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Advance Care Planning



Foreword



The National Centre for Post-Qualifying Social Work and Professional Practice has produced a series of brief guides to help all health and social care professionals navigate through and apply the principles of the Mental Capacity Act for decisions regarding treatment and care. This is one of those guides and should be read in conjunction with the other guides in the series. These guides can be downloaded for free from www.ncpqsw.com

We trust that these resources will assist all health and social care professionals in delivering the very best possible care in this difficult time of the Covid 19 response and also into the future when we get to the other side of the Covid 19 pandemic.

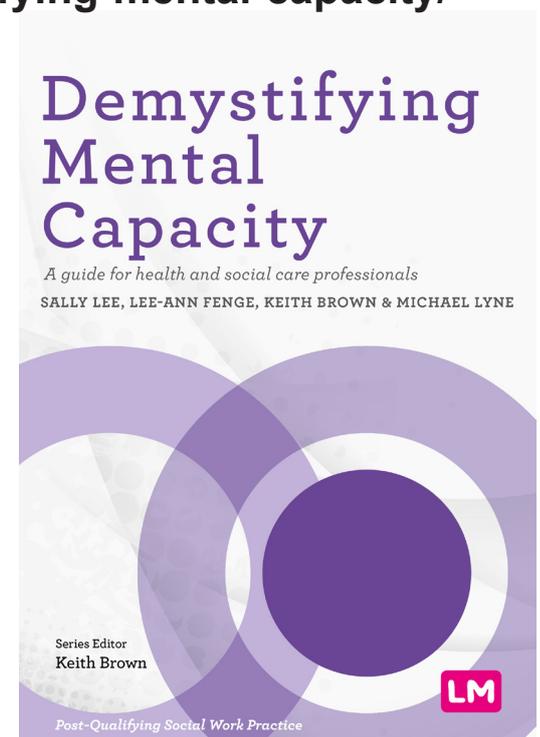
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The new Demystifying Capacity Sage book available to order at <https://uk.sagepub.com/en-gb/eur/demystifying-mental-capacity/book269861>

Set against the backdrop of the Mental Capacity Act 2005, this book explores and addresses issues raised by mental capacity within adult safeguarding, and provides clear guidance on the use and value of the MCA, and how to ensure that the rights and choices of individuals are heard, listened to and acted upon.

With contributions from a range of subject experts across the legal, social work, nursing and healthcare disciplines, this book will be invaluable to practitioners in the health and social care profession, and indeed any role where issues of mental capacity may be a concern. Case studies, reflection points and exercise are used to develop understanding and support critical engagement with practice.



Introduction

Supporting and encouraging individuals to look forward and consider the treatment and care they may require in the future is an increasingly important aspect of clinical care – in health and social care settings. Whether the person is in an acute hospital, community hospital/unit, care home or receiving care in their own home, practitioners need to be mindful of decisions individuals may need to make, or have made, regarding future care – for urgent treatments, such as resuscitation, acute treatments or priorities for end-of-lifecare. At this time of pressures on NHS services, due to the Covid pandemic, individuals and clinicians are facing difficult decisions at a time of crisis. Advance Care Planning is therefore even more important at this time – and will continue to be so – in order to support individuals to make choices and decisions about their future care.

The underlying philosophy of treatment and care, under the Mental Capacity Act (2005), is to promote person-centred care, in accordance with the individual's known choices, wishes, values and beliefs. To this end, the principles of the MCA are to encourage individuals to make their own decisions wherever possible and to ensure that decisions for those individuals who lack the capacity to consent to treatment and care are made in their best interests. The MCA aims to balance an individual's right to make decisions for themselves with their right to be protected from harm if they lack capacity to make decisions to protect themselves. Advance Care Planning is one way in which a person can make known their decisions regarding treatment and care, to be considered in the future.

What is Advance Care Planning?

Advance Care Planning (ACP) is a way in which individuals can discuss and make clear their wishes and choices for treatment and care, which may become relevant at a future time, when they lack capacity to make decisions for themselves. ACP may involve an individual setting out their decisions regarding choices of treatment and care in documents such as Advance Decisions to Refuse Treatments (ADRTs) or through Lasting Power of Attorneys for Health & Welfare (LPA) – both of which are legally binding. ACP may also result in the individual setting out their decisions and choices regarding future care in Advance Statements of Preferences (ASP), Treatment Escalation Plans (TEP), Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) and other forms of advance care plans. ACP may simply involve an individual making their future wishes known verbally to their family, LPA or health professional involved in their ongoing treatment and care.

“ Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness. ”

(International Consensus Definition of Advance Care Planning 2017)

Health & Social Care practitioners must be aware of the purpose and usefulness of ACP and the legal responsibilities they have in considering any wishes or choices and following any ADRT. They must also support and assist individuals wishing to use ACP and/or their LPA, as a means of planning their future treatment and care they would wish to receive and making decisions regarding any medical treatments they would not want to have.

Advance Care Planning – Person-Centred Care

ACP enables personalised care for the future; it can make the difference “between a future in which a person makes their own decisions regarding their care and a future where others do” (NICE 2019). By following decisions from ACP, the individual’s wishes and preferences may be followed; their respect, dignity and personhood may be protected. For people with progressive conditions, terminal cancer or end-stage long-term conditions, ACP can promote choice and control over their treatment and care preferences, relevant at a point when their health declines. Decisions made through ACP can provide peace of mind for their family and confidence to the clinical team, ensuring that elements of care which are important to the person are known about and followed (NHS England 2018).



NICE (2018) recommended that ACP should start as early as possible after a diagnosis of any life-limiting condition, to enable individuals to make informed choices about their future care. This is particularly relevant at time of crisis, such as the Covid 19 pandemic, when individuals may be receiving news of diagnosis which may or may not be life limiting. NICE guidance is clear that support and advice should be given at the most suitable time, following any diagnosis and then repeatedly throughout the illness, to allow people to think through and address different issues in their own time, to make ACP as useful and meaningful for the individual.

ACP becomes even more important in planning for end-stage or end-of-life care for terminal conditions or frailty. Patients with terminal cancer or progressive long-term conditions should be supported by healthcare professionals, to set out the care they would wish to have, for the end-stages of their condition – with a range of decisions and wishes recorded to influence future care; this may include decisions for refusal of certain treatments (ADRT), and the care which may be provided by other agencies such as social care, family or private carers (ASP). Nurses can play a vital role in supporting individuals with such planning, going beyond the clinical care and treatment and helping individuals explore what may be unthinkable (Kay 2016); enabling individuals to make their own difficult decisions about treatment and care for the end of life, some of whom would be too frightened to do so on their own. Whilst these conversations are not always easy, this element of practice should be viewed as a privilege, to enable individuals to influence their future care, be engaged and involved in decisions and take control of their lives, at a time when little control is left to them (Kay 2016; Lewis 2019).

Advance Care Planning – The Process

In the Gold Standards Framework (2018), ACP is described as a process which encourages people to clarify their wishes, needs and preferences for the kind of care they would like to receive, in relation to the MCA (2005). It provides the means for individuals to clarify:

What is important to me – what treatments and care the individual wants to have. These may be recorded through Advance Statements of Preferences (ASP), or discussed with close family. Although neither would be legally binding, the person's stated wishes, made through a process of ACP, would have to be considered in any Best Interest decisions regarding future care.



What I want to refuse - what treatments the individual does NOT want to have. These should be set out in Advance Decisions to Refuse Treatments (ADRT). They may include decisions regarding resuscitation, other emergency and life-saving treatments, which must be recorded.



Who will speak for me – A person's next-of-kin has no statutory rights to speak or make decisions for the individual. Although the MCA requires the clinical team to involve and consult with the family members of an individual, when the person lacks capacity to consent to treatment and care the family

have no automatic right to make decisions (The National Centre for Post-Qualifying Social Work and Professional Practice 2016). When a person has appointed a Lasting Power of Attorney for Health & Welfare, the LPA must follow the person's known wishes and always act in their best interests. The LPA has the right to consent or refuse treatment on behalf of the individual, when they lack capacity to make decisions themselves, including decisions regarding life-sustaining treatments if the person has given this particular power to the Attorney.

(Based on The Gold Standards Framework 2018)

ACP is a voluntary process which sets out a person's decisions about future care. Many people will want their family and friends included in the discussion, but it is important that the decisions regarding future care are in accordance with the choices and wishes of the individual. Whilst discussions are really helpful, the person should be encouraged to document these decisions for future care (ASPs) and any refusal for future treatments (ADRTs).

Checklist for supporting people through Advance Care Planning:

- ✓ **Check** - has the person already made provision for future decisions?
- ✓ **Think** - some people may not want to talk about future care or planning for this.
- ✓ **Remember** - everyone is different – their wish for knowledge, autonomy and control.
- ✓ **Be prepared** - to explain the purpose and process of Advance Care Planning.
- ✓ **Respect** - people may make choices that seem unwise; this does not mean that they are unable to make decisions or their decisions are wrong.

