether or not they will commission further work from us. I am not suggesting that people who give these lectures act more mentally distressed that they are already, but merely that they have to keep in mind that some delegates are more difficult to engage than others and that this becomes a real test of their teaching skills. We are fortunate in the Dorset Mental Health Forum to have Peer Specialists who in their previous lives were teachers and lecturers, and who find this business second nature. They are a resource that we can use to train other Peer Specialists in the arcane arts of teaching and lecturing, thus freeing up more people to carry out this task.

Another task for the Service User Representative, or Peer Specialist, is to represent DMHF at local and national level. We have representatives working with the County Council, with the local National Health Trust, with national Mind, with national Rethink Mental Illness, and with Time to Change, where our Peer Specialist sits on the national guidance panels. In the past we have also worked with the King's Fund in the design and remodelling of Forston clinic's ECT suite. This meant working as a team with allocated NHS staff over a period of almost 2 years. This was successful. The next vignette describes a time when I was despatched to London to represent our Dorset service users and the DMHF at the King's Fund. We were now, as a team under the Enhancing the Healing Environment programme of the King's Fund, invited to conference at their head offices in London. Our team consisted of a lead Mental Health Nurse, two workers from Forston Clinic's Estates Department, a Publicity Officer from the Strategic Health Authority, and me. The day was drizzly and blowy and we had to get up early to get there on time from Dorchester Station. We caught the train from platform 1 to Waterloo and, two hours later, found ourselves in London.

King's Fund Badges Story

November 2007. London. Central London. London West 1. The King's Fund head offices on Cavendish Square. It is overcast grey with a light cold wind brushing past the people hustling along the streets. We have travelled up from Dorchester on the *Virgin* train for two hours or more and arrived at Waterloo to beetle our way through the underground: Bakerloo Line to Oxford Circus, then walk the wrong way and hurriedly retrace our steps. And there is the King's Fund building. We walk in and are greeted with badges to identify us, to keep us under surveillance as Foucault might see it, the social Panopticon, for there lies power. I look at the badge the greeters give me and shudder: *'Richard Peacocke. Service User. North Dorset Primary Care Trust'* it says. Bloody hell, bloody 'service user'! I thought this had all been sorted out ages before.

Flashback to a cold January day in 2006 in Manchester, with the same team attending a conference arranged by these same people. We are in a spacious conference room in a large hotel. The walls are a golden beige, the carpet patterned in blue, red, and gold, and the floor to ceiling curtains are a deep red velvet. Our tables are circular, covered in starched white table cloths supporting drinking glasses and white cups and saucers (from the coffee break); jars of sweets; half-empty bottles of water, both fizzy and still; covered in discarded paper and art materials; pens and pencils; white plastic folders at our elbows. The room is host to about a hundred people, or more, all in groups around similar tables. The air is fresh and clean, warm and comfortable, and there is a quiet hum of muted conversations as we wait for the King's Fund's Enhancing the Healing Environment (EHE) team to begin their presentations.

We are given conference ID badges and we wear them as we are told. I am the 'Service User', with a 'Publicity Officer' from the Strategic Health Authority, a 'Lead Nurse' and two ladies from 'Estates' as the rest of our 'EHE' team for Forston Clinic near Dorchester. Each badge denominates the person and identifies the workspace - except mine which might have said 'Dorset Mental Health Forum' or 'Voluntary Sector' or similar, but actually says 'Service User'. I find this to be

somewhat off-putting but accept it.

I am reminded of the DayGlo incident of a little while before. Debbie from Dorset County Council Training Department approached us in DMHF for assistance in running a series of courses around a stepped programme of mental health education. We sat with Sue one sunny day in the Forum meeting room and thrashed out a working agreement and plan of action. I recall the sun and sharp shadows slanting across the large sash windows as we sat around the table. Sue was very nervous in those days and Debbie was unsure of her way forward. Fortunately, I was feeling quite well for a change in that I was able to think clearly without the usual mash of unbidden thoughts and emotions running through me making any job at least twice as difficult to accomplish. I was also physically quite well, which was unusual for me at that time. This meant that I had no problems in engaging fully with the other two. We planned a comprehensive programme and set about delivering it.

The first course day was the most fraught with all those strangers in a professional setting, staring and waiting for our pearls of wisdom. What on earth could I tell them that they didn't know already? Who was I to lecture at these workers? Debbie seemed keen that I express my views the way I wanted to, but which views would be acceptable? The only lecturing I had done had been in the Army 20 years previously. I was not even sure on how to start no matter how the delegates would receive me. I fell back on my trust in Debbie. She had assured us that all would be well, that the delegates would be gentle with us, and I kept in mind as I prepared to engage with the group.

The attendees, like most attendees since, were mostly women of varying ages, all waiting patiently. There were no men in this first session but, subsequently, men would make an appearance. Most of the audience looked interested in what was about to happen, but some looked like they might nod off. I didn't much mind if anyone dropped off, or even left, as I thought that the course was for their benefit and not mine. Of course, I was naïve at the time and did not recognise the benefits I would accrue as a lecturer.

As far as I can remember, the talk I did went down well. I began with a potted

history of DMHF and its doings. This lasted for 10 to 15 minutes. I then said what I was currently diagnosed with, and how I was suffering from that, and how it affected my social life. We then discussed how common my reactions and so on were. Here, I drew on my experiences working and living among sufferers of the effects of mental distress on their life. The second half lasted another 10 to 15 minutes talking about the stigma attached to being a mental health patient, or service user, and ended with any questions.

At the end of the class we would collect up the response forms and see what aspects of the morning or afternoon had gone particularly well. I was astonished to see that several class members named me and my bit as the best part overall! I thought Debbie might be disappointed that they did not mention her major teaching role, but she was delighted and saw these comments as a vindication of her work with us. Surprisingly, though, one lady suggested in her feedback that I should have worn a badge denominating me as a service user so that everyone would know what I was. We did laugh at that, imagining a large Day-Glo orange star on my breast pocket, but a serious point was also underlying this: that sometimes, no matter how hard you try, the stigma of mental illness will persist, even in these supposedly enlightened workers, and even after an afternoon of being lectured at on this very subject.

Anyway, back to the topic in hand. I was approached some months before, in about September 2005, as a SUR, and asked if I would like to take part in a long piece of work to redesign and rebuild Forston Clinic's Electroconvulsive Therapy (ECT) suite. Having already nursed there in the past, I knew that suite was long overdue a substantial modernisation and the Dorset Primary Care Trust (PCT) had taken the opportunity offered by the King's Fund to get their hands on £30,000 funding to help bring arts into health areas and at the same time upgrade the facilities. All the PCT had to do was supply a dedicated team and some money. This was where I came in, because the King's Fund wanted service users to be involved from the start. I agreed to take part and, so, now find myself, after a couple of shorter chats, in this Manchester hotel for the three-day long conference.

I notice other people have similarly distinguishing badges and that some of the delegates are staring intently to see the status of people before speaking to them. I

decide that, apart from reinforcing the stigma associated with being a 'service user' that these badges are also constraining the free flow of information between delegates at a more subtle level. "So," I think to myself, "what shall I do about it?" I decide to hold my counsel until the end of the conference so as to see what others think.

'But I don't want to go among mad people,' Alice remarked.

'Oh, you can't help that,' said the Cat: 'we're all mad here. I'm mad. You're mad.'

'How do you know I'm mad?' said Alice.

'You must be,' said the Cat, 'or you wouldn't have come here.'

(Carroll, 2007, pages 56-7)

I fall back on my admittedly limited training and decide to consult. The first people I ask are my own group and they report that the designations, as far as they are concerned, are redundant and should be removed. I agree and set out to ask others. One of the first people I meet is another 'service user', who is very nervous and grey and retiring. I am not sure why he has come to the conference if he is too ill to take a proper part and, indeed, the next day he is gone back to wherever he came from. I continue among the delegates and ask anyone who will stand still long enough to say what they think. Most people who express a preference, as they say on the adverts, say that the designation is redundant - but they still look intently at mine, offering the lie to their statements.

This goes on for the rest of the three days, among team building tasks and communal meals and drinks parties in one or other of our rooms with one of the ladies hanging out of windows to smoke cigarettes, as the hotel is totally non-smoking. We are up early and finish late and the strain of it all is telling on me. My physical health is not great and I am feeling very rundown by the end. Happily, my mental health is steady and I don't have to drop back on the effort front.

Just about the last thing we do before mounting our Trust minibus for the journey back home is to have a mass meeting where questions can be asked of the organisers

and suggestions put to them. This is my moment.

Me: I would like to ask a question.

I am on my feet before I can decide that a hundred or so people staring at me might be a bad thing.

Me: I would like to ask why we are designated as to our jobs or positions on our name badges. Surely, it would be enough to say where we are from and our name?

Lady: Why do you ask?

A kindly lady's voice reaches across the room to include me and everyone else, to wrap us in its velvet.

Me: The designation I have is as a service user. Other people have their jobs, high and low. These false distinctions are entirely worthless and divisive.

I'm quite proud of myself, blushing slightly.

Me People see them as barriers to full and free ... getting together.

I end having lost the last word and sit down again. I find this always happens. I start off well and finish lamely, but the point seems to have been accepted.

I hear no more and we all depart to our various homes.

It is June 2006 and our team is on the road again, this time to London to take a part in the King's Fund's celebrations for some award or other. We are in their head offices in Cavendish Square and have all been issued with name badges. I look at mine closely and am approached by the kind lady from Manchester.

Lady: Hello, Richard. How are you?

I said that I was fine and looking forward to the event.

Lady: You might notice that job designations have been left off the badges this time. We thought about what you had said and felt you were entirely correct, so left them off.

I feel vindicated and happy that this big organisation has listened to a service user's voice and acted on it. The lady moves away back to the posh lady someone says is the Minister for Health, who cuts the huge, square, white-iced cake with the EHE logo on it and the celebration commences. We all get a bit tiddly on the high class Champagne and are glad we are not driving back to Dorset.

Now I am back here in that same place and the badges are back to what they were. I see the kindly lady from before and move through the crush towards her.

Me: I was wondering... These badges. They are as they were before. Have you changed your minds?

To say I am puzzled is only part of it. I am hurt and surprised as well. The lady sees this.

Lady: No. We haven't changed our minds but the new Minister's security team insisted, nay demanded we keep the job descriptions or he wouldn't have attended.

She snorts, that's the only word for it. Snorts in derision.

Me: I am sorry to hear that.

I *am* sorry, as it seems that this is a step backwards brought about by the security forces unconsciously wanting to tighten their control of us. I am sorry that a man

should fear that which the woman before him had accepted.

The power in the hierarchized surveillance of the disciplines is not possessed as a thing, or transferred as a property; it functions like a piece of machinery. And, although it is true that its pyramidal organization gives it a "head," it is the apparatus as a whole that produces "power" and distributes individuals in this permanent and continuous field.

M. Foucault, *'The means of correct training'* page 192.

*

It is all down to presentation in the end, isn't it? How a person presents can have wide consequences on how he or she is perceived. Partly this presentation is imposed on us. Hence the use of badges, describing in clear terms who we are and where we stand in the hierarchy. This must give fearful power holders a sense of comfort and control they don't really deserve as manipulators of a power embodied in society as a whole rather than as wielders of a power embodied by them, as puppet masters almost, controlling society's strings by means of the acceptance and agreement of the majority of people. Gone are the days of the God-derived power of Royalty and, as Foucault went to great lengths to explain, come are the days of power residing within and throughout society itself. The manipulation of this energy is what determines who are the 'Power Brokers' in society today and, as the Arab Spring and the fall of the Communist Eastern Bloc have shown, this can change at the blink of an eye.

It had the opposite effect on me in that I recognised that it was another way of stigmatising me. It made it seem as if being a mental health service user was a full-time job, equivalent to being a Nurse Practitioner or an NHS Manager – a designation of perceived worth. If they had wanted to describe my role within the team, they could have asked me for a title. In fact, they decided unilaterally to impose a title on me. This is what I found disturbing, that the King's Fund would turn out to be so much like other organisations I had met. I had really thought they

would be different and would have the service users' feelings in mind when planning events and working with us. To give them their due, they altered their badges after I had pointed out the perceived error. That they have to change them back again at the behest of the security detail looking after the new Minister is a reflection on the security officers and their mindsets. Obviously, more work needs to be done but these people are notoriously difficult to engage.

As I said, it is all down to presentation in the end. If one is presented, and presents well, then the effects of stigma can be minimised, although they will never be totally wiped out. The next vignette in my narrative focuses on this.

Presentation of Self in a Post-modern World

I receive a rather rude email from a service user – more correctly, an ex-service user or survivor – who lives in the area of Christchurch in Dorset, an area into which I am trying to make inroads. But then, I am perhaps being overly sensitive.

*Sent: 06 February 2010 16:11
To: RP*

*Hi Richard, I think you have your wires crossed voicebox is Richmond fellowships baby not mine. I was involved at one stage but, now as I explained we are totally independant of Richmond fellowship and as such have our own group devoted to mostly crafts that we run from ***** church hall every tuesday afternoon made up from former users of RF who have been discharged from cmht, and have no further affiliation with RF. By the way I received this email not GM. Just getting the facts right.*

I am left wondering whether the rudeness is real or accidental, or just my imagination. As I sit here, away from the computer with just the memory of the

message in my mind, I consider that I could be imagining things, which is why I have blind-copied (bcc) my rather robust reply to Becky.

Hi D.

Thanks for that. I hadn't been told that Voicebox had changed so, not being in the know I thought it was all like it had been. Do you know, I much prefer self-help groups to the one's run by RF or Rethink or even Mind.

Thanks for telling me.

The reason you received a copy is because I sent you a copy - seeings as how you were mentioned in the message, I thought that only polite to keep you in the know.

Let me know if there is anything I can do to help.

Best wishes

Richard

I shall follow it up later to discuss a way forward, but also to see if Becky thought it rude, or just born of lack of education, or mental illness. This last is because I have irregular contact with a chap who suffers from Asperger Syndrome and so I have to make allowances for his lack of social awareness (NAS, 2011).

JC: *i have large chunks of my memory gone*

RP: *so have I. Strange.*

JC: *like looking at a book or dvd and theres something that says that you've seen or read it but you have no memory of if you really have*

RP: *Mine is more like my "Access All Areas" pass has expired.*

JC: *i dont know who i am or were ive been
yea but you are at an age were bodily and mental functions
start to degrade. i'm 35 and i dont know where ive been or
why i whent somewhere
you need to go to bed
PHAB tommorow eve*

RP: *Yes. I'm off very soon. Need my kip.
Good night, JC. Good speaking with you.*

JC: *thanks and would like to talk again*

RP: *So would I. Bye.*

I also wonder that it might be based on a lower level of education, not just generally but also in the skills necessary for effective communication (Martin-Young, 1996). This comes from my online experience with another service user who uses little or no punctuation whatever in his emails, making them difficult to interpret – but he doesn't come over as rude.

Subject: Rem me from dean park

*Hello Richard,
Sorry not got back to you sooner been dealing alot of
other people problems at moment and a few of my own but i
have emailed Chris the director who was at the service
users and carers meeting at Dean court but i think by his
email has fobbed me of and i'm none to happy but there you
go what kind of work do you do and dose it make a small or
big difference to people you deal with if you remember i
mostly interested in the mental health of soldiers a bit
selfish i know but i think they can be saved if found
early or even some like me who's be wondering around with
PTSD for 15 years and didn't know what was wrong, well if
you have ideas about this system that Dorset mental health
work so i can get started in some way i'd be so great-full
to you and if i can help you in some way do not hesitate
to call me ***** *****. Thanks for your time.
Yours ******

Rudeness makes it very difficult to help people or develop meaningful relationships between organisations (van de Ven, 1976), and it is the development of these that grows organisations, which is what I am aiming to do over there. To try to build a relationship on a firm and equitable footing, I reply in a more robust manner than I might normally, but to try to ensure fairness I copy in Becky, my manager at the DMHF, and, as I have said, will chat to her about the attitude in the email. It might be that she doesn't see the rudeness as I do, or she might say that I should concentrate my efforts elsewhere.

One of the problems is that I need to make contact with people who, firstly, have a reasonable level of intelligence. That sounds terrible, but for an organisation to make any headway it needs to be directed by people who know what they are about. Secondly, we need to identify people who are willing and able to manage the work. If they cannot do this without making themselves ill then we are not looking after their best interests and, in fact, will be doing harm (Gillen, 1994). Thirdly, we need people who display a basic level of manners so that they won't get up the backs of people who might then be tempted to withdraw their full cooperation, to the detriment of the work as a whole. Fourthly, we need people who can look after their personal hygiene and dress standards. This sounds so obvious that it should not need mentioning but there are people out there receiving services who also seem to lack the ability to keep themselves clean and tidy, or present themselves in an acceptable manner, and this often has nothing to do with their mental health. One would not ask a person who is badly presented, either in word or dress, to represent one's organisation to others, so why should service users have someone like this represent them? To do so would work to bolster bad perceptions and stigma, and would tend to work against the professionals taking them seriously:

The impact of image management can be measured on two levels. The first is how you see yourself. Get your image handled in a way that is going to serve you... and watch your confidence increase. Guaranteed. Secondly, people around you will start to see you in a whole new light. Your potential will be clear for all to see.

Robinett, 2011).

Broaching this very subject during one Service User Representative meeting, I was met with dismay and almost anger when they thought that I was decrying their wearing of denim. One SUR stated that he would continue to wear his denim at meetings and that it had no bearing on how he conducted himself. I hastened to reassure them all that the issue was not the wearing of denim but the wearing of dirty clothes, ripped clothes, of bodies not being washed. None of these points appeared to refer to anybody in the room, and I expressed this quite forcefully. My lecture partner also agreed with me. I think we got the point across.

I think further that this is what exercises me when I get a rude email and have my mind sent back to the Voicebox meeting I attended at the Richmond Fellowship café. The majority of the service users present were unkempt and in one case greasy and dirty. This did not endear them to us and would probably have frightened away other service users who would not wish to mix with them. During this meeting, it was obvious that the service users were also well out of their depth administratively and academically even at this level, but they didn't seem to realise this or feel able to accept our sponsorship and help when it was offered by Anna or me. Thus, their new network failed to develop. Another thing about being presentable and reasonably bright and with vision is that other service users and survivors will feel able to join you and take some of the strain, thus developing a viable network of SURs able to take their place at the committee table.

There is a school of thought around the mental health service user world that holds that to modify or alter your presentation to the type of audience you will be meeting with is dishonest and manipulative. Neither I nor Helen Robinett (see above) agrees with this, though. Rather, I see it as part of being professional - as opposed to 'being a professional'. We all wear a uniform of one sort or another, that is what fashion is after all, but it depends what that uniform says about you, about which 'Army' you're in. It is okay to be in another *Unit* as long as you are part of the same *Army* with the others on the committee, or whatever. Therefore, to be taken seriously it is not necessary to dress smartly; but to be listened to when they do not know you, it is best to fall into broad line with the others. Fran, who dresses comfortably in floppy

clothes and long loose hair, became worried when the time came for him to attend as a Trust Governor on committee. We discuss various things during our meetings and one of those things was the Presentation of Self. But that was last year sometime.

10th June 2009

We, Fran and Carol and I, meet in the Forum meeting room as usual and I offer drinks around – we men have water and Carol drinks her pop out of a plastic bottle. Carol has brought cake – walnut and carrot cake - as a treat, but I am fresh from the dentist so am not allowed any food for the next hour or so, hence the water. The meeting goes reasonably well even though the thought of how Jack-the-dog is coping distracts me constantly. Fortunately, Stephanie is at home asleep after her nightshift last night, so not too much can go wrong.

We talk about the focus of my writing and how it must be informed by the research question. This is a reflection on learning, reading and life's events and how they all apply to my study, looking for links on how higher education is acting as a therapeutic tool in my care.

The title of the study is '*Solace: Relationships in Care*' and under this banner I can write about anything that seems appropriate – like my distractions regarding Jack-the-Dog. His illness has left me worried, anxious and despairing of ever seeing him well again, and this is driving my mood down, too, so that I am finding it hard to concentrate on my work. At one level, my work distracts my attention from Jack's situation but at another level, Jack's situation distracts me from my work. It is a vicious cycle impossible to break.

Jack is getting weaker and weaker. He has lost a huge amount of muscle in the last 6 weeks and is barely able to walk. I do not know what is wrong with him and so make an appointment to visit the new vet's clinic tomorrow.

Jack has been my companion for almost 12 years, after my daughter could not look after him anymore and he came to live with me in my flat. I know he has to die one day, but it does not seem to me to be the 'right time' for him now. I suspect a disease process but none of the tests showed anything at his previous vets – let us see what

these new ones say.

Losing Jack in this way enables me to see what others go through, especially when their only companion is their pet, as Jack has been for me for some time. Stephanie now loves him, too, as he is a very loving dog and her upset hurts me as much as Jack's illness and decline.

Away from Jack's problems, I have written about smoking and the rear stairwell into the Forum offices, and Carol, as an intermittent smoker, notices it:

Carol: The thing about *Smokers' Corner* is really interesting . . .

I recall the piece. It is the 6th of January and I touch base at the Forum. The Forum occupies the upper offices in an old converted warehouse and one enters it, generally, by the back stairs through a coded, locked door. At the base of the stairs outside the door is where all the smokers from the Forum congregate for a puff. It means that the lower part of the stairs smells like an ashtray and I always wrinkle up my nose when passing through it. Wrinkling, I mount the stairs as usual.

Carol: . . . because it's almost like it doesn't fit the mould of a professional organisation and you'd quite like to get rid of that down there.

Me: Oh, yes.

Carol: It's a sort of blot on the landscape because of the association between mental health problems and smoking, and it gives a bad impression to professionals and other people coming here.

Me: Well, sometimes you have half a dozen people smoking in a circle, which isn't very nice when you get visitors coming in. I ... I think, if you want to smoke, leave the area and smoke and then come back again. I have not a problem with that. If I'm feeling that way, and I've been coming here for years, how do people who are first-coming going to feel? That's all. If you

want to smoke, close the door and smoke. There's ash and fag ends everywhere ...

Carol: It's also about the presentation of the organisation that you take responsibility for, isn't it?

Me: Yeah. That sort of thing.

Fran: Sort of 'The Presentation of Self in ... in ...

Carol: ... Everyday Life'. Stuff from those other books.

Fran: It could be 'The Presentation of Self in Everyday Life: The Story of a Modern Service User Representative.'

Carol: Really? 'Modern'? Post-modern?

Fran: Yeah. Post-modern.

Fran: You know, you talk about the suit, you talk about the effects of the medication, you talk about the committee ...

Carol: You talk about the furniture, the architecture ...

Fran: Hmm ... and it is about the presentation. Yourself, isn't it? About how important it is to be on time, to know what you are talking about, to ... and all this kind of stuff.

Me: Yes.

Fran: We've got a title, folks!

Carol: Fran's got a title.

Me: Another title ...

Fran: (sotto voce) Bloody social workers!

Carol: (louder) Bloody autoethnographers!

So, I write it down with their encouragement: “*The Presentation of Self: The Story of a Post-modern Service User Representative*” and mark it as “*TITLE*”. It has potential, though I also take Carol’s assertion that it is Fran’s idea not mine. I am, however, minded that we only see further when we stand on other people’s shoulders.

Dicebat Bernardus Carnotensis nos esse quasi nanos, gigantium humeris insidentes, ut possimus plura eis et remotiora videre, non utique proprii visus acumine, aut eminentia corporis, sed quia in altum subvenimur et extollimur magnitudine gigantea

(Trans: Bernard of Chartres used to say that we are like dwarfs on the shoulders of giants, so that we can see more than they, and things at a greater distance, not by virtue of any sharpness of sight on our part, or any physical distinction, but because we are carried high and raised up by their giant size.)

(John of Salisbury, 1159)

So, perhaps I should stand on his shoulders in this instance. I will think on it a little more.

We end our discussions with an interesting side issue on dressing appropriately for various events. Since Fran was elected a Governor of Dorset Hospital NHS Foundation Trust, he has been agonising over what to dress in and how to wear his long hair when called to attend the Governors’ committees. My views are clear in

that you dress to suit the occasion, but Fran is torn. I hold that as he is an elected Governor and not an employee of the Trust, he can dress as he sees fit and wear his hair as he wishes. He seems to think he should wear a suit and pull his hair back into a ponytail, canvassing our opinions. Carol asks him for whom he is dressing and he thinks this through without answering.

Carol: I get really excited when I read things here that leap out and smack me round the head, but they are not necessarily the same as what you would see, and they have to be different because, you know ... I'm coming here as the designated social worker, so I have to play that role now, and Fran, you'll play Pixy sitting in the corner.

Fran: No, but was I given any other choice to do anything else?

Me: You're not 'supine' today, though, are you?

I am referring to the description I wrote of the position he took during one of our previous meetings.

Fran: No. And I can't be anymore. Not after you wrote that down! I dread to see what's going to be the next Field note! That's why I'm stood up. Upright.

Me: I know ...

Carol: Says Fran, all defensively.

Me: Fran pulled his hair back and I saw him as a Corporate Man for once!

Carol: (laughs loudly) He's doing it again now!

Fran: I'm agonising now about whether it's okay to put my hair back now, you see.

Me: Completely different face. I wouldn't recognise him in the street!

Fran: How do you think it looks? Appropriate, or what?

Carol: Appropriate for what?

Fran: Life. Living. Walking down the street ... you don't care?

Carol: Well, it's the 'appropriate' bit ...

Fran: Do you like it or not?

Carol and I take a long look at him with his hair back. He poses for us, one arm raised, hand clutching his hair and drawing it back.

Carol: No ... but I have a thing about men with ponytails anyway, so ...

Fran: Oh, well. That's no surprise, is it, being a social worker and ...

Me: Now you mention it ... I walk around with imaginary scissors. Snip. Snip.

Fran: Yeah. But you're ex-Army ...

Carol: There are very few men who can actually get away with it.

Fran: That's true.

Me: You've got to have a bald patch and a beer belly to go with it.

Carol: Johnny Depp's one.

Hmmm . . . Johnny Depp doesn't wear one, or so it would seem. Perhaps Carol has let slip a little of her phantasy world to us?

In Klein's concept, phantasy emanates from within and imagines what is without, it offers an unconscious commentary on instinctual life and links feelings to objects and creates a new amalgam: the world of imagination (Mitchell, 1986).

Freud recognised phantasies, but looked to the unconscious wish as the prime mover. He saw phantasies as imagined fulfilments of frustrated wishes (Freud, 1920/1961). Klein puts phantasies beneath unconscious wishes, rather than alongside them (Spillius, 2001).

Carol once told me that she knew of no meeting that did not have a sexual element to it. At the time, I thought she meant in a feminist researcher way, but now I wonder . . . but this meandering is taking me away from the point. The point being that we, all of us, project an image of our Self through the way we present to others.

Carol: Jude Law? Probably. Brad Pitt? Definitely not. But Fran? Well, it's just a part of you.

Fran: Don't you go on ...

Carol: (loud laugh)

Fran: (sulkily) All I wanted you to say was yes or no.

Carol: What I'm amazed at is that the answer was so important! 'Cos if I wanted to tie my hair back because it was warm and it was summer and ... I'd just do it.

Me: Yes ...

Fran: I just don't want to look a fool at this meeting, that's all.

Carol: You won't look any more a fool than when you've got it down, so (laughs) ...

Me: With it up, it changes your face quite considerably.

Fran: Does it?

Me: Yes. Makes you more sort of like a drug dealer or something. What you need is a black suit and a black tie . . .

Fran: I've got to go and meet the Chairman of the Trust. I've got a suit but I've got to decide if I should get a haircut before that.

Carol: Why!?

Fran: Well, I just feel that I should ...

Carol: For you? Or for them?

Fran: Probably both. Presentation is so important.

Now we get to the nub of it! I listen carefully as Fran expounds on his dilemma.

Fran: Anna was laughing last night when she said that they would all probably die when they realise that they've just elected somebody with a pony tail to the Dorchester Hospital Trust!

How important seemingly innocent remarks can be when uttered by someone you hold in high regard, such as Anna's to Fran. I am always mindful of the words I use in my work and at home. I learnt my lesson one dreary afternoon in the Verne Prison on Portland Island, Dorset. We had taken custody of about 25 new prisoners and among them was a man whose only crime had been to plan to repatriate his daughter from his estranged wife in Spain. She was barred from seeing him by her mother even though he had a Contact Order under the Children Act.

Children Act 1989 Chapter 41 Section 8 (1): "a contact order" means an order requiring the person with whom a child lives, or is to live, to allow the child to visit or stay with the person named in the order, or for that person and the child otherwise to have contact with each other.

He was apprehended trying to make plans for her kidnap back to his (UK) residence. He was jailed for 18 months for conspiracy to commit a crime.

The offence of conspiracy.

(1) Subject to the following provisions of this Part of this Act, if a person agrees with any other person or persons that a course of conduct shall be pursued which, if the agreement is carried out in accordance with their intentions, either—

(a) will necessarily amount to or involve the commission of any offence or offences by one or more of the parties to the agreement, or

(b) would do so but for the existence of facts which render the commission of the offence or any of the offences impossible,

he is guilty of conspiracy to commit the offence or offences in question.

(<http://www.legislation.gov.uk/ukpga/1977/45>, accessed 11FEB13)

On his admission to Her Majesty's Prison the Verne, we were informed that he had told his girlfriend that he was going to kill himself. As a result, he was admitted to an observation cell in the Segregation Unit and placed under our 15-minute observation routine, having had his belt and laces and so on removed from his possession. The routine was that he should be seen to be alive at least once every 15 minutes. What this meant in practice was that a Prison Officer would observe him through the hatch in the cell door. It was considered best practice to try to engage the prisoner in conversation while he was being observed.

I was called to assess him. When I arrived at the cellblock at about 3:30pm, I found a dull, grey unfurnished cell with a barred half-sized window. I was surprised it was unfurnished but was used to the drabness of these rooms with their grubby windows

and heavy steel doors with no handle on the inside and a tiny peephole covered by a flap of metal. I asked about bed and bedding and so on and was told that he would be given a mattress closer to lock-down, and that this was 'procedure'. I let myself in to the cell and found a tall slender man of about 35 years with dark hair sitting with his knees up, his back against the outside wall.

Me: Hello. I'm the Hospital Officer on duty. I hear you have just arrived and have been saying you want to die? At least, so your girlfriend tells us.

No reply save a sullen glare.

Me: I am here to chat about this and see if there is anything I can do to help.

Still no reply. I paused for a while, waiting for some sign that he would speak, but none came. After about 5 minutes of this, I asked why he would not speak to me.

He: Because I don't want to and I don't like you!

He had snapped this out. I was tired and answered without too much thought.

Me: Well, I don't like you either, but that doesn't mean I want to see you die here.

I left the cell, ordered a strict 15-minute observation routine for him, and returned to the Hospital Wing. As the officer said, that was procedure.

Those were the last words the prisoner would hear. I was called back to his cell at about twenty past eight to find he had hanged himself from the window bars by using his coat sleeve as a ligature. The prison officers were trying to resuscitate with mouth-to-mouth and closed-chest massage to no avail. The cadaver, for that is what he was now, was cold and clammy to the touch and decidedly blue, with no life signs at all. His neck was constricted, so I opened my emergency pack, inserted an airway and began bag-and-mask resuscitation. Showing the officers how to continue this,

along with their closed-chest massage, I called for an ambulance and doctor, and the Duty Governor at a rush. The work continued with no result for the twenty minutes it took the ambulance crew to arrive and take over. The doctor with them declared the prisoner dead a minute or two later. That was it. We all went back to work.

This was the very first suicide in the history of that prison and it had to happen on my watch. Now the young girl had no father and me and my colleagues were traumatised. Suicide is rarely a singular act, having many repercussions. A prison behaves differently when there has been a suicide, with, sometimes, copycat suicides happening, and at the very least a sense of foreboding across the cell blocks, of quiet, as if of watchful waiting. The point is that I felt very guilty about the last words I had said to him, and these still prey on my mind. This all happened many years ago but I remain watchful about what I say to people, especially people in distress.

Me: Well then, don't wear a pony tail.

Fran: Oh he'd love that! I've got to get my photograph taken and all sorts.

Carol: Just get a bobble hat and wear that, then he won't know if you've got long hair or short hair.

Me: Or do what women do and go and spend eighty-seven quid on a haircut.

Carol: That's a MAJOR generalisation, Richard! That's a major generalisation.

Me: Well, it is in my experience that they do.

Carol: It's in my experience, too.

Fran: Is it true?

And so the discussion travels around the minutiae of haircuts. Fran brings it back:

Fran: Well, I won't be paying that much. I think I'll leave my hair as it is.

Me: Cost you a lot of soul searching just now, didn't it?

Fran: Yeah ...

Carol: So, you will be wearing a suit, will you?

Me: You're going to be doing the whole corporate thing, are you? ... Why?

We discussed around why he applied to be a Trust Governor in the first place. That ended the discussion around personal presentation, but it was left in the air, hanging like the prisoner on my conscience, and I continued to think around it.

As we leave the building, the matter is still unresolved and we leave him to his next appointment.

How do I feel about this interchange? Well, somewhat uncomfortable because I have grown used to thinking of Fran and Carol as tutors and guides, not me as their guide. I know this is unreasonable in that they are human beings as well, but it echoes back to my school days where the teachers were a class apart from us pupils. I also feel very privileged in being included in their discussions about such a private subject as Fran's feelings about his hair and his presentation, and how he exposed the vulnerable Fran to us.

I go home and take a by now very ill Jack to the vet. Trevor, the young veterinary surgeon, looks worried and does a lot of tests declaring Jack has a heart murmur and needs tablets, also an eye infection and a general infection, but that he wants to take blood and urine samples. He takes the blood down in his clinic room; poor old Jack has trouble getting up the stairs, and is carried back up by the veterinary nurse.

I take him home and take a mid-stream urine (MSU) sample as soon as I can. This involves waiting for Jack to urinate and then slipping the sterile catcher and bottle

under him after the first couple of seconds have gone by, collecting the urine in the bottle to the sample line, and then withdrawing. In this way, one can sample the sterile middle of the urine stream. Jack doesn't seem to notice at all. His MSU is murky and full of protein indicating a systemic infection. We try to get Jack to eat but he is in no mood and just lies about on his bed or on the lawn. The MSU has to go back to Trevor in 24 hours, so we might know more then. It is all very worrying because poor Jack is just skin and bone. He has declined very rapidly over the past few weeks and this has worried us a lot, distracting me from journaling and working, and generally preying on my mind.

Anyway, back to the present. I decide to ask Becky what she thinks of the tone of the email and she agrees that it is rather abrupt and rude, so it was not just my imagination. She asks how I replied to it and I show her the answering mail.

Becky: Yes. That seems just about right to me, Richard. Keep it on a light touch, loose but keep contact if you can, and we'll see what can be done later in the year.

Me: I think you are right. The light touch is needed here. Keep in contact without aggravating the situation.

Now that is sorted out, I feel a bit better about not following up on the group I met that day at the Richmond Fellowship meeting.

Jack has developed diabetes and must be injected with 10 IU of *Caninsulin* twice a day, and kept on a diabetic diet. He nearly died.

*

Here, the narrative has accessed original research and relevant references in order to talk about three things: the presentation of self, suicide, and the importance of pets to their owners. The presentation of self builds on the Dress Code discussion above in

the medication changes chapter. The issues around suicide have also been discussed above in connection with the death of a Service User Representative. What we have not yet looked at is the importance of pets to their owners.

If you have never owned a loving pet, the chances are that you might think people foolish for getting so attached to them. But pets, especially dogs, cats, rabbits, birds, and horses, have a therapeutic effect on their owners and the people they visit or who visit them (TherapyPets, 2003). The main thing is that the animal holds some interest for you.

The therapeutic use of pets as companions has gained increasing attention in recent years for a wide variety of patients -people with AIDS or cancer, the elderly, and the mentally ill. Unlike people, with whom our interactions may be quite complex and unpredictable, animals provide a constant source of comfort and focus for attention. Animals bring out our nurturing instinct. They also make us feel safe and unconditionally accepted. We can just be ourselves around our pets.

(http://www.holisticonline.com/stress/stress_pet-therapy.htm, accessed 11FEB13)

Often, the work of a Service User Representative can revolve around building relationships not with animals but with people, especially those other than directly involved with whatever it is you are doing at that moment. For example, support staff can make your life easier or more difficult depending on how you treat them.

It used to happen that I would be asked to attend development committees as a Service User Representative as part of my professional development. These often happened in social services buildings. Such buildings would tend to be uniform and drab, but the Hanham Centre in Wimborne, Dorset, was nicely decorated and furnished. The only problem was that parking was very difficult with the easiest solution being to park in the public car park down the hill. The administration staff were always very friendly and helpful. All this made going to meetings there much more pleasurable than going elsewhere. I recall one late November when I was called for one such meeting.

Erecting the tree

Wimborne, Dorset. A cold and sunny day, dry, with a little wind. It is fortunate that I can park quite close to the buildings so that I do not have to walk too far carrying my briefcase.

I am early so I am the only one there for the meeting of the Direct Payments Consultation Group. The meetings are held in the salubrious surroundings of the day centre in Wimborne. Freshly decorated and furnished to a high standard, it makes a nice change from the other meeting rooms I am used to, and I enjoy going there.

Entry is from the car park, through two glazed double doors and past the unit's general office. The two workers are busy at their desks. There is a large cardboard box tied with green plastic twine sitting in the corridor between the meeting rooms.

Me: *Good morning ladies. How are you? What is this big box?*

Hannah: *Good morning, Richard. We are fine, thank you for asking. The box is full of Christmas tree that needs to be assembled today.*

Me: *Would you like me to lend you a hand?*

I look at the box. It is quite large and dusty, and it seems stuffed with something. I wonder what I have let myself in for.

Hannah: *You are more than welcome to have a go, if you think you can help - and if you have got time.*

We gather at the box and she leans over and opens the lid. Inside, it is a jumble of green twisted wire and plastic leaves. There is also a sheet of instructions that we open up. Following the instructions, we soon have the basic shape of the tree up and are fixing and shaping the branches so that it looks reasonable. By this time, I am a bit dusty and heated and the other group members have arrived and are settling down

in the large meeting room. I go for a quick wash before joining the meeting.

The meeting goes very well. There are eight of us discussing self-directed support and direct payments. The main thrust of the meeting is to map the process an officer would follow when advising a disabled person on how to go about applying for direct payments. My role is to act as the service user voice in the meeting. Other people there are various senior managers from county council social services departments, with a helper from the research office.

I am particularly keen that the accompanying letter must reduce stress and lay out the different ways that the form might be completed. Notwithstanding all the other decisions we have to come to during the meeting, I hold that the assessment needs to be outcome focused and look at what the client wants to be the end result, and this is accepted.

I am pleased with the results of my interventions during the planning committee and end the meeting on a high note. After I have said goodbye to the other members of the committee, I look in on the administration offices.

Me: Hello again. All done with the tree, I see?

I look at the tree and that everything is working but that the lights are not flashing.

Me: What's wrong with the lights?

Hannah: We've plugged them in but I think one of the bulbs is duff. We haven't got the time to fiddle and that's what is needed, I think.

Me: Would you like me to have a look for you?

She nods at me, so I check that everything is plugged in and then start to reseal the bulbs one at a time. Suddenly the lights come on and I step back. The tree is very pretty and covered in decorations, and now that and the lights are working it looks

great.

Hannah: Thank you so much for helping us with the tree, Richard. We would never have got it up so quickly without you. Perhaps you can be around after Christmas when it has to come down again?

She smiles broadly at me and winks.

Me: You never know. I might well be around after Christmas, and if I am, I'd be pleased to help you with your tree. Doesn't it look grand? Anyway, I'll see you before Christmas. Bye.

I give a little wave and walk out of the building.

*

It does not take long to tend to the needs of staff who can help you and can make your life run easier. Such staff are normally ignored in the day to day work of office people but their opinions are often sought out, and alert Service User Representatives or Peer Specialists, should be making relationships work all around them.

An important part of being a mental health Service User Representative is to explain to others, perhaps who have no knowledge whatever of mental health and illness matters, how things seem to you with, hopefully, a resonance in the reader, or at least a fresh understanding of the life of a service user, an illumination into a dark corner of life. Just such a request comes by email from the editor of DMHF's *Reflections* magazine.

Do you remember I asked you to think about doing something towards an article for Further Musings on staff attitudes in mental health day services? I was thinking something along the lines of service user perspective, government directives - patient led NHS, challenges to staff who don't necessarily see service users as stakeholders in their services?

What do you think? If you could rough something up that I could use along with other stuff - say 500 words?

So I did.

Service user perspective

Day services for the users of those services can be a lifeline to normality and a contact point with the real world. Day services need to be responsive, flexible, and open, with local and accessible centres. People should have access to a ‘safe space’ where people are able to be themselves and be free of undue pressures – in some cases this can also mean an absence of newcomers. The day services need to be a part of overall care planning. There should be access to a wide range of activities, and, crucially, there should be involvement and control by service users.

What does national policy require day services to deliver? The legislative context.

The purpose of day services is, through use of a person-centred approach, to promote social inclusion and recovery.

The duty to provide day services is embodied in mental health legislation and, more broadly, through legislation for services to disabled people as a whole. Local authorities’ powers to promote the welfare of people who are substantially and permanently handicapped are to be found in the 1948 National Assistance Act; and local authorities are explicitly required to provide day services for people who have a mental illness, as defined under the 1959 Mental Health Act as was, through the 1977 National Health Services Act (Schedule 8) in combination with Circular LAC(93)10, Appendix 3. This duty was extended to include people who have been compulsorily detained in

hospital by the revisions found in the Mental Health Act (1983) and these have been continued in the new revisions in the 2007 Act.

Although there is little in legislation to indicate the form or amount of day services that must be provided, a wide range of legislation impacts on the way that day services are organised and accessed, even with few other specific references. The 1986 Disabled Persons (Services, Consultation and Representation Act), places a duty on councils to assess the needs of a disabled person; the 1990 NHS and Community Care Act sets out the process of community care assessment for social care services; and the 1996 Community Care (Direct Payments) Act, permitting local councils to make payments to disabled adults to secure their own services, which includes those disabled through a mental disability.

Guidance on the principles and goals that should be followed by day services is most clearly stated in three documents:

1. *National Service Framework for Mental Health (1999)* is concerned with standards for the delivery of NHS mental health services, and presents “ten guiding values and principles to help shape decisions on service delivery”.
2. *The Social Exclusion Unit Report: Mental Health and Social Exclusion (2004)* includes a section on day services but also has a relevant vision statement and action plan. The report highlights the importance of helping people to sustain or re-commence employment.
3. *The Social Care Green Paper: Independence, Well-being and Choice: Our vision for the future of social care for adults in England (2005)*, while technically a consultation document, offers a clear sense of the general direction of social care. It also makes it clear that people who use services will increasingly be able to act as the purchasers of their own services, using Direct Payments or individual budgets.

Such was my reply to the query in 539 words.

In all my dealings with staff, the grassroots seem almost bewildered by the scope and speed of change happening around them. This is reflected nationally. They seem to have retreated to a position of just doing their jobs to the best of their abilities and going home at night exhausted. Higher up the scale, the changes also seem to be taking their toll with service managers becoming enervated when you address the ways services are delivered or changes are taking place.

Involving service users as stakeholders takes a positive effort to change years of nurse training, mostly based in places like the old Herrison Hospital. Moves away from delineating roles in Community Mental Health Teams can help to break this ‘Them and Us’ mind-set, but this is going to take time. It does not help when Government policy is disjointed as well, with Patient and Public Involvement Forums (PPIFs) being replaced with Oversight and Scrutiny Committees (OSCs) and Local Involvement Networks (LINKs), and the term ‘Service User’ being replaced by ‘Patient’ in the latest legislation all seeming to point to another about-face and more changes in the offing.

Staff reeled from the onslaught of change in the late 1980s and early 1990s, and many of those staff remain in post today bringing with them their shared memories of those chaotic times, when people were forced to apply formally for their own jobs and not everyone was successful; a time when nursing care practices were changing with the wind and leaving everyone tottering. It is no surprise, then, that staff today – hearing their senior colleagues talk of those days – are less than enthusiastic for more changes. But changes there have to be.

We are moving from the *Medical* model of care, through the *Biopsychosocial* model, into a new era of *Recovery Approach* thinking. The latest drive is in integrated services caring for the mental and physical health of the whole community, with the slogan ‘*No Health Without Mental Health*’ going before. This has resulted in renaming services from the older Community Mental Health Teams, which were multidisciplinary in nature and followed the Care Programme Approach (DoH, 2008), to Recovery Teams and the like, with a whole new set of game rules going

with them.

As always, it is the grassroots troops who suffer the most with Chinese Whispers and lazy management practices often resulting in a lack of the whole picture being trickled down to them. Often, these workers feel resentment, feel side-lined by all the new changes, and would love to have things back the way they were, but this is not an option. SURs can help with their fears.

SURs have firstly to grasp and understand the new mode of working. This comes from studying what is being said in meetings and reading leaflets and handouts, journal articles and flyers, and having discussions among themselves to raise awareness of the area under study. Once that understanding is in place, the SUR can then work at grassroots level to help those workers and other staff struggling to accept their new reality by explaining things to them. As has been seen in *A Conversation with Harry* above, it comes from a person whom they perceive as not only having lived experiences of the new system but also who has privileged access to their hierarchy. The message is a powerful one and should be used sparingly, in a friendly and supportive manner when it is called for.

The Dorset Mental Health Forum *Reach Out* Campaign

We have been following one model of Service User Representative working, that pertaining within the Dorset Mental Health Forum (DMHF). The DMHF started life back in 1992 as one man's dream – latterly earning him the MBE - focused only on helping users from West Dorset, and is now pan-Dorset and in some respects national in its reach. It is also pan-disability in many ways, being a foundation organisation for Access Dorset, a pan-disability organisation itself, as well as having members working with the Time To Change campaign, national Mind, the Expert Patient Programme, Rethink Mental Illness, the Enhancing the Healing Environment programme of the King's Fund, and by working with the Norah Fry Institute of the

University of Bristol to name but a few. The specific part of the Forum's work that concerns us here is the employment of people who access mental health services as Peer Representatives and Peer Specialists, part of the Big Lotto funded *Reach Out* programme, formerly known as Service User Representatives or SURs.

Throughout the thesis, we have seen that the working life of a person who uses mental health services is a precarious one. Things can so easily go wrong; wellness is so fragile, that any plan of work must encompass 'bad' periods as well as not burning lamps too brightly in the 'good' times, which often leads to a 'bad' time. A judicious use of energy and time can result in a productive work-life balance. This is to a great extent in the hands of the person using the services, but employers can make necessary adjustments to the workplace under equality legislation to enable people accessing mental health services to work again.

Work has been recognised by many authorities as having a beneficial and healing effect on disabled people and, make no mistake, those people suffering from a chronic, serious and debilitating condition such as Schizophrenia or, in my case, Complex PTSD are disabled in a social sense just as much as someone confined to a wheelchair. Often more so, as their condition is hidden from the casual gaze, as are diabetes and cardiac concerns. This hidden and secretive aspect of our lives leads to fear and suspicion from others, especially prospective employers. They worry about how that person's condition will affect work, as they should, but they often then dismiss the person's application out of hand missing the benefits coming with that person, benefits like an education – a large number of the people I know suffering a severe and enduring mental illness have higher educational qualifications yet still find it hard to find meaningful work. The Peer Representative and Peer Specialist roles in DMHF offer a supported way back to paid employment.

By far the bulk of people with mental health problems want to undertake paid employment (Grove, 1999), but only about 1 in 5 of those with long-term mental health problems currently have jobs, compared with over 1 in 2 of those disabled people who have physical problems (ONS, 2000). However, it has been shown that up to 58% of adults with severe and enduring mental health problems are able to maintain a work schedule when receiving the right levels of support, (Bond *et al*,

1997) but just under half of those who wanted help finding work were offered it (Healthcare Commission Survey of users of mental health services 2007).

Some common misconceptions about mental health and employment seem to have become embedded as 'facts'. A list of the most frequent has such as the 'fact' that people who use mental health services don't want to work; but research shows that the majority of them would like to find paid employment but often need some support to do so, and there is also evidence that unemployment is more detrimental to one's mental health than is working. Recent research has shown that work is good for our physical and mental health (Waddell and Burton, 2006). Being in employment and maintaining social contacts will often improve mental health, work towards preventing suicide, and reduce people's reliance on mental health services, whereas unemployment can damage one's health and can lead to a range of social problems such as debt and social isolation (SEU, 2004; Black, 2008). Another problem that is often encountered is that people who access mental health services are told that they cannot (or should not) work and consequently are not given the opportunity to find out if work would suit them. This is exacerbated by the attitude of many prospective employers. A 2007 survey of employers in the UK found that around a half (52%) of them stated that they have never knowingly recruited anyone with a history of mental ill health (CIPD, 2007). Health care staff often do not help matters for the best of reasons (Marwaha, *et al.*, 2009) when they focus on maintenance of treatment rather than on a person's recovery and return to an independent life. The result is that only half of people who access mental health services say they have received any help at all with employment (Healthcare Commission, 2008). And finally, the positive social, financial and personal benefits that work brings far outweigh the detrimental effects such as increased stress (Bristol Mental Health Employment Forum Oct 2008, page 3).

So, work being so good for you, the DMHF's Big Lotto-supported Reach Out Campaign has been offering those people who are or have accessed mental health services a supported and remunerated route back to paid employment. Initially termed Service User Representative, it was realised that the various tasks formed two broad areas of responsibility and so the two roles, Peer Representative and Peer Specialist, were conceived in its place. The job descriptions for both jobs are shown

at Appendix C and D below. This change in titles occurred in 2010, so the title Service User Representative, or SUR, has been used extensively throughout this thesis.

As was mentioned above, the Dorset Mental Health Forum has evolved from humble beginnings in 1992 to its current size and reach. It is guided by a Board of Trustees, all of whom have lived experience of mental health distress, which is responsible for the running of the Forum to the Charity Commission in the usual way. They delegate some of their powers to the Forum's management team consisting of a General Manager and a Services Manager. The day-to-day running of the Forum is accomplished through the office staff, all of whom (as at 2010 at least) also have lived experience of mental health problems.

On-going support is offered in three main ways: there are regular meetings of the whole of the peer support workforce hosted by DMHF; there are regular, monthly supervision periods for peer support workers by an experienced senior staff member, aimed at identifying and supporting the person as well as helping them to engage with any emergent challenges; there is the day-to-day support of the other members of the Forum, which maintains a positive, non-discriminatory, and even-handed corporate approach. Also offered is a guiding hand from two Consultant Peer Specialists who undertake more complex duties and help the Representatives and Specialists whenever necessary. This might mean shadowing them at their first few committees or other meetings to offer assistance and support as they find their feet, developing and delivering training packages for them, and so on. I am one of the consultants. Over the period covered by this thesis my practice has developed from that of office helpmeet to Consultant Peer Specialist. A lot of this practice development has been enhanced through my original research at doctoral level. It has been informed by the focussed reading required to create the requisite systematic review, and the results of these studies are evidenced in a narrative way in this thesis. The result has been that I have developed a clear idea of the most effective model of services user representation, whereby they are helped, educated, supported and assisted via membership of an organisation of other, similar services users. That support is necessary has been emphasised by thinkers on the subject such as

Professor Peter Beresford of Brunel University (Beresford, 2012) where he discusses the case of ‘Kay Sheldon, board member of the Care Quality Commission, to be stigmatised as mentally ill by its chair Dame Jo Williams’ and how that case highlights the need for protection of vulnerable people at all levels of participation.

In-house training takes place monthly and as-and-when-required, either as a group or individually. Workers may also access specific training courses offered by the various councils and the NHS Trusts’ training departments. These latter courses are laid on by these organisations for their own employees, and Peer Specialists and Peer Representatives would attend them as individuals, which in itself is good training in interpersonal skills and cross-agency working as well as an introduction to the organisations and their staffs.

How long does each worker spend on his or her tasks a month? Well, that depends entirely on the particular circumstances of the worker. Some might manage many hours a week while others only a couple. Such things are decided in consultation with the Forum management taking the wishes of the person into account. However many hours worked, unless the SUR wishes to be employed in a voluntary capacity for benefits reasons, payment is made monthly net in arrears, on the evidence of a countersigned time sheet and expenses form, direct to the worker. Volunteers are offered their expenses.

This model of service user involvement has worked very well for Dorset Mental Health Forum and is well thought of by the statutory agencies that use the representatives and specialists in their work. The model allows people to be supported in all aspects of their engagement with the Forum, be it meeting with constituents, attending committees with commissioners and providers, delivering training, or carrying out research projects. It allows for early recognition of and personalised support through any mental or physical health crises so as to allow the worker to recommence work when the crisis is over.

(The DMHF website is at: <http://www.dorsetmentalhealthforum.org.uk>, accessed 11FEB13)

Towards a sense of peace

We two stand hand in hand and gaze out over Old Harry Rocks and the blue Solent beyond. The water moistens the warm summer breeze. It cools me from my exertions of a moment before. The walk up to this spot with Stephanie and Jack-the-dog has left me breathless and heart-thumpingly tired. I am no longer the fit young 29-year-old bomb disposal officer chatting with a Police Inspector during a call-out, but a 50-year-old coming through a serious mental and physical crisis.

I look out over this so familiar scene. My mind wanders back to how I was when I quit the forces, and when I retired from the Prison Service. The divorce was harsh on my 8-year-old daughter. Then eight further years of court appearances fighting clinical depression, PTSD, and the court cases at the same time cost me my house, my job and almost my sanity. The breeze throws up some fine sand. It stings my eyes and grits my teeth. Jack pulls on his leash. A young boy in a blue and white T-shirt skims stones over the cliff's edge and Jack is keen to chase them into the void. I know how he feels.

I think of how my daughter came to live with me after the madness, and took up the role of carer. She was only 14, yet grew quickly into her new reality. Now I am with Stephanie, who just at this moment squeezes my hand. My daughter will be free to pursue her own life once again. I feel relief and a tear stings my eyes.

I reflect on my work as a Service User Representative and how it has, over the years, built into an important part of my life, offering structure to an otherwise chaotic world, offering friendships and successes, offering a place to be me again. I realise that without the effort I have put in, the SUR post would never have panned out as well as it has; that the acceptance of help as a first step is brought home to me by my experiences since first starting this journey; that many sufferers will not accept that help, will not get near others so that they can help support one another through the rough times; and that those service users often then find their recovery path a rocky uphill struggle.

Slowly but surely, with the help of friends and family and Jack-the-Dog, I have moved through madness to a sense of peace. My progress from 'envelope stamper and stuffer' to Peer Specialist Consultant has been enhanced by my studies for this doctorate. In the beginning was the idea that I could study service user representation across the whole of the UK; this was reduced to three council areas; and reduced still further to the local council area, to compare and contrast ways of working. But this did not give me any sense that it would be either useful or fulfilling on a personal level, so my studies led me to autoethnography. This method of formal study of oneself in the social arena appealed to me almost immediately as a way of both exploring the life of a SUR/Peer Specialist and also expounding a model of best practice, all wrapped up in an engaging story. The only sticking point had been that it was to be me under the microscope, but this trepidation did not last long and further study and reading showed me what the masters had done with the concept.

As I worked through these academic issues, the work affected my role at DMHF, and I was promoted to Peer Specialist Consultant and given my own areas to work in, which meant the development of the East of the county including Poole and Bournemouth, and working or liaising with other bodies, both statutory and third sector like *MIND* and the local councils.

But let's go back to the cliff top high over the sea, looking across Old Harry Rocks, out to the Needles off the Isle of Wight under a beautiful blue sky.

A helicopter buzzes towards us from the Isle of Wight: "Oh look," says Stephanie, "a boat!" This becomes a new chuckle and a fresh-shared memory cementing our own new reality.

I feel at peace at last.

TODAY AND TODAY

There is a certain person that I seem to need today;
The problems that erupt within won't seem to go away.

*When you feel bad then you must phone us up, they always
say,*

But then what happens when today is everyone's Rest Day?

The Samaritans are there for you, so everybody say,

As are your friends and family - they never go away.

But you don't want your friends to feel all sad and blue
today,

And what d'you tell a stranger who just might not go away?

To take a chance, and bare your soul to someone miles
away,

When anything could happen? They might try their best to
sway

You from your planned demise, when all you wanted was a
say;

To have a listening ear for you - and no-one else - today.

*So, Soldier on! Work at your tools! and other things they
say,*

Today you have survived the call! Today. And then today.

For everyday will be today. And today yesterday.

And tomorrow, when it comes all gay, will be again Today.

Richard Peacocke, Dorchester, 2000

Concluding Section

In this section we will discuss where we have come from in reading this thesis, and how we got to this point, the lessons learned, and some limitations to the study. The way this is addressed is through a reflexive look back at the various vignettes and their respective analyses with a further reflection on the reflections in light of the whole. Thus we achieve some measure of iteration and depth to the thesis as a whole.

Conclusions

This part of the thesis offers an overview of my journey, and reflection and consideration of lessons I have learned along the way. It will also illustrate how the various strands of the Doctor of Professional Practice programme have been completed. The way I will do that is by revisiting the vignettes in a condensed form to bring you back to the intentions expounded in the introduction, to where we are in relation to those intentions, so that you may experience the journey alongside me.

Within the Abstract, I first mention some of the challenges I encountered in the course of this journey. These were personal ones, such as having to take time out from my studies to attend several short and then one long courses of psychological treatment with Combat Stress in Leatherhead, or suffering from physical disabilities curtailing ease of movement, and having several heart attacks leading to hospitalisation. All these events disrupted the flow of my studies. Then there were more general ones, such as the denial, blocking and obfuscation encountered from not only various officers and service providers but also, perversely, from some service users themselves who were suspicious of my motivations. There were difficulties of access to hard to reach groups. For example, I had no access to groups representing for example younger people, LGBT, immigrant, or Romany and Traveller people. This was not through lack of trying. Indeed, we in the Dorset Mental Health Forum devised various strategies and working groups over the years to engage with disparate groups such as these, but we found they either were not

interested in joining with us – and this was particularly true of the younger people - or, which proved much more likely, were found not to exist in any organised form in Dorset. Those very few overtures we managed to make to individual sufferers of mental distress who might be considered part of such communities were not successful. The upshot is that this study is based quite squarely on a population of white, British men and women of voting age and older generally settled in either rural or urban communities within Dorset

At the beginning of the thesis, I explain in narrative form how I selected autoethnography as the method and the methodology for this study, and how it morphed over time to become original research of myself in the role of Service User Representative or SUR. Latterly, through development of my practice as a result in no small part to this doctoral study, I end the thesis study period as a Consultant Peer Specialist with the Dorset Mental Health Forum. I show how I decided to explore the route I took through the early days of the Doctor of Professional Practice course to come to the decision to progress my work as I did. This progression from first becoming a service user and having lost almost everything once again, to completing a doctorate in professional practice, to being promoted to a Consultant Peer Specialist within Dorset Mental Health Forum, and being recruited, employed, and successfully acting as a tutor with the Expert Patient Programme, and also as a Mental Health Act Hospital Manager with two NHS Trusts, offers, I would argue, a chronological evidence trail of professional practice development.

Autoethnography is a research tool that allows me as the researcher to reflect on and draw conclusions about my life in my particular social setting. I have used it to look at myself as I progress from becoming a mental health service user to morphing into a service user representative, no longer merely a survivor but a ‘fighter’ of (and, to some degree, within) the ‘system’, an advocate for other service users who perhaps have not travelled as far along their personal recovery paths or chosen a different route yet still want their voices heard in discussions regarding them and their lives. However, it is important to remember that this study has been about me, the researcher/writer, not other people. What I report on and reflect on, and must be ethically aware about, is primarily the effect the study has on me. Purely to illustrate this process, there may be times where others’ views have been indicated in the

study, but only as a means of illustrating to the reader the process of reflection and modification going on within the researcher/writer, going on within me. I evidenced how I do this, and it is to treat my area of operations (decided jointly between myself and DMHF leadership) as a constituency much as a politician might. Within this physical or virtual constituency are necessarily constituents. I position myself so as to meet as many of them as I can, canvas their views, relay information and news to them, and reflect on and carry their views and concerns to decision makers in the health and social services, as well as to other service users and SURs. This autoethnography is yet another tool towards achieving these goals.

I then consider the ethics of autoethnographic writing and how "doing no harm" is as applicable when applied to oneself as it is when applied to others. Autoethnography is looking at one person, myself, and as such my ethical considerations need to be cognisant of the effect the study may have on me as well as the impact on those I have reported within the thesis. The stance I take, the ethics I use has been developed through life experience, reflection, and reading. I have been particularly swayed by Frank (1997) and his concept of *narrative ethics*, being that ethical stance that is about thinking *with* stories rather than *about* them. Coming from this angle, considerations about how one's writing can affect oneself and others may be seen as paramount when conducting this sort of research. Both Ellis (2004, 2009) and Muncey (2010) agree that this consideration of ethics lies between the author and the reader with both being affected one way or another, and that allowances and considerations must be given to this when writing up one's research. I felt I had to choose among the different models of ethics, modifying what I'd read to tailor my ethics to my needs. I needed to be comfortable within myself in the choices I made so decided that my ethics should be soundly based in the Western Christian utilitarian principles with which I have been brought up, and that I must work from specific cases back to those guiding principles in reiterated style to ensure that I have not caused harm (*primum non nocere*) to either myself, to others, or to the academy. It was always incumbent on me to have a clear view on the boundaries on what to use and what not, what information to use. Throughout this part of the research, I draw on relevant references from the literature around the subject to help expand the various areas of research.

As mentioned above, continuing the narrative report I undertake original research looking at elements of practice progression in how I became a user of mental health services, and offer various vignettes to try to develop in the reader an understanding of how I came to be as I am. At the end of each vignette I offer further analysis referring to relevant literature as the narrative progresses. I explore the differences between being a SUR and being a service user. I explain that, for Dorset Mental Health Forum at least, a SUR is much more than just a service user espousing his or her views, but someone who professionally gathers the views of other people who use the services and uses these views to give colour and depth to his or her work. Each contact with the service commissioners and providers as an SUR is wrapped about with psychosexual and gender role issues, interpersonal and interagency negotiations, continuously combating systemic stigma, and social positioning among self and others, all of which must be dealt with as they arise, and often several at a time.

Word limit constraints on the production of this thesis inevitably means that several aspects of a SUR's life are not explored to the full and some not touched on at all. The reason for this is because they weighed less heavily on my particular story, my personal experience, which is what this autoethnography is, after all, all about, but some aspects bear mentioning here to illuminate some of the darker corners of my life.

Existentially, there are aspects of becoming a SUR that can weigh heavily on a service user, and one who wishes to be a SUR must be prepared for these. I was lucky in certain respects in that I had undergone mental health nurse training and worked as a healthcare manager, and had the benefit of a bachelor's degree in psychology, before I became ill. This gave me grounding in the sort of work we might encounter as SURs when we first started out as well as a certain insight into the types of person with whom we might be dealing and how their problems might show themselves. I think to a certain extent it also allowed me to exercise a greater degree of educated compassion than I might have had I come to the work directly from the Army. However, we were all very new at being SURs in those early days and that basic training, although helping me with my self-confidence and background knowledge, soon became rather irrelevant to the work in hand. SURs are

not engaged in formal therapeutic work and are not empowered to interfere with the work of any clinical professionals they come across. This would be highly unethical. Some workers see your regular attendance as a member of key meetings and committees as the same as having what they perceive as privileged access to ‘the bosses’, consequently seeing you as a bridge to decision makers within the statutory services, someone who enjoys access to certain decision-making groups. When this happens, this indicates to me a failure in their own management communication structure. I encountered this most blatantly with a psychiatrist who was trying to make his preferences known regarding the remodelling of the ECT suite at Forston Clinic during the time I was engaged with the Kings Fund, where he made several strong suggestions during our supposedly therapeutic consultations for me to take back to the Kings Fund team in order that his ideas be passed to the Trust Board via us, an almost back-door intervention. Others are more subtle and use their meetings with you to gently question you as to what happened in this or that committee, or what the future might hold in certain settings. This happened a lot during staff and services restructuring exercises, where workers were fearful for their jobs and yet their management structures were in such disarray – or just so badly managed – that their only source of information about their own professional futures was me, the SUR. This disgraceful lack of management skills seems to pervade the services and points to a lack of basic management training. My opinion on this is based on years of successfully filling various management positions myself, one post as a registered nurse manager in charge of a prison healthcare centre’s operations.

Other service users sometimes see you as either a busybody to be avoided or someone who can help them get what they want (as evidenced by the vignette about the lady I met during an Expert Patient session, which was fine), if they consider you at all. Some, no matter how much you try to tell them otherwise, see the SUR as a person holding a position in

a rank structure. This is vigorously opposed by right-thinking SURs as it leads to division and a lack of flow of information (when I was feeling a little wicked, I would introduce a colleague as ‘my boss’ and enjoy the consternation on her face). There should be a flat management structure where each person knows his or her place with concomitant expectations and jobs in the organisation, and where no one person is ‘above’ any other. The *Outside World* likes to see a ‘CEO’ or ‘Chief

Executive', but this should be in title only and not a social fall-back position whereby one person wields all the control, takes all the 'plum jobs', and does not delegate, does not feed the machine. Power, as explained by Foucault - 'Power is everywhere' and 'comes from everywhere' so in this sense is neither an agency nor a structure (Foucault, 1998, page 63) - exists within the body of an organisation and that organisation acts almost as an unconscious organism to elevate certain more skilled parts of itself to positions of authority. 'His [Foucault's] work marks a radical departure from previous modes of conceiving power and cannot be easily integrated with previous ideas, as power is diffuse rather than concentrated, embodied and enacted rather than possessed, discursive rather than purely coercive, and constitutes agents rather than being deployed by them' (Gaventa, 2003, page 1). Such preferment should not be seen as carte blanche for that person to run rough-shod across the heads of the rest of the organisation, or the result will be that the organisation will become dysfunctional or break up altogether. As has been seen above, this is evident in the social services and NHS and is certainly not needed within a democratic organisation like DMHF, or similar, where one of the primary major functions of the organisation is therapeutic mutual self help. There is also in-fighting within and between groups of representatives where there should be none. Such antagonism was evident when we went to visit a service user group in the east of the county leading to my discussion of rudeness in communications. To unpick such rivalries would need another thesis.

Having examined the negative existential aspects of being a SUR, it cannot be denied that there are positive aspects as well. The main one, I believe, is embodied in that of doing the work itself. Being entrusted with the work of a SUR endows one with a certain amount of self-belief and self-reliance. A SUR is, to a large extent, expected to do his or her job, both by other SURs, other service users, and the statutory services staff with whom you engage, especially their senior management. This is not to say that the SUR is expected to become as one with the professionals, but it is commonly expected that the SUR pursue his or her work with a professional mind set as described in the text. The development of this level of trust is a slow but sure one through carrying out one's promises, following through on jobs, and so on, entrusted to you. This entrustment is key and can be very therapeutic. Serious mental illness, when it strikes, often destroys the sufferer's life, often strips the sufferer of

most if not all their social supports and sometimes can result in that person losing the majority of their material possessions, their jobs, their families, and their self-respect. Becoming an effective SUR can often slowly move such a person back towards a reality that has more to do with self-belief and less with believing what others think of you, of developing a new base from which to grow and to begin to develop a new reality. Ultimately, this can lead to a re-engagement with the work-a-day social world, developing a new private life, and ultimately a disengagement with the mental health world and a move to a new reality. This is the major positive power of becoming a supported and effective SUR.

It has been through reflecting on my performance during my work, in great part using the methods and tools I have gained during this course of study, that I have been empowered to finesse my practice and progress up the career ladder to where I am today. Without this reflexive drive, I would not have achieved the successes I have to date.

Being a SUR is highly skilled work when done in the right way, and it is proposed that it is this right way that the narrative illustrates. I use narrative as a conduit to explain my understanding of my original research, the story of my journey from service user to SUR. I take into account how my practice has developed alongside the development of the *Big Lotto* funded SUR project of the Dorset Mental Health Forum. Gone are the days of ‘rolling out the dribbling idiot in the corner’ for his burbled views just to tick a box, although I have heard that this still happens in other regions. The message is that to be useful to our professional colleagues, SURs need to be intelligent and articulate professionals in their own right, trained in committee work and negotiating skills, steeped in the views of their peers and the aims and values of their organisation, and be able to act as critical friends. How they obtain these views, the methods they use to upgrade their own knowledge of their mental health condition so as to be more conversant with the way other service users are affected by the stigma and labelling a society gives them, and how this affects them day by day is very interesting in its own right and forms one of the main areas of this study.

There can be no doubt but that becoming a user of mental health services is a

challenging and life changing event and so it has been in my case. Aspects of the way this has come about can be of interest in their own right, but is pertinent to the development of this narrative. This is why *Hands and a Grenade* was included. As an anecdote of war, it explores an event and its long-term effects on me. These effects have included altered affect and numbness, anger, a lack of self esteem and love, and an almost disastrous destructive urge. This story and its analysis was followed by *The Final Straw*, the story of the final car crash of a series of three, which experience sent me over the edge and "switched on" my PTSD and clinical depression. Both these vignettes are analysed in the light of relevant research but are included to offer some sense of the degree of doom that some service users experience in their lives. We do not choose to become mental health service users. It is not a lifestyle choice. It is arguably the vagaries of fate that put us in a position of tremulous hopelessness and helplessness where anger and self-destruction seem to be the only positive forces acting on us – at least, on me.

Having offered two stories from my life to try to illustrate the route to becoming a mental health service user, I then turn my attention to the effects of the mental illness. In trying to explain how PTSD pervades every part of my thinking, I offer *Where Are the Sirens?* in which we see that even the simple act of relaxing on holiday can be disrupted by the action of flashbacks taking your mind to past events and emotions and allowing them to have an effect in the present-day. Such distractions can have varying levels of disruption to daily life ranging from unpleasant memories to total dissociation. Reflecting on these events allows the reader some insight into the internal struggles I suffer daily and have suffered for years. The severity does not diminish, just the tools needed to deal with them are learned, and then sharpened and honed with practice.

The loss of libido through medication side-effects is discussed next. It is explained that it is not a purely sexual matter but one of acceptance and love. Often the medication steals one's libido and this can seem to a partner as if it were an aspect of the mental problem causing distance and coldness way before closeness warmth were before. This is often a hidden side-effect, as many people become distressed and embarrassed when faced with discussing their sex lives. I became angry and express this anger to the reader and I do not apologise for this. It is part-and-parcel of

an autoethnography to examine one's 'inner workings' and anger is one of those. Being British, it is sometimes seen as somewhat tasteless to discuss a person's sex life, especially if the questioner is of the opposite sex, but it is important that this intensely personal subject be broached so that help in some way might be offered.

Dissociation follows, where I describe a journey through a dissociative event written to illustrate how, often, control is totally lost, and the effects that this can have before, during, and after the act, both to one's self and on oneself, as well as on others. Dissociation can have a devastating effect on one's life, especially if you rely on your senses to carry out your work, such as when I worked as a professional driver, or as a bomb disposal officer. As might be imagined, any loss of contact with reality, perceived reality of day-to-day living, could be very dangerous for me. Indeed, it can be very uncomfortable if you are in a non-occupation, such as being a full-time mental health service user 'on the sick', a 'benefit scrounger', a 'skiver' rather than a 'striver' as the latest rhetoric would have it. The analysis which follows calls on relevant literature to explore dissociation and make it a more understandable concept for the general reader. I come to the end of this section with a look at self harming, about myself in particular, and more generally. Again, this is followed by a more in-depth analysis.

As a way of ending one section and beginning another, I offer *Medication Changes* wherein I discuss power differentials and how the medics wield their influence over their patients by examining how it happened to me and what I thought about it. It is illustrative of the medical model in practice. The analysis that follows this looks more closely at the subject of power and how it is used and abused with regard to mental health service users. That power corrupts is axiomatic, but a person does not need to be in a position of absolute power for that subtle corruption of sensibilities and world view to take place. This changing of sections is also illustrative of progression through a practice development project based on original research and analysed in the light of relevant references. This particular vignette demonstrates the narrative nature of this report and how it connects the two sections together.

The next section looks at original research into how SURs can help other service users even when they are not acting as an SUR but working in a completely different

area. The story about *Widening the Net* illustrates how a SUR who is alert to the needs of others can be effective when working away from role. Mental disorder does not leave you when you are 'out of role' but remains with you as a constant reminder of your frailty. When it is exhibited in another, there is a sympathetic connection to how the other might be feeling and so a connection is born. It is along this connection that fears and worries flow, switching on one's protective, 'want-to-help' neurons that leads to our working as SUR 'out of role'.

Death in its many forms is a constant presence in everybody's life, but death can be felt more personally and significantly by people suffering mental distress. They are much more likely to harm themselves than others, and such harm can often result in either accidental death or deliberate suicide. Thus, a story on how the suicide of another SUR affects us. *Death of a Service User Representative* is followed by *Facebook Support Session*, both of which explore aspects of the effects that such a tragic death can have on the service user community and how peer support is sought and given. Often such support can be fleeting and subtle but sometimes more specific help is needed. At such times it is useful to reach out to those one suspects may be affected by this and offer help in whichever way is appropriate. It is described in these two stories how this help was offered to, and given by me when the time came.

Having offered several different facets to this part of my narrative, I then lead you through a series of more mature SUR reflections, showing professional progression, wherein I explore more esoteric subjects such as the *Conversation with Harry*, which expounds the rarely heard views of a service provider on the effects the attendance of a SUR can have on a group of professionals in an executive meeting, how the mere presence of a trained SUR holds the other members in that meeting to account, in that they must follow words with action. Such insights are rarely discovered and all the more valuable for that. *Harry's* honest disclosure continues to help SURs and Peer Specialists with understanding how powerful their presence can be in a meeting, especially when they are feeling powerless and despondent.

The narrative continues with a description of a training session by two SURs to statutory services workers wherein aspects of recovery are discussed and mental

health issues are compared with other 'hidden' diseases such as diabetes and cardiac problems. Audiences are always very receptive to these concepts and consider the training sessions as useful and beneficial, and certainly not just a chance to relax away from work for a day. This is evidenced in the overwhelming number of positive feedback reports we get from them at the end of each training period. Both the positive and very few negative comments are all fed back into the management systems of the people who commission us to deliver the training. As our contract hours come to an end, these positive and negative aspects of each course are summed in a report and they inform any future decision on the part of management to re-employ us, via the Forum, to deliver future courses to their workers. As these organisations pay a commercial fee for us to educate their workers, they would not do so if they believed they were not getting value for money. Our greatest accolade is to be employed.

Beyond this vignette is a report on two trips I made in 2006 and 2007 in support of the King's Fund's *Enhancing the Healing Environment* programme with reflections back to an earlier training session that I had undertaken and its feedback. This report shows the national reach that even a smaller service user charity can have on the mental health world. Followed by subsequent reflections on the uses and abuses of name badges, I explore stigma, power relationships, fear, and presentation of self. These reflections are based on my original research, I also offer a systematic review of the pertinent literature, and my professional development during that period, all held together in a narrative report. I found working outside Dorset a very rewarding, self-empowering and informative process. I was able to bring our values, ways of working, and experiences to the wider SUR community and return with a sense that perhaps we in Dorset are not that badly off.

This is followed by a more in-depth discussion on presentation of self in everyday life; how wearing the right clothes, and badge, and being well-prepared, and clean and tidy, and being on time, and knowing how committees work, and so on, all enhance one's effectiveness as a SUR. Such considerations revolve around concepts of them-and-us and being seen as members of an in-group rather than people outside. Although such considerations may be considered shallow, in many ways they work to regulate and modify our working environments and must be seen as relevant to the

work of SURs. References are offered throughout the narrative report to aid in further research and reading but the main lessons are within the meat of the section wherein the wider concept of self-empowerment is found to be rooted in a sense of self-worth and personal value to others.

This part of the thesis is brought to a conclusion by a short story on how SURs can affect other workers by a bit of thoughtfulness. In this case, I enhance my standing with the workers at a social services day centre by offering to help them erect their Christmas tree. As I had a bit of time to spare, this was no skin off my nose but the results on subsequent visits were more than well worth it. It is a small but important point that, as a SUR, you are in the public gaze representing your organisation at all times. What you do can enhance or detract from the organisation's corporate image. This can have effects far into the future when management personnel are looking to employ the voice of the mental health service user representative in their decision-making.

I look at the DMHF *Reach Out* campaign that employs and supports people with lived experience of mental health problems ('Experts by Experience') into paid employment as, previously, SURs, and now Peer Representatives and Peer Specialists. I was at the beginning of this way of working, helped plant the seeds and nurture the soft and fragile growth of the system, planning and implementing alterations and additions, shaping a solid foundation of good will and the concept of proper support and reward for SURs for their work until it has blossomed into the strong and vibrant tree it is today. This example of a peer support model is offered to other organisations as an exemplar, an excellent and cost-effective way not only to support service users in their efforts to become volunteer representatives, often leading to paid employment with the Forum and ultimately elsewhere, but also to maximise the benefits they can offer through their insights to the organisations that use them to guide their service provision decisions whilst supporting them in their illness. Each step of the way, I draw on research from relevant publications to support my narrative.

I end this part of the narrative with a short story demonstrating how I achieved peace of mind with my new partner. This is offered as a way to end the narrative on a

positive note.

So, what is generally emergent from this large amount of material? The answer is, of course, “a huge amount of things,” and many of these things are dealt with as we progress through the chapters. In general though, the first issue that I try to explain is that there is a core of anger running through the text. Anger also underlies the work of SURs. It is not the raging anger of a cuckolded husband but the cold drive to make life better for oneself and one's contemporaries. I go on to looking at the large number of facets that go to making the story, indicating the complexity of the life of a person accessing mental health services. He or she is not just “that manic-depressive over there” or “this schizophrenic here”, but a life lived through a detailed intertwining of mental health challenges with every aspect of a sufferer’s daily existence, colouring everything he or she thinks and does. I look at the array of things that interact with the person on a material level, such as iatrogenically-induced sexual dysfunction through medication side-effects or the debilitating effects of dissociation and PTSD flashbacks. This has all to be controlled and minimised in ways peculiar to each individual, and how all this is dealt with on a day-to-day basis can be very interesting.

One way is through the use of medications and other mental health interventions such as Cognitive Behavioural Therapy. These are designed to give the sufferer some control over the symptoms of their illness, so that they can continue at work, or a return to work can become possible, or at least can be contemplated. It is also apparent that employers may need to give some thought to making adjustments to a person’s work environment and conditions to try to accommodate the symptoms of such distressing illnesses, and thereby help to keep the sufferer in his or her work place. This is because it has been evidenced, so that there can be no doubt, that remaining in work is the best thing that can happen to a person suffering mental health problems – as far as possible, of course.

It is heartening that it is becoming widely recognised that satisfying work and remaining useful in the workplace can be of both personal and corporate benefit, as well as benefiting the country as a whole. This has been recognised by many businesses in Britain, such as BT and RIAS, who see retention of the workforce as a

cheaper option than continuously recruiting new members and training them up. For the country, it is cheaper as a whole to have taxpaying active workers rather than people languishing on sickness benefits for a long time.

How the Dorset Mental Health Forum deals with the more difficult end of the spectrum of mental distress is fascinating and a model recommended to be followed in other regions. That there are other models of service user representation and involvement is clear but I have yet to find one in the UK that emulates theirs. For example, Julie Gosling tells of her 20 years experience inside a user led organisation called Advocacy in Action (AIA) based in South London, described in detail in chapter 2 of the book "Mental Health, Service User Involvement and Recovery" edited by Jenny Weinstein (Gosling, 2010). Although AIA operate under a different system to DMHF, she describes similar challenges to ours:

"At AIA we quickly learned along the way that speaking your mind was OK, was rewarded even, when you were involved in mini-decisions such as what colour the walls of the day room should be painted. But when people spoke out against the service itself and demanded alternative types of solutions, the advocacy facility was curtailed; it was no longer necessary or desirable for people to be involved. Advocacy, empowerment, involvement are apparently OK as long as they are toothless! The system appears to be unable to deal with threats; it draws in and ingests what it finds palatable and spits out everything else. The outcome is a diluted compromise that disappoints and disempowers those service users who believed they were being involved and consulted."

(Gosling, 2010, page 41).

Reading her story, and seeing that AIA's systems of service user support are so different to DMHF's, yet their challenges are much the same when working with providers, and having discussed the same issues with service user representatives from Merseyside and Manchester, Cumbria and Cornwall, this illustrates the fact that mental health service user involvement and representation problems are ubiquitous in England. The model offered here of paid and supported SUR involvement

purchased by commissioners, albeit for perhaps only two hours a week to begin with, is a step further than AIA or others have gone. I think this has to be developed a little further in a perhaps more personalised style to bring to the front some pertinent lessons.

Whilst it is true that it can be entertaining and educational to read stories of other people's lives and troubles, the most important message offered herein is that describing a model of mental health service user support and encouragement, of an SUR organisation such as demonstrated by DMHF. No matter their sources of funding, these organisations have to be run exclusively by service users for the employment, training and support of their SURs.

Any 'stray' SURs found working alone outside the organisation must be encouraged to become assimilated within the organisation by both other service users and service delivery staff, the medics and so on. This does not often happen because there are service deliverers who always seem to 'know best' and refuse to cooperate. They have misled themselves. It should be emphasised to them all that this is for mental health and safety, secured through supportive association with like-minded people, as well as to maximise the service user representative product for the SUR organisation's customers. Further, the SUR 'message' must not be diluted by personal misconceptions and vendettas, as sometimes happens. As an example, I know of one individual brought in as a SUR by a NHS Trust to bring her own personal agenda with her and have no other viewpoint to offer. This person also presented in such a dishevelled way as to reinforce a stereotypical perception of a mental health service user thus tainting staff perception of the SUR's message. This is not good for the furtherance of service user involvement in the planning and development of local services, and such behaviours should be strongly discouraged by all.

With proper training and support systems in place, the SUR message will be more unified, and, further, those sometimes-found destructive people will be allowed no niche or edge to be able to prise apart such a unified front. Who might such people be? Well, apart from disgruntled, disaffected or disordered service users and carers, of whom there are many, there have been instances of deliberate interference from

statutory services' senior management and sometimes, surprisingly, medical staff - who one would much prefer to find working to the benefit of service users rather than against them. Of course, those of us with a jaundiced mindset might feel that there are some people who have a will to power and just enjoy flexing their muscles at those less powerful than them (I have observed a male nurse flinging a disturbed patient bodily into the corner of a side ward, so they do exist even in nursing), but the more forgiving of you might think that such people truly believe they are doing what is right and best, even against the evidence all around them (and now within this thesis). Their effects should still be guarded against. Such are some of the ill effects of induced ideology and incorrect training (as discussed above with regards to what I consider to be the outdated but socially ingrained views of Irwin Goffman).

As has been discussed at length, such association would allow the SUR organisation's management team to formalise as much as practicable, through regular feedback, supervision, and externally- or internally-sourced training sessions, the skills needed for effective SUR committee work including personal presentation, standards of dress, and so on. Such uniformity builds confidence by engendering a sense of belonging and team pride, of team working, within the SUR, and a feeling of confidence in the quality and consistency of the SUR product within the customer base. But why should this be? It is rather obvious that we mental health service users are not 'Normals' in the Goffman sense but carry many psychiatric and social burdens as described below. Some might think that these would be unusual to be found in the staff employed by the services. However, I have found that the recognition of such 'hidden talents' can be of great benefit within their working environments, and that such staff should be supported by their organisations into utilising their insights in their work with their service users.

Mental health service users like me labour under extra stressors to other sufferers of ill health, many of which lie hidden from the casual observer for the most part. As explained, also often hidden is the effect of the power imbalance between service users and service providers. No matter the care taken by providers, doctors and AMHPs and so on to minimise this effect, it persists. As demonstrated by my story of visiting the GP, there is often a misunderstanding among us service users that we might be 'sectioned' at almost the drop of a hat, should we step out of line. For most

of us, this, of course, is untrue, but the belief persists as a nagging doubt modifying social interactions. These fears are rooted in a long history of mental health service users becoming institutionalised through our contact with the services. Proper support and training from a SUR organisation such as described can help alleviate these fears and break down the effects of any potential institutionalisation. The positives of working as a SUR, however, far outweigh the dangers, the negatives, all of which can be guarded against through creating a support organisation such as DMHF using the model as described.

I have found that my employment as a SUR over the years has increased my self-confidence and widened my social milieu, not only within the mental health world but outside it as well, thus opening opportunities in the wider world. For a small example, being accepted as a SUR in the early days encouraged me to try other routes to inclusion back into a world I truly believed had forsaken me. I identified an opportunity to help with my local Parish Council and explained my psychiatric and health position to them during my interview. They were not bothered by my medical history but wanted to use my strengths. I was co-opted as a Councillor within a short time, opening avenues into other local non-mental health social circles. This reflected back and encouraged me to participate more fully as a SUR and I increased my working hours a little, and this cycle continued to the benefit of all over time until I have arrived at where I am now. Another example or two? An effective SUR developed to the point where he felt able to leave DMHF and take up a full-time administrative post with another local non-mental health charity, and a key SUR has moved on from a beginning as a tea and sandwich maker in one of the Forum cafés in North Dorset, through a position as SUR and then a manager within DMHF, to take up a senior position with a national charity in London. To say that opportunity knocks for trained and supported SURs is not too strong a statement when those SURs can demonstrate an ongoing work ethic and training history within a supportive organisation like the DMHF.

To sum up a little, this study is offered as original evidence that the model described herein is both viable and acceptable to those statutory authorities who value SUR input and are willing to support this form of self-help organisation. This particular structure offers support, training, experience, and specific-to-area knowledge for the

SUR from other more experienced SURs in a non-threatening, welcoming environment with the built-in reward of payment for services rendered. I think I have shown that the product of this form of organisation of peer support is also perhaps of a richer and deeper nature than that from the most well-meaning individual offering his or her services as a representative of a group of service users. The story of how successful the Dorset model has been might be pointed to as evidence to be used by other areas and fledgling service user organisations as justification in their bids to achieve similar outcomes.

As has been stated above, the purpose of this thesis was to describe the development of a SUR model that works well in Dorset. That model being one of SURs acting as paid employees of a ULO. The ULO would employ officers to ensure the SURs are supported in their work and, similarly, ensure a consistent level of quality from the SURs in their work. Funding would be sought from the ULO's customers, and this funding would not be dependent on the ULO pursuing the customers' agenda.

When all this has been successfully achieved, the useful tools that come out of this new learning will be suitably promulgated via the appropriate media. I believe that this thesis would easily transfer to a series of articles in subject-specific journals such as *One in Four Magazine*, *Mental Health Practice Magazine*, and the *British Journal of Mental Health Nursing* to name just three, or even a book directed at mental health service users and their representational communities around the country, firstly, to offer other people who might find themselves in equally difficult circumstances as I did, that there is a light at the end of the tunnel (and, no, it is not a train coming towards you!); and secondly, that such a model of paid SUR peer support and involvement can indeed be generally serviceable to those individuals and statutory organisations looking to enhance their service user voice.

Critique and Limitations.

I end this thesis with a reiteration that my original contribution to research in this area has been that through the medium of autoethnography I have described the

development of a service user representative model via my journey through the mental health service user's world. I now look at how authentic and trustworthy this model is, and the limitations from which it suffers. I offer the reader some measure of how my findings are transferable to the wider world, in particular to that of the mental health service user or psychiatry survivor who would like to become a SUR.

As an autoethnography, this is necessarily a description of an individual case and, as such, generalisations, even if statistically meaningful, would have no applicability to it, the 'nomothetic/ideographic disjunction' (Guba and Lincoln, 1994, page 106). Criticism might be laid that the thesis' methodology leads to a lack of trustworthiness in its findings in that the areas of credibility, transferability, dependability, and confirmability are weakened by an autoethnographical approach. I beg to differ, as I have demonstrated how such factors are enhanced by the personal approach to the subject, populating it with more normally inaccessible evocative and rich data. As to authenticity, I have written fairly from my own standpoint as a mental health services user but have ontologically and ethically widened my discussions with reference to my reflections on the anonymised and in some cases combined observations of other such services users and survivors within the analysis parts of the various vignettes, leading to an improved understanding of the work of others, and as a stimulus and empowerment to action.

With regards to the limitations of my study, I have endeavoured at all points to allow contrary viewpoints to obtrude where necessary and applicable. Such concerns that autoethnography is 'self-indulgent' and so on have no meaning to me. I know that, were I to be self-indulgent, that my library of vignettes and poems is much wider than those offered herein. They await publication elsewhere. This thesis contains only those deemed necessary and relevant to the development of the argument embodied by the offer of the model of service user interaction delineated towards the end of the paper. It has been closely supervised by my highly skilled, educated, and challenging supervisory team, and they would most assuredly have flagged up any deviations into self-indulgence on my part.

As was stated above in the Background Section, further reflections on the disadvantages of using a qualitative method reveal that various factors should be taken into consideration. The demands of qualitative research and especially

autoethnography on the researcher are clearly onerous and can lead to a temporary worsening of mental health, but this has been shown to also work in the other direction. Qualitative research also fails to provide factual information such as the numbers of service users who become SURs in a particular area, or measuring the impact SURs might have had on the quality or provision of services. Influencing practice and policy often relies on this as its 'evidence', particularly around the notion of effectiveness in services or treatments. However, qualitative research cannot usefully 'test' efficacy in that different parameters and measures need to be taken requiring the use of a different methodology. Further, as was mentioned, NICE currently maintains a Positivist stance toward evidence. This is lately starting to come under challenge as reported in the press. This is because the evocative power of subjective lived experiences revealed through qualitative research is beginning to have an influence, particularly in terms of mental health and wellbeing and around the privileging of the service user voice in shaping and delivering services. It must also be cost-effective - without any 'proof' being offered here beyond the lived experience observation that financially hard-pressed Healthcare Trusts and Councils continue to use and pay for our services.

I also acknowledge that the scope of my thesis has been limited by my day-to-day and working life as a SUR. That said a core aspect of the offered model of service user representation is that it is flexible and adaptable to circumstances beyond those described herein.

The original contribution to knowledge that I offer is the study of a life led within the mental health services in a county in England, Dorset, a mixed environment of rural and urban areas, through a rigorous investigation of my practice. The model of service user representation I have outlined and advocated is that in use for the past few years by DMHF and works well. This is shown when services users have 'gone it alone' and become despondent, with one ending her life in despair.

This research has shown that this model of peer supported service user involvement is both practical and utilitarian.

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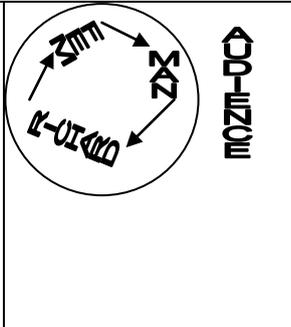
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Appendix A

Playlet

<p>START</p>	<p>Starting line-up as shown. It is debatable whether to have the audience in a circle around the speaker or as shown. Either way, the object of the clockwise rotation is to present a different face to them each turn so that they do not begin to feel that any 'One' is speaking 'to them'</p>	
<p>MAN</p>	<p>SHIFTING FROM 'MODEL' TO 'SOLACE' we begin at "LISTENING TO PATIENTS: TOWARDS DEVELOPING A MODEL OF SERVICE USER REPRESENTATION"</p>	<p>Commanding voice</p>
<p>FEM</p>	<p>There is a knot within, a hard place that lies deep inside the layers of life, a nut suspended above and away from any contact yet closely guarded and surrounded by layer upon layer of softer, more disposable me. The secret is to be able to fashion a safety net below the nutshell so that when it finally breaks down, the contents will only fall safely into the net.</p>	<p>Gentle, soothing, empathetic voice</p>
<p>RICHARD</p>	<p>I recall sitting here among you and feeling very lost and alone. I was the dummy and you were all so very bright. You knew what you were doing and I was lost and alone.</p>	<p>Matter-of-fact, 'telling-it-like-it-is' voice.</p>
<p>MAN</p>	<p>Albert Einstein once said: "The intuitive mind is a sacred gift and the rational mind is a faithful servant. We have created a society that honours the</p>	<p>Cold voice. Academic. Brisk. Business-like.</p>

	servant and has forgotten the gift."	
RICHARD	I had spent years of study honouring the servant of Modernism and disavowing the Postmodernist within. A look at my Masters dissertation threw some light on my discomfort, but at that time just a glimmer.	Matter-of-fact, 'telling-it-like-it-is' voice.
MAN	DISCUSSION: This study aimed to conceptualise an information-processing model for the underlying psychology of the decision to speed. Our results, although exploratory, present preliminary evidence for a four-fold structure based on the right-angled interaction of two continua – Cognitive-Affective processing and internal (Self)-external (Other) generated cognitions and emotional responses.	Cold voice. Academic. Brisk. Business-like dropping into almost an automaton's monotone. Boring voice.
RICHARD	I felt uncomfortable, and my study had removed statistical outliers and a selection of voices that had been scribbled across some of the questionnaires.	Matter-of-fact, 'telling-it-like-it-is' voice, seeking understanding from others.
MAN	A driver's cognitions are loaded with more or less affect, resulting in either positive or negative feelings (anger, thrill from speed, enjoying the feelings of control), due to the behaviour of others, or due to a consideration of one's Self and its needs – a complex and dynamic system energising moment-to-moment driver decisions.	As before. Continue monotonically.
RICHARD	And still I felt discomfort. And still I ignored it. I wanted to complete my education and I had also been using study as a form of social therapy. I had	More energetic. Quicker. More life. Trying to explain

	started as one of the Prison Service's bright young things. Then I had a breakdown and lost everything, including my will to live, except for family and one steadfast friend.	why this happened.
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ROTATE THE GROUP : CLOCKWISE, ONE PERSON

FEM	A poem written by Richard in 1999: 'TODAY AND TODAY'	Crisp and business-like.
RICHARD	I had lost my house and was living in a rented flat found for me by the mental health services.	'News item' delivery. No soul.
FEM	There is a certain person that I seem to need today; The problems that erupt within won't seem to go away. <i>When you feel bad then you must phone us up, they always say,</i> But then what happens when today is everyone's Rest Day?	Crisp and business-like voice. Tone of someone 'telling it as it is'. <i>Italics in a higher, nurse-knows-best voice.</i>
RICHARD	My job had gone as well, so I had no aim, no goal in life. I had just finished my Masters and was now alone with my thoughts.	Sadder. Less enthusiasm. See a chasm in front of you.
FEM	<i>The Samaritans are there for you, so everybody say,</i> <i>As are your friends and family - they never go away.</i> But you don't want your friends to feel all sad and blue today, And what d'you tell a stranger who just might not	As before, but breaking slowly down. <i>Italics are in a relentlessly nurse-like tone</i>

	go away?	
RICHARD	I joined the local Parish Council and started to do a couple of hours at the Dorset Mental Health Forum offices, licking stamps and so on.	Losing hope slowly, but trying to appear brave.
FEM	To take a chance, and bare your soul to someone miles away, When anything could happen? They might try their best to sway You from your planned demise, when all you wanted was a say; To have a listening ear for you - and no-one else - today.	As before, but breaking slowly down.
RICHARD	I had swapped a nurse for a social worker, and he was truly socially-trained. He brooked no nonsense and set small realistic goals for me. I also took steps towards a second Masters.	Bit more hopeful. Help is on the horizon. The cavalry are coming.
FEM	So, <i>Soldier on! Work at your tools!</i> and other things else they say, <i>Today you have survived the call!</i> Today. And then today. For everyday will be today. And today yesterday. And tomorrow, when it comes all gay, will be again Today.	As before, but breaking slowly down. <i>Italics are in a relentlessly nurse-like tone</i>
RICHARD	All the way through the new course, I was uncomfortably aware of the people the skeletons had once been, almost as if they were looking over my shoulder as I measured and weighed their dry brown bones. Having completed that to Diploma level, I was still uneasy but knew not why, so I	Puzzling over a new discovery. Reportage. Business-like yet seeking approval for deviant

	<p>threw about for a doctorate I could try. I had to be careful of not over-doing things, so chose part-time courses. I also wanted to explore my situation and my new post at the Forum of Service User Representative, so I fell on this Prof Doc and here I was, being interviewed by Jerry first, meeting the existing cohort, and then by Carol and others around a motley group of shiny tables. I explain my ideas.</p>	<p>thoughts.</p>
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ROTATE THE GROUP : CLOCKWISE, ONE PERSON

MAN	LISTENING TO PATIENTS: THE PHILOSOPHY BEHIND CONSULTING USERS OF MENTAL HEALTH SERVICES ABOUT SERVICE DELIVERY	Commanding voice
RICHARD	I had it all worked out.	Pathetically victorious
FEM	Legislative changes are driving the development of many differing styles of service user involvement. Given, then, that “ <i>services should help to maintain the independence of the individual by giving them greater choice and control over the way in which their needs are met</i> ” (Dorset County Council, 2005), what is the best model to use to enable this to happen?	Business-like, crisp, dry delivery
RICHARD	And I was thinking big!	As before
FEM	My study would address this question from a service user’s perspective by surveying users and	Business-like, crisp, dry delivery

	providers across England, assessing and comparing the effectiveness or otherwise of each system, and drawing conclusions based on that assessment.	
RICHARD	Yes. I had it all worked out . . . then came a delay of a year before a new cohort could be found. In that period I tried to keep up with my reading of white papers and so on, and I tried too hard and fell back off the edge again.	As before. Lots of life moving through despair.
MAN	PAIN Leaden Dark shadows; Endless corridors of pain Screaming silently through time To fall on ears deafened And buffeted By life. To fall, Quietly and unnoticed, To smile, To vanish into the past And be forgotten At last.	Depressed, dull, slow, darkness engulfing you, pain in voice, knowing no one will come, alone. Defeated.
RICHARD	At last the course started and I was where we started, looking around the room at all these highly intelligent people and feeling rather out of place. I nearly ran ,but thought: “No. You have committed yourself and you will succeed in this. I was still, though, stuck with my Modernistic role.	PAUSE . . . 5 clicks. Let them sink Back to life. Sharp and quick-voiced. All forgotten and a new start is at hand.

ROTATE THE GROUP : CLOCKWISE, ONE PERSON

MAN	I would conclude with a discussion on whether mental health service user involvement in England is myth or reality, and whether this is changing for the better, worse, or is remaining static as the service providers change and mutate around them.	Back-to-business. Cold, hard science academia. Brook no nonsense.
RICHARD	I was still uncomfortable with the study design but put my disquiet down to it being over-large, covering as it did the whole of England - “enough for three doctorates,” as Carol later said. So I shrank my target down to three sites: a rural, a semi-urban, and an urban. And shrank it once again to cover these area types in just the Southwest of England. I still kept to my search for a model, though.	Wondering, trying to explain to one’s Self. A sense of Other-ness. Conversational.
MAN	I intend to finish with suggestions for best practice and recommendations for the way ahead.	As before
RICHARD	My discomfort led me to exploring Mixed Methods during the POER phase, and I realised – quite suddenly – where I was going wrong. Being an academic hypochondriac, I soon ‘caught’ mixed methods and had redesigned my studies around them. I was feeling better with the study now, but still not right. First off, though, it was RD6 time and I was not feeling too puckah, as Jamie Oliver might have it. I was angry with the whole world and it showed in my writing.	As before
FEM	The uncertainty that the NHS amalgamations and loss of effective lay involvement through PPIF has	Back-to-business. Cold, hard science

	had lends itself to more of the same behaviours, resulting in power being held centrally. Indeed, if the Government itself is not sure whether to call us service users, clients or patients, who else has a chance of clarity? A mental health-specific philosophy of inclusion would mean that those voices would be more difficult to side-line.	academia. Brook no nonsense. Very different to your last voice, more like MAN
RICHARD	But the RD 6 passed, much to my amazement, and I could continue. I now had a new title	Puzzled and amazed.
MAN	LISTENING TO PATIENTS: TOWARDS DEVELOPING A MODEL OF SERVICE USER REPRESENTATION	Quickly in after RICHARD. and quite loudly.
RICHARD	And a new central research question	Quietly, offering
FEM	The efficient representation of the aspirations and views of mental health service users in the planning, commissioning, application and management of their services requires an overarching model for those service users, commissioners, providers and managers to follow. This research is to find whether such representation and involvement is useful or would it be better overall to leave the professionals to their work, or would some middle path suit best? And, anyway, what model of representation would be most beneficial to all parties?	Back-to-business. Cold, hard science academia. Brook no nonsense. Just like the MAN voice was before.

ROTATE THE GROUP : CLOCKWISE, ONE PERSON

RICHARD	And a new methodology	A little more life,
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		not much
FEM	I think the main point is that this is envisaged as being a combination-methods research project where objective-subjective and qualitative-quantitative dichotomies will be avoided, and service users and carers' direct personal knowledge and experiences will be engaged. This is in line with the latest emancipatory paradigms in social science research theory.	As before
RICHARD	It was at about this point that I discovered Alvesson's book on Postmodernism, or PoMo as he calls it. At first I couldn't read it but, after some recovery leave in Portugal, it became clearer, and I found myself agreeing with almost everything I read. This feeling had a different quality to it than my revelation about mixed methods and the realisation that I had actually been using them for years: November's was more a Damascene conversion, where I became a full-blown PoMo-ist. Then came Christmas.	Back to normal conversational tones. Slow realisation dawning. Sad for final sentence
FEM	It is a strange feeling having taken the tablets and settled down for the evening. I feel the creeping lethargy snuffing out strength and liveliness as it moves through the system. The sensations flow and bubble from . . .	Sad, depressed, slow, sickly
RICHARD	February came, and with it the final stirrings of the new idea, which had sprung up before Christmas but got lost in the Festive Hell. From a liking for Mead's symbolic interactionism, and the finesse of Coley's looking glass self, came my final turn. I	Back to normal conversational tones.

	<p>liked the neat arrangement of the central three components (Yeung, et al. 2003).</p> <ol style="list-style-type: none"> 1. We imagine how we must appear to others. 2. We imagine the judgment of that appearance. 3. We develop our self through the judgments of others. <p>But I could see a further development in the case of myself. Amid the chaos of rebuilding a crushed life, symbolic interactionism has a grasp on two components, 1 and 2 above; but the third, in my experience, is the manipulation of significant Others' judgements by the service user employing a kind of feedback loop to gain the exact effect on the significant Other required to achieve an aim, whatever that might be.</p>	
MAN	"The thing that moves us to pride or shame is not the mere mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this reflection upon another's world." (Cooley 1964)	Academic, yet happy and liltng

ROTATE THE GROUP : CLOCKWISE, ONE PERSON

RICHARD	We had already discussed methodologies and epistemologies at our October supervisory meeting and I had taken it away with me on holiday. The Christmas Crash had pushed everything away and I had to rekindle my enthusiasm. I now needed to reformulate the central research question urgently.	As before
MAN	"They solaced their wretchedness, however, by duets after supper" Jane Austen. : Pride and	Sad, lonely voice

	Prejudice, Chapter VIII of Volume I (Chap. 8)	
RICHARD	It then came to me and I tried it out on the group during one of my down periods – just read from my sheets, and this was as much as I could do on that particular day.	Excited once more, energised again.
MAN	AND SO, WE END WITH “SOLACE: RELATIONSHIPS IN CARE”	Triumphant, commanding, an air of ‘ending’!

COME INTO LINE ABREAST FACING AUDIENCE, HOLD HANDS, AND COURT BOW

Relax and take questions

*

My experience of reading the piece: Les

An experience of integration

Three of us stood as in the diagram, each representing the ‘voice’ and ‘figure’ of a distinctive quality that each of us had taken on. The three of us moved in concert so that the dominant voice was facing the audience. The other ‘figures/voices’ were ‘there’ but ‘in the shadows’ or ‘dormant’ for the moments that a dominant voice spoke. Each voice had its turn at different times and each portrayed a distinctive quality.

When I was asked to participate and to ‘be’ one of the voices, I did not know in advance what voice I would represent. However, I was willing to lend myself to this process and made an internal commitment to ‘become’ the figure behind the voice, and thus enter that position both emotionally (as far as I could understand it), as well as expressively (in order to communicate it evocatively to the audience, and not just its cognitive meaning). I appreciated the risk that Richard took in allowing others to re-present what I imagined must be ‘aspects’ of himself. These could easily be misunderstood by others re-presenting them. I also appreciated the aesthetics of what we were doing in that, by ‘embodying’ these different voices, Richard was encouraging others to imagine ‘what it was like’ to be in a particular position and also to dramatize how the complexities of personal/professional/academic development involve a struggle in which one is not

just negotiating with 'other' voices, systems and bodies out there, but that one is also negotiating with 'inner' voices, rhythms, moods and moments.

It became clear to me fairly quickly the 'ballpark' of the voice I was representing, although some of its precise meanings only unfolded as the text filled out further details. First I seemed to be the 'announcer', announcing the formal characteristics of what was 'supposed' to be professed in Richard's doctoral journey. The 'title' of the thesis was announced by me. The prompt notes said that it was a 'man' speaking, in a 'commanding voice' and this prompt was enough for me to enter into the beginnings of this character: a rather demanding critic, that carried an awareness of the 'rules' of academic discourse. I had to find my own 'authority' and spoke like someone 'in charge'. But I also did not feel particularly creative, and even felt a bit mean, or at least, a bit of a disciplinarian.

It was very interesting to me that my next utterance was to almost work against myself in that I said something about the value of the 'intuitive' over the 'rational'. Yet I intellectualized this by following the written prompt of the 'cold voice—academic—brisk—business-like'. As this voice, I felt rather smug by taking refuge in the authoritative, academic way that I venerated 'intuition'.

After this 'lip service' to the world of intuition, I, as this voice, returned to where 'I' felt comfortable in the 'academic' 'briskness' etc (as in the prompts). A whole lot of information was 'delivered' in between Richard's and Kate's (feminine) voice. I have to admit that I did not like the potentially 'dominant' voice I was playing and was relieved to feel that it did not have much of a role to play for the next page. I was also relieved that when 'I' came back, the interaction that had occurred between 'Richard' and the 'feminine' voice had appeared to result in a creative outcome so that 'I' as the 'authoritative one' had 'changed my mind'. At that point I began to feel a hope that my own power as the 'commanding, boring' one would not necessarily prevail on its own.

Another interesting twist came for me when I then read out the next section in which I, as the so called 'confident', 'commanding' one, was 'brought to my knees'. Only poetry could express this and in this section I entered a confession of 'pain' and 'depression'. This phase somehow reminded me of the archetypal story of that great tough, confident hero, Hercules, entering the underworld. Faced with Hermes, the messenger of the gods, Hercules pulls out his sword. Hermes just laughs. So this reminded me of a certain humbling of my 'commanding' figure through going down into the loneliness and the darkness of the underworld. I then warmed to my figure and who I was. The possibility of transformation, even if painful, sparked my interest and empathy, and I wanted the audience to empathize with the value of this figure as well. I thus gave myself to communicate something of the pain, the loneliness and the longing. I was pleased to see in the rest of the text how this process was productive and that I, as the 'masculine' side could have a productive role to play by exercising language that could become helpful and communicative. As the prompt notes said, I finally could be 'academic' yet 'happy

and liling' (softened) and even arrive at a creative, articulate outcome (the title) in which my figure's 'power' could have a valid face.

While going through this whole process of 'being' my figure, I was also listening to the others in the triad (Richard and 'Kate'-the feminine). I had become increasingly aware of the experience of integration as the dialogue unfolded---me being very different from Richard and Kate in the beginning, but increasingly involved with them, open to their influence, and being changed by them in good ways towards the end.

Reflecting on all this now, I see that we were never separate, always three-in-one, needing one another, and finding a way to complement one another's strengths.

*

The 'playlet experience'.

At first I felt a little nervous, just a wee bit of an edginess, would I be able to do justice to this work as I had not read it before and entered the experience with no prior consideration or reflection on the material.? I think it was a benefit to 'dive right in' as I needed to respond spontaneously with my voice, in reflecting what I was reading for the first time. This experience came as a bit of a liberation as I was flowing with the words as 'new' words and found the instructions of the author in what tone I should use as very helpful, but all the time wondered if I had achieved the tone that had been envisaged.

Initially I was very concerned as to whether I would get the rotation right but did not give the effect 'or power' of this on the audience any thought. It was only in the three of us enacting the turn' about face' that I sensed the impact of it on the audience. I was facing the wall for the first half and did not know how the audience were engaging but on facing them, I could see, even though I was concentrating on text, that they were intensely following every word and held a gaze on the three of us.

There was something about listening to the other parts and their voices and then entering with my own voice too, that aided the process, it did feel a tripartite and each voice of the other, helped me focus on mine. So I kind of lived a feeling of the story as it unfolded through listening and speaking in turn.

Kate

Appendix B

A CONVERSATION WITH HARRY

26 June 2008 1520-1605hrs

Dorchester, Dorset, UK

HARRY (a pseudonym) - H - Interviewee

RICHARD - R - Interviewer

H Hmm . . . It's towards the end of June <CHUCKLE>. It's the 26th today, isn't it? I think it's the 26th . . .

R 26th of June? I think you're right.

<PAUSE>

You've had a bit of a rough week yourself, then?

H Well . . . um . . . I don't tend to look at days . . . it's more as: Monday, I've got to do that; Tuesday, I've got to do that; Wednesday, I've got to do that. And so on and so forth.

<MICROPHONE MALFUNCTION>

R Oh . . . oh, try again.

H Old technology, you can't beat it! It's reliable, innit?

R <SIGH>

Oh yeah. All I'll do then, is I'll put the . . . erm . . . when I get back to Steph's, I'll put the . . . I've got a digital voice recorder. If I'd have brought it with me, I could've recorded direct onto the computer from that. I'll just play that into that and it will come up with a digital file.

H It's very technical.

R If I had the wire, I could do it straight into the computer.

H Very technical.

R Well. It's twenty past three, which is 20 minutes later than expected and . . . and what I was thinking of doing . . . if . . . if . . . if you don't mind, is . . . erm . . . talk about your experience, your *lived* experience, in whatever depth you want to go – I'm not going to dictate anything to you but your experience of working with . . . erm . . . service users, especially mental health service users.

H Yep.

R Erm . . . as a provider, because you're providing a service, aren't you? So, if you could say what that service is that you're providing. You can say as much of your name as you want, if you like.

H Uhuh.

R Or . . . or whichever name you want to be known by . . . okay?

H Absolutely.

R If you want to be known as ‘Colin’ that’s great . . .

H Yeah.

R And . . . and just let me know a little bit of how you feel.

H That’s absolutely fine. That’s a big question, though . . .

R It is. So we can break it down, if you want?

H It’s a big question . . . erm . . . just to take it as . . . I’m *Harry*. Umm . . . I’ve been a mental health nurse for 10 years, during which time I’ve nursed on an acute admissions ward; I’ve nursed in the Royal Air Force, as an air and medical evacuation nurse, as well as ward-based; I’ve worked in eating disorders at the Priory in London; I’ve worked in a home treatment team, and also run a home treatment team; and I presently work as a Nurse Advisor with the Well-being Support Programme; but my current role is . . . is non-clinical.

R Umm . . .

H However, when I was a clinical practitioner . . . I think . . . I think we go back to the beginning. I remember, when I very first started, being a little disconcerted and a little bit nervous around certain people because I didn't have that understanding, and I think most student nurses actually have that feeling when you go on a ward for the first time.

I do remember the first time I went onto a psychiatric ward. There was a lady there. She was bi-polar and, at the time, her mood was very elated. I was asked to do Special Obs on her - I remember this vividly – and I spent the next hour being sworn at, being abused, having cups thrown at me, and none of my colleagues seemingly caring, or willing to help me. This is from *my* perspective. I . . .

R <INTERSPERSED> Umm . . . umm . . . yeah.

H . . . can only tell you how I felt.

R Because this is one of your first jobs?

H Yeah. And I remember thinking: "I can't do this. This is completely and utterly impossible."

However, about three years later, I met the same lady again and, again, she was elated, but now I was a qualified nurse. And, I remember it very well because she behaved in a very much similar fashion.

I was by no means the competent practitioner that I am now, but I *did* have more of an idea of what I was coping with, and I remember being very boundaried with her; I remember being very assertive with her; I remember her swearing, telling me she hated me . . . erm . . . I remember her making my life very difficult.

And then, one day, she disappeared off the ward, and we all got into cars, and we all looked for this lady, and . . . er . . . eventually we . . . we found her. After a lot of . . . a lot of talking to her, eventually she returned to the ward.

The reason I speak about this was, I remember two weeks later her becoming completely well, it was like a different person, and she came up to me and kissed me on the cheek, and she said to me: “Thank you *so* much.” And *that*, I think, was the first time that I knew that I’d cracked it. Not that I knew *everything*, but I knew what I was dealing with.

R A powerful moment.

H Yeah. I knew what I was dealing with. I knew that I w . . . was . . . no longer should I judge somebody by how they behave, but rather recognise that the illness is having a definitive effect on that individual’s personality and the way that they’re coming across.

And, from that day forth, I’ve been relatively confident working with most disorders within psychiatry. Umm . . . and most individuals.

<PAUSE>

Umm . . .

R So that was sort of . . . umm . . . what do they call it now? A '*Tipping Point*' for you?

H It was. Absolutely. Yeah.

R It was very powerful?

H Yeah. It had a . . . it had . . . it had a profound impact on me because, even though I had been qualified for a short period of time now, I was sort of going through the motions, I think. But I was failing to recognise where the illness started and where the person started, and . . . and I think it was at that stage that I recognised the person for the first time, and it definitely . . . definitely had an impact on how I have nursed thereafter – I've always tried to look for the person.

R Yeah.

H I used to get very upset with handovers where a new admission was on, and you'd get these incredibly long handovers that would be telling you everything about this person from the age of one. Most of it was completely irrelevant but, without meaning to, it left you with a judgement of that individual before you met them yourself.

And I have always always *always refused* to hear *anything* about . . . when I have had the capacity to do so . . . refused to hear anything about that individual other than Risk, before I actually go in and see them. Because I think, *otherwise* you have preconceived ideas and you do just start to see the illness and not the individual.

R Yeah . . .

H Because the *individual* is the aim. The . . . the aim is Recovery. So, if you're aiming for that, then you're actually aiming in the right place.

R Yeah . . .

H That's . . . that's a *personal* feeling, anyway.

R I understand what you mean and I think that's quite right.

<PAUSE TO PET THE DOG>

H Umm . . . would you like, umm . . . ? I'll tell you an aspect of psychiatry, if you like, that I *don't* like . . . ?

<PAUSE TO FIT NEW BATTERIES>

H They're referred to . . . do you know what they refer to it, though, mental health professionals, rather than 'Munchausen'?

R Go on . . .

H They refer to it in a fashion that is quite derogatory. They refer to it in a fashion of 'Personality Disorder.'

R Oh, yes. I've heard of Personality Disorder.

H What they do is . . . well, Personality Disorder . . . you know that if . . . if they did a test on all of us, every one of us would have a . . . a degree of Personality Disorder. None of us are perfect.

R That's if you believe in 'Personalities'.

H I do . . . *personally*.

Both <LAUGHTER>

H But . . . er . . . but, yeah . . . umm . . . yeah. They refer to it as 'Personality Disorder', which they say is 'untreatable', so . . .

<DISTURBANCE OCCURS AS R'S CHAIR BREAKS AND PEN IS LOST IN THE RESULTANT CONFUSION>

R Yeah . . . I'm just looking for my pen.

H I've got a pen in my bag.

R Oh . . . hang on . . . no.

H Hold on. I've got one in my pocket you can use.

R It's here! Yeah, it went down when . . . when the chair broke.

H Quite a wrench, then?

R I'll come and sit in this one.

<MOVES A SEAT CLOSER TO H>

R Makes more sense, anyway. Do you want some more chocolate biscuits?

H No, I'm alright, thank you.

<LAUGHTER . . . SIGH>

R Me sitting here, I can see if it [*the tape recorder*] goes off. See, this one [*the chair*] has gone on the same side. I had it repaired. Is this too close for you? Are you uncomfortable?

H Nah. I'm alright. I'm actually . . . umm . . . if . . . if you don't mind, I'll just . . . regarding the 'Personality Disorder' thing, I think, actually, I've probably gone off on a tangent . . . you know how, once you start talking, your mind goes off . . .

R Yes.

H Actually, it isn't *that* that disturbed me particularly. I think actually what upset me the most in psychiatry, and I've found the most difficult thing about my career, is how *exhausted* it makes me . . . and what I mean by that is: I've seen people doing this job for 20 or 30 years but, by the time they get to that point, I don't think they *care* . . . bottom line.

<PAUSE>

They can do their job and, to their Manager and some of their colleagues or whatever, they *look* like they're doing a great job because their paperwork is perfect, y'know, everything you need to do is right, but they become like a machine . . .

R Yeah . . .

H . . . and I *think* the service users know that this person is just giving them lip-service rather than actually wanting to make a difference, but what . . .

<PAUSE>

- R I think you're right, yeah. You have that in all sorts of professions, don't you? I've heard a teacher say there's a big difference between a new teacher and an old, burned-out teacher.
- H Completely different.
- R Yeah . . .
- H Absolutely. And, you know, that's why I decided to take the Nurse Advisor's job, because I knew that I was burning out. Because whenever I sit in front of someone, if . . . if . . . if I'm supposed to be caring for that individual, then my intention is: 'What can I say?' or, 'What can I offer?' or, 'What can I give?' or, . . . 'What would help this person to improve?'
- R Yeah . . .
- H So, if you go with that intention all of the time, then it's only natural that you want that person to feel better having seen *you* rather than through work.
- R Yeah . . .
- H So, subsequently, you end up by giving a piece of yourself. You can't see it; it's not something you can see; it's not *tangible* . . . but you do sometimes leave a visit, or you . . . especially after a number of visits, and you feel absolutely drained yourself. And I think that's why so many *good* mental health professionals take so much time off sick.

R Yes. Well, it's very stressful.

H Yep.

R But also, do you think that's why so many take promotion into non-clinical roles like management, stuff like that?

H Unquestionably.

R And they're going into management all burned-out already so, when they meet a service user on a committee or something, they've got this negative view. Do you feel that, or . . . ?

H No . . .

R Or do they feel refreshed because they are meeting someone from their past life that they can work with?

H No. It's *fear*.

R Fear? That's interesting. Fear of what?

H Fear about having to step outside of their Comfort Zone.

<PAUSE>

If . . . if . . . if you've got a committee of ten healthcare professionals, and they're all sitting there, from all walks of life, then you . . . you *know* what you're trying to deliver, and you can talk for ages, and you can leave that meeting, and . . . it's okay . . .

R Yeah . . .

H . . . it's okay. No one's really going to get too upset. You're going to meet again in a month's time. If you've got a service user in the room, then you're having to think all of the time: 'Is this the right thing for my Trust, or my staff?'

R Yeah . . .

H 'Is this the way forward? Is this beneficial?' . . . erm . . . and I think it's *fear*. I don't think it's being burnt out, I think it's fear. Fear of looking . . . like you don't know what you're talking about . . . or looking like you're not doing anything proactive.

R Uhum . . .

H Umm . . .

R Are there different dynamics to having a meeting with a service user and without a service user?

H Definitely!

R Hmm . . .

H Unquestionably. Yeah.

R Do you think it holds back on business, or does it just ‘modulate’ business; does it change things?

H Umm . . . ‘modulate’ is a good word. Yeah, I’d say ‘modulate’ because I think people are much more careful about what they say as well . . .

R Yeah . . .

H . . . and, certainly, how they say it. It’s a . . . I’ve seen people, but . . . ah . . . ah . . . the trouble when you say that, is you . . . you put everybody into the same bracket, don’t you?

R Yeah . . .

H You’re stereotyping people when I know there’s . . . you know . . . people who *will* speak out . . .

<A DISTURBANCE ON THE TAPE>

H . . . basically be the same, regardless of whether a service user is there or not. But I do genuinely think, on a general basis, that . . .

<PAUSE>

R Well, as a service user, Harry, I don't see the other side . . .

H Hmm . . .

R But I can remember meetings when I was a manager, without service users present and *with* service users . . . umm . . . and the best meeting members were the ones that didn't alter.

When we were in a prison, we had a meeting with the chefs and the head chef, when he was talking to us as a group of managers was the same and had the same attitude as when he was talking with the inmates there as well, which I respected in that: 'Well, he's standing up for himself, you know, not messing about. And I tried to model myself on him all through my career, which was good . . .

H Yeah, I think it . . .

R . . . and was that the same thing you're talking about?

H Yeah. Absolutely. No, but again this is a personal perception, I think that things are

slightly different with a service user, yeah, because there is a degree of expectation – they *have* to do something – so there’s an element of fear. And also, you know, their professional pride, you know . . . erm . . . they know how to make their *colleagues* like them, but how do you make the service user think that they are doing a good job, too? But that’s just a . . .

<PAUSE>

R Is it important to have the service user think you are doing a good job?

H Well, if a service user doesn’t think you are doing a good job then you’re *not* doing a good job. So . . .

R So, then, it matters, then?

H If you’ve got a conscience, then it matters.

R But is it necessarily so? I mean, would the service user necessarily be representative of all the service users?

H No. That’s very true, actually, because everybody’s very different . . . umm . . .

R When we spoke earlier, it was ‘embarrassing’ about personality disorder and Munchausen and things like that?

H That's a very good point . . . *it is* a good point, but I don't think it changes the dynamic. Whether that person represents . . . erm . . . themselves or a whole group of people, it's still that the dynamic would remain . . . y'know . . . umm . . . but it's like . . . it's . . . it's like . . . y'know . . . the Prime Minister . . . umm . . . a number of people wouldn't . . . won't vote for him next time, but a number of people will. Everybody's different and it doesn't matter how good your self-values are, they're not going to meet with everybody.

R That's true.

H You know . . . and erm . . . but I don't think it changes the dynamic.

R So, how do you . . . as . . . as a member of that committee, how do you, inside yourself . . . umm . . . *manage* that change?

H I *trust* myself.

R You *trust* yourself?

H I *trust* myself. I trust myself that what I'm saying . . . erm . . . is right . . . erm . . . that it's what I believe. Not saying that my mind isn't changed because it often is through conversation – that's what demate . . . debate is for.

R Yes. That's what the meeting is for.

H Yeah . . .

R Umm . . .

H But I . . . umm . . . but I *trust* myself. And if . . . I genuinely think, if you're coming from the right place, then . . . in other words, if you're coming from a *good intention* then even . . . even . . . wh-wh-whatever you do, it can't be 'wrong'. So, even if, from good intention something bad were to happen then, in my eyes, I haven't done anything wrong . . .

R Yeah . . .

H . . . because it's come from the right place . . . you know . . . and that's . . . er . . . somehow, I just trust myself. I just go with the good intention, really, and . . . er . . . sometimes it puts you in more trouble than not, actually, being that way than just going with the crowd, to be honest. You know. And . . . er . . . to say, it can certainly make your seniors feel very very threatened by you when you don't follow their philosophy.

R Has that happened in the past?

H Oh, many many many times. Everywhere I go . . . everywhere I go, Richard . . . *But* . . . but . . . you know . . . I know in my heart-of-hearts that I am going with good intentions, that my intentions are good, that I want to create something positive. For example, with this job now, the Well-being Support.

R Uhum . . .

H Ahh . . . my intention now, every time I go out, is to . . . to get people on board so, ultimately, service users will get better physical healthcare. When I go to visit the nurses, my intention is to keep them motivated so that that continues. When I do the training, I put my heart into it, and I hope I express it correctly.

But it's all for . . . it's all for the same goal, and that is improvement in service . . . umm . . . you know and I know and . . . you know . . . that these are times when I don't teach the lessons particularly well, or I have a blank and I can't think clearly, or I might make a booboo about something that I say in a meeting, or I upset someone in a meeting because I've got a completely different viewpoint to them, but it's *their* Trust, so they're annoyed because I've said it . . .

R <CHUCKLE>

H . . . *but* . . . I just *trust* myself, and I have to, otherwise I wouldn't go to work.

R Yeah, really?

H I wouldn't go to work.

R How did you build up that self-trust?

H That's . . . ah . . . I'm not sure if I want to go down that route, but that's . . . erm . . .

R That's okay.

H . . . but that's . . . ah . . . that is my faith.

R Umm . . .

H Yeah . . . I know . . . I know that my heart is good, and . . .

R You based yourself (if I can help you a bit, maybe . . . maybe?) You based yourself on a firm moral standing in a particular faith mould that you . . . you're a member of? And that mould, that good moral grounding, informs your practice. Is that what you're trying to say, . . .

H Unquestionably so.

R . . . without going into detail?

H Unquestionably so. If I . . . well, I *am* a Christian . . . umm . . . but for . . . but . . . yeah . . . Jesus . . . erm . . . my personal relationship with Jesus . . . erm . . . is one whereby I trust in Him and I know that His good works are in part done through me and . . . er . . . I'm very blessed for that.

R That's good. So, if you entertain immoral forces then you're actually going against your faith yourself . . .

H Yes!

R . . . and it would be 'sinful', basically?

H Yes . . . yes . . . but . . .

R And it is a powerful guiding light you've got, isn't it?

H Yes.

R And some people haven't got that.

H But it gives you strength when things are bad as well because . . . erm . . . I'm sitting here as a mental health practitioner but, in truth you know, I've . . . I've been down. I've had bad days. I've had bad months, y'know? And, y'know, it's not like I'm going crazy. I think most people *have*.

R Yeah . . .

H . . . erm . . . but for me, that's always been my saving grace, and a way of actually bringing me back to reality, because psychiatry has exhausted me on three or four occasions, whereby I thought: 'I just can't *do* this anymore!'

<A TELEPHONE RINGS>

R Gosh!

H It's alright. Take it.

<BREAK WHILE PHONE IS ANSWERED>

H . . . I think that . . .

R I'll just reiterate that: What we've got so far is *brilliant* and I know you're short of time . . . umm . . . What we've talked about so far (if I can go over it, Harry?) is . . . er . . . we've talked about fear of what the service user might think, basically. Is that what you were saying about that fear?

H Yes.

R Or fear of doing the wrong thing . . . um . . . and . . . and trusting yourself to do the right thing, and basing it on a moral grounding. That's . . . that's what I've got here at the moment.

H Umm . . .

R Erm . . . So, put yourself in this position: There's this . . . erm . . . there's a committee you're on – usually just you and other service providers and commissioners on this committee . . . umm . . . Just put that in your mind. And you're going into it and, suddenly, you hear that a Service User Representative will be joining you, and it's the first time they've been on that committee. What would go through your mind, and how would you deal with other people's negative and positive comments? Or, positive and negative comments so as not to slant it in any way.

H I tell you what's frightening, and I think is almost indicative of our society, is that *nobody* in that room would say *anything* about it. If people were concerned about it, they'd keep it to themselves. If people were frightened of it, they'd keep it to themselves. If . . . *everybody* would keep it to themselves because they know they need to be 'PC'. But there'll be individuals in that room that'll be thinking: 'Oh shit!' And you can see it on their faces rather than you'll *ever* hear it – 'cos *I've* never heard it . . .

R Yeah . . .

H . . . but I know it happens, and I can see it, and . . . er . . . but it does, unquestionably, change the dynamic. But I think, actually, it's a very positive thing because it means, normally speaking, you get something from the meeting. In other words, it direct . . . it becomes directive rather than just . . . erm . . . reactive. It becomes directive; they're looking for a solution. Whatever it is that the agenda has brought up, they're more likely to actually . . . and *also*, as well, what a service user does is it makes it *real* because it's like anything, isn't it? You can *plan* something until you're blue in the face, but it's not until you *implement* it that it actually *means* anything.

R Yeah . . .

H And I think what happens in these meetings, often, people plan things and they over-plan them instead of just saying: 'Right, this is . . . we've done this element of planning but we're going to start it on this date, and we're going to go ahead, and we're going to do it.' And it's more likely to take it from the planning to an implementation stage if you've got a service user - that *wants that* service - in the room . . . because it makes it real. Otherwise, it's just four walls. That's a . . . that's kind'a how I see that.

<A DOG BARKS FURIOUSLY OUTSIDE>

R It's . . . umm . . . that's Jack seeing off the helicopters. I've got this theory: as long as Jack's in the garden, a helicopter won't land. Because, every time he's there and barked, a helicopter's never landed.

H Huh.

R It's good science.

H It is. He's . . . he's obviously scaring the life out of them.

Both <LAUGHS>

R I'm terrified of finding a helicopter out there, d'you know what I mean? The . . . yeah, I like to play the science a bit like that. Sometimes science is a bit like that, isn't it?

But, I know as a service user I go into these meetings and all I can see is people being friendly and I know that's not the case, y'know that . . . some people aren't friendly towards me, and one woman is quite honest and unfriendly and I prefer that – if she's honest and not friendly rather than to be dishonest and friendly – if you know what I mean? Because it's like back-stabbing, almost, isn't it?

H Umm . . .

R And I'd rather be told: 'I don't think your opinion is valuable,' than . . . than for people to say to me: 'I think your opinion is valuable, *but* I'm going to ignore it anyway,' you know, in the back of their mind. So, tokenising . . . tokenism . . .

H No. No. I actually respect you as a man for saying that. However, I don't think everyone in the room would be aware of that.

You've got to remember, as well, that *if* someone like yourself were to have a meeting and put in a complaint about an individual in that room, then that person is accountable to that. If I'm sitting . . . I was sitting in a meeting and *I* don't like what my colleague has said, then *I* say something to them, alright? The chances are, it's going to be dealt with there and then. If I put something in writing, my Manager's going to speak to the two of us and sort it out. If a *service user* puts in a complaint, then that person should be suspended.

R Umm . . .

H And that's one of the reasons why that fear exists . . . you know . . .

R It's a shame, isn't it?

H Yeah.

R I think I'd rather go into a meeting at *your* level, then, if we had a breakdown of communication, that one of the Managers would take us both aside and say: 'Look, this has happened. Let's sort it out,' rather than let me go away and make a complaint. I think I would feel much more a unitary person within a . . . or . . . a person within a unitary body than an outsider coming in, in that case.

But I can see your point . . . y'know . . . there's . . . er . . . some service users, I'm sure, like in the world as a whole, would complain about anything anyway.

H But the thing is, those complaints do have an impact on that professional's life. I mean . . . umm . . .

R What sort of impact does it have?

H It's quite devastating. If he . . . er . . . I mean, I've got friends working on the wards and they've been looking after people, then accusations have been made . . . erm . . . and then, subsequently, they've ended up being suspended, they've had to go through Tribunals, they've ended up being sick, they then . . . it's very difficult for them to get another job. It *actually* is really *really* detrimental.

Now, I'm not say . . . of course, if someone has a genuine grievance, then it needs to be put forward in that fashion, and it should be put that way. But there are times within this profession that sometimes those grievances are actually brought on by delusion. But there is no . . . there is no flexibility in Law. That says: 'A complaint's a complaint. Whether or not that person is unwell or not, a complaint's a complaint.'

R Yeah . . .

H So it goes through those channels. Y'know?

R Yeah . . . That's very interesting because that gives a flavour to the meth . . . to the fear-thing you mentioned right at the beginning. One can see why the fear exists, now.

R <TAKES SOME TABLETS>

R I know it's a sick-room, but I'm made more comfy with these painkillers.

H Yeah yeah . . . I mean, I'm not in the NHS as a nurse and I'm not 100% sure of the protocol, and I'm sure the protocol changes from Trust to Trust, but what I do know is . . . umm . . . yeah, it has a significant effect on that . . . on . . . on that . . . on . . . on that nurse or that doctor or that OT.

R That's interesting, and maybe that's why people try to keep service users off those meetings.

<PAUSE>

I've got one example in Dorset at the moment where the . . . umm . . . there have been discussions and the service user rep has decided not to go to the meetings on a request of the two managers on the meeting.

H Crikey!

R Yeah. I thought that. But . . . umm . . . I thought it was a little bit odd, but maybe that's why?

H But maybe . . . but maybe . . . just . . . just ta-talking out loud now . . . would be . . . y'know . . . actually just . . . actually just speaking to the person who's running it, before you start, and saying, y'know: 'I want this to be completely relaxed. I want people to say just what they feel. I don't want my influence to have any influence on it,' . . . y'know . . . and . . . er . . . y'know, it's . . . umm . . .

No. You can't really do that, can you? You can't really say something along the lines of, y'know: 'If I'm unhappy about something, don't worry. I'll . . . I'll . . . I'll talk to them about it myself.' It's a very difficult position for you to be in because you can't really make that statement, can you?

R No. The only way I've found of doing that is to go continuously to the same committee meeting, month after month, and get 'known' and being 'used to' . . .

H . . . umm . . .

R . . . and *know* the people, and . . . and *meet* the people – like I met you – and *talk* to them before the meeting, after the meeting, during the coffee break. And . . . and what I tend to do is go and pick different people each time, and just make contact. That's the way I try to allay that fear. And I think, after a few meetings, people get used to you being there. Would you say that was the case with you?

H Yeah. I think so . . .

R Or does the fear carry on?

H No. I think you're right. It does dissipate. Of course it does, because you become comfortable with individuals, y'know, but that's human nature, isn't it? Y'know, the more you see someone, the more comfortable you are in their company. No. It definitely gets easier.

R So. It gets easier with, say, me going to the meeting than . . . umm . . . what happens when I'm off sick and 'Jack' goes to the meeting?

H I think it would bring up the anxieties we've already mentioned.

R Because it's a personal thing?

H Yeah.

R So, having . . . wh-what I'm trying to get at is, if whether having a role as Service User Representative is still . . . umm . . . not as powerful as being a person . . . umm . . . I don't know how to put this . . . 'Richard, the SUR' rather than 'the SUR called Richard'.

H Yes. I understand what you mean.

R So: 'Richard is coming as an SUR.' Not: 'We're having an SUR and it's going to be Richard or it's going to be Matt or it's going to be Harry or it's going to be Jack or it's going to be Sue. . .'

H Hmmm . . .

R Yeah? But that's a difference in that? That's quite an important difference, isn't it?

H I think it is, yeah. I think we all become comfortable with certain individuals . . . umm . . . because . . . as . . . I think also as well, because you actually learn what that person's agenda is, as well. The first time you meet someone, y'know, unless you're Mystic Meg, you can't just look at them and think: 'This person has this view on this and that view on this and this view on that.' You don't know. That person is . . . is a completely new box of tricks.

Whether someone is a service user – in inverted commas – or a psychiatrist or a psychologist, if you've got to know them over a period of time, you *kinda* get a feel for where they're coming from. But when you get somebody new, that person is new, so you don't really know if what you're saying is in line with their common thoughts or trends, or if it's on a complete tangent, or if it's upsetting them, or

they're happy with it, or it's . . . y'know it . . . it . . . it causes ob-obvious anxiety.

R Yeah . . .

H Bit like going for a new job, really. You don't really know exactly what the boss wants to hear when he asks you that question . . .

<PAUSE>

. . . y'know . . . I *do* think it's a good thing, though, service users being . . . umm . . . being more influential . . . umm . . . when it comes to . . . erm . . . policy-making . . . erm . . . with regards, y'know, groups and activities, and what's actually needed, and with the . . . the actual care that they actually get when they're on . . . in hospital, and so on and so forth.

Because it's a completely different perspective than you can ever have as a mental health professional on that ward. I do think . . . I do think, sometimes though, mental health nurses do get . . . very much . . . do get a hard time at times, because the paperwork that they're asked to do – *unbelievable!* And the *amount* of time that it takes, and really and truthfully it ends up that you've only got one or two people working on a ward that . . . umm . . . aren't qualified, that are actually, if you like, caring for the patients on the ward.

And that, to me, is the biggest sham of mental health nursing, to be honest, because, if you went . . . if you went to the University tomorrow and you spoke to a cohort of mental health nurses that were about to qualify, I would – I admit, it's hypothetical – but I would say 90% of them would say they went to mental health because they wanted to work with people . . .

R Yeah . . .

H . . . and that is true but, three or four years down the line, they'll be . . . their . . . 90% of their time will be on administration and it will up . . . and that the only time that they're genuinely 'on the ward' is when they're reacting to a problem that's taking place and . . . erm . . . I think that's a shame.

R Which, arguably, is the wrong way round? He should be . . .

H Completely.

R . . . proactive, shouldn't he? And make sure the problem doesn't start in the first place.

H Completely. But, unfortunately, it doesn't seem to work that way.

R No. But it's the same complaint from the Police, isn't it? And the same complaint from other . . . other services that the paperwork is swamping them.

H Yeah, that's true. But you . . . you know that, in places like Finland, they have . . . er . . . one qualified nurse for every four service users?

R No. I didn't know that.

H Yes, they do. We don't quite do that in England, do we?

R No. I think it's more like two for a whole ward full.

H At two for twenty-four, I think.

R Yeah . . . ah . . . I . . . I remember . . . umm . . . when I first went to Guys Marsh as a Healthcare Manager there and saw all the paperwork I had to do, I said: 'I need a Ward Clerk every afternoon.' I . . . I did say every day, at first, but I knew I'd have to break it down a bit. So, the Ward Clerk came in . . . sorry, every morning . . . the Ward Clerk came in in the morning, did the four hours of the morning and then went to work somewhere else and, because we could split the budget like that, we could both have this extra Admin person.

H Huh!

R Umm . . . so she went and did the mail in the afternoon with . . . with the . . . erm . . . with the other Admin staff. So, I get a Ward Clerk for the mornings. Once that paperwork had gone from me, I could get away from my desk – I actually . . . I actually got *rid* of my desk and had a little room like this with some chairs and a stereo, where I could sit and talk to people – flowers, you know . . .

H Like you do.

R In the centre of a hos . . . prison, in the centre of a prison hospital, there was this little room that you could just go . . . and we used to have the Governors come down, they were so stressed. They'd come and say: 'Could I use your room for an hour?' I'd say: 'Yep. Go on.' I said: 'Do you want people to know where you are?' 'Only in emergencies . . .'

H <LAUGHS>

R . . . and they'd go in their and the inmate would bring them a cup of tea, and they'd sit and quietly *defuse* themselves.

H Really important, that is.

R Yeah . . . yeah . . . and they were better for it.

H That's very healthy, actually.

R Umm . . .

H Very, very healthy.

R I haven't been back since; I don't know what it's like now. That was some years ago, of course.

H Umm . . .

R Probably all gone down the drain.

<PAUSE>

Be a shame if it has. That's another thing, its different views, isn't it? Do you find, when you're on committees and you're all . . . em . . . professionals together, do you find the quality of the argument is *richer* and more . . . em . . . more *informed* than if you've got service user and carer representatives there?

H I think it's so dependent on who's taking the meeting. If you've got an autocratic person taking the meeting, then you . . . you're pretty much aware that all you're doing is annoying that person if you're going against them, because you know, at the end of the day, you're going to go with what they want anyway.

R Yeah . . .

H So, it is very much dependent on the group of people you're working with. If it's an open forum, then it's very positive, and that's regardless of who's involved.

Erm . . . but em . . . as I . . . as I said before, I don't think I can add much to your . . . I just think it changes the dynamics when you have a service user in the room. But . . . erm . . .

R I think that's a very valuable piece of work you've given me. Thank you very much.

H You're more than welcome.

Appendix C



DORSET MENTAL HEALTH FORUM Role Description and Person Specification



Peer Representative 'Expert by Experience'

Hours Per Week: Variable

Hourly Rate: To be agreed

Based at: Variable

Responsible to: To be agreed

Purpose of the Role:

To improve the lives of people with mental health issues and their carers by:

- Participating in local involvement opportunities as a person with lived experience of mental health problems, representing a range of lived experience views, supported by the Dorset Mental Health Forum.
- Promoting Wellbeing and Recovery to peers, staff and the general public, from a lived experience perspective.
- Promoting the Forum's philosophy and practice of involvement of people with lived experience.

Examples of Peer Representative Involvement:

This list provides some examples and other opportunities may be developed and / or become available....

- Participating in local groups of people with lived experience, such as local Peer Support Groups, Sports and Leisure Activity Programme (SLAP), Hearing Voices Groups, Learning from Lived Experience / Recovery Network Groups and so on.
- Sharing lived experience with others and becoming part of a network.
- Giving feedback on experience of mental health services.
- Taking part in consultations and focus groups about mental health services.
- Reaching out to other people with lived experience and becoming representative of their views and experiences.
- Helping at local events which promote and raise awareness of mental health issues, challenging stigma and discrimination within local communities and services.
- Other activities that support the work of the Dorset Mental Health Forum.

General:

- You will be required to fulfil your role by fully implementing and supporting the Dorset Mental Health Forum's Policies and Procedures.
- Be aware of and act in accordance with the provisions of the Data Protection Act 1998.
- Undertake Induction and Training as required and later as identified in role.

Peer Representative
'Expert by Experience'

Person Specification

Criteria for Peer Representative:

- Direct personal experience ("lived experience") of mental health problems.

- Awareness of mental health issues and mental health services.
- An understanding of the day-to-day issues affecting people with lived experience of mental health problems.
- A wish to participate with other people with lived experience, for mutual support, self-help and as part of a collective voice and network.
- An understanding and awareness of the principles of Wellbeing and Recovery and how to manage and support your own mental health and wellbeing.
- Willingness to take part in Recovery and Self-Management training within the Dorset Mental Health Forum.
- Good communication and interpersonal skills.

The Dorset Mental Health Forum wishes to encourage applications from people with disabilities. Where the Person Specification calls for particular qualifications or experience, we will consider waiving these requirements if an applicant who could not achieve them because of a disability can demonstrate he/she would be capable of performing well in the job and fulfils the criteria in other respects.

Appendix D



DORSET MENTAL HEALTH FORUM Job Description and Person Specification



Peer Specialist 'Expert by Experience'

Hours Per Week:	Variable
Hourly Rate:	£8.32 per hour
Based at:	Variable
Responsible to:	To be agreed

Purpose of the Post:

To improve the lives of people with mental health issues and their carers by:

- Promoting Wellbeing and Recovery to peers, staff and the general public, from a lived experience perspective.
- Modelling Recovery to other people with lived experience of mental health problems and to staff in mental health services.
- Supporting the Forum's Peer Representatives in their roles.
- Collecting and representing the views of people with lived experience.
- Assisting the Forum in achieving the outcomes and milestones which form the basis of the Forum's agreement with the Big Lottery Fund.
- Promoting the Forum's philosophy and practice of involvement of people with lived experience.

Possible Areas of Work for Peer Specialist:

This list is intended to give some examples of areas of work only.

- Liaising and consulting with Peer Representatives and other people with lived experience, who may or may not access services in local areas.
- Representing the views of people with lived experience at local meetings.
- Representing the Forum and the views of people with lived experience in a variety of settings in local areas.
- Assisting in the development of peer led groups in the community.
- Raising awareness of mental health issues in a variety of settings.
- Assisting in the recruitment and training of mental health staff in the statutory and voluntary sectors.
- Establishing good working relationships with Peer Representatives and mental health staff in local areas.
- Representing the Forum at relevant conferences and local and regional events.
- Assisting in delivering Psycho-Educational Courses with primary care mental health staff.
- Working within statutory mental health services (e.g. Community Resource Teams) to promote and model the Recovery approach to people accessing the service and to staff members. Acting as culture carriers.

General:

You will be required to fulfil your role by fully implementing and supporting the Dorset Mental Health Forum's Policies and Procedures.

Be aware of and act in accordance with the provisions of the Data Protection Act 1998.

Undertake Induction and Training as required and later as identified in the role.

Essential Criteria for Peer Specialist:

- Direct personal experience (“lived experience”) of mental health problems.
- Awareness of mental health issues and mental health services.
- A clear understanding of the day-to-day issues affecting people with lived experience of mental health problems and a proven ability to be representative of those issues.
- Evidenced understanding and awareness of Wellbeing and Recovery principles and how to manage and support your own mental health and wellbeing.
- Willingness to take part in Recovery and Self-Management training within the Forum, for oneself and with an aim of then training and supporting Peer Representatives and other people with lived experience.
- Good communication and interpersonal skills, including ability to work within a team.

Desirable Criteria for Peer Specialist:

Please note that although experience in these areas would be an advantage, training will be provided and available through the Forum.

- Some information technology skills.
- Knowledge of the infrastructure of mental health commissioners and mental health service providers in the local area.
- Ability to prepare and present reports.
- Full driving licence and own transport.
- Ability to work alone with access to day-to-day supervision.
- Ability to organise own work schedule and be self motivated.
- Some knowledge of regional and national organisations involved in mental health.
- Ability to read and summarise detailed information in preparation for meetings and in order to disseminate to others if required.
- Some experience in delivering training to a variety of people and settings.
- Knowledge of mental health legislation.
- Knowledge of Government policies that relate to mental health service delivery.

The Dorset Mental Health Forum wishes to encourage applications from people with disabilities. Where the Person Specification calls for particular qualifications or experience, we will consider waiving these requirements if an applicant who could not achieve them because of a disability can demonstrate he/she would be capable of performing well in the job and fulfils the criteria in other respects.