(Based on NICE guidance 2019)

Advance Care Planning to Inform Best Interest Decisions

Where an individual is found to lack capacity to consent to care and treatment and there is no LPA appointed or ADRTs known, the clinical team must make Best Interest decisions for treatment and care; the MCA requires a consensus of those involved, having considered all relevant information pertaining to the proposed treatment and the individual person. The MCA Code of Practice published a statutory checklist for all Best Interest Decisions (Department for Constitutional Affairs 2007). This includes the consideration of any known decisions and choices for treatment and care and legal standing of any Advance Decisions to Refuse Treatments.

The MCA Code of practice makes it clear that a “person’s best interests must be the basis for all decisions made and actions carried out”. Working out what is in someone else’s best interests may be difficult, and the Act requires people to follow certain steps to help them work out whether a particular act or decision is in a person’s best interests. This includes finding out the person’s views and wishes which may have been “expressed verbally, in writing or through behaviours or habits”. (Department for Constitutional Affairs 2007). This was firmly supported by Baroness Hale in *Aintree University Hospitals NHS Foundation Trust v James*¹, who stated, “The purpose of the Best Interest test is to consider matters from the patient's point of view” (paragraph 45).

Advance Care Planning to Identify Refusal of Medical Treatments

Decisions to refuse certain medical treatments may have been made by an individual, as part of ACP. The wishes and rights of the individual are paramount; this applies for refusal of care and treatment and ADRTs are legally binding (Brown et al. 2015; Kay 2016).

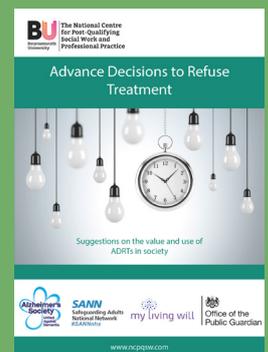
The MCA Code of Practice (2007) sets out specific responsibilities of clinical practitioners with regards to ADRTs:

- To check for ADRTs.
- Confirm the validity and applicability of ADRTs.
- If the ADRT is valid and applicable, ensure that the person’s prior decisions to refuse treatments are followed.

ADRTs must be made when the individual has the mental capacity to make informed decisions to refuse a treatment. ADRTs for refusal for life-sustaining treatments must be recorded in writing. They cannot be used to request or demand treatments, nor can they be used to refuse general care and treatment such as the provision of food, fluids, personal care (The National Centre for Post-Qualifying Social Work & Professional Practice 2018).

ADRTs can cause professional dilemmas and disagreements within clinical teams, as the professional opinion of health staff may be overridden by a valid ADRT to refuse certain treatments. However, the law is clear that where individuals have made clear statements to refuse certain treatments through an ADRT, in writing or perhaps verbally to others, at a time when they had the mental capacity to do so, the clinical team must abide with this refusal of treatment. Treatment which has been commenced in advance of the discovery of an ADRT should be discontinued as long as the clinician is happy that the ADRT is “valid and applicable” (see *Advance Decisions to Refuse Treatment - The National Centre for Post-Qualifying Social Work & Professional Practice 2018*).

Your Trust may have policies and guidance for staff on the recording of verbal and written ADRT. For more information see *The National Centre for Post-Qualifying Social Work & Professional Practice (2018a)* and <https://compassionindying.org.uk/>



Advance Care Planning for Decisions About Emergency Care

The importance of planning in advance for future care and treatment is particularly important for decisions regarding resuscitation and other emergency treatments. By having discussions when the individual is able to be involved and informed of emergency procedures, appropriate clinical decision-making can be recorded clearly, for use if and when the person's clinical condition deteriorates and in the event of cardiorespiratory arrest.

Resuscitation status (Do Not Attempt Resuscitation - DNAR) is a clinical decision, made in advance by the clinical team, on the basis of whether the individual is likely to respond to cardiopulmonary resuscitation and would benefit from ongoing care for major organ failures in critical care settings. As with any proposed treatment, the individual's consent to CPR should be sought and recorded. Where the person lacks capacity to consent to resuscitation decisions, these must be made following the MCA Best Interest principles. It is good practice to involve and include the patient's family, if appropriate, but the decision remains one to be made on clinical grounds and recorded by the clinical team. Professionals do need to remember though, that making such a decision without consultation with family, or people with an interest in the person's welfare may well result in a breach of the individual's rights under Article 8 European Convention on Human Rights ².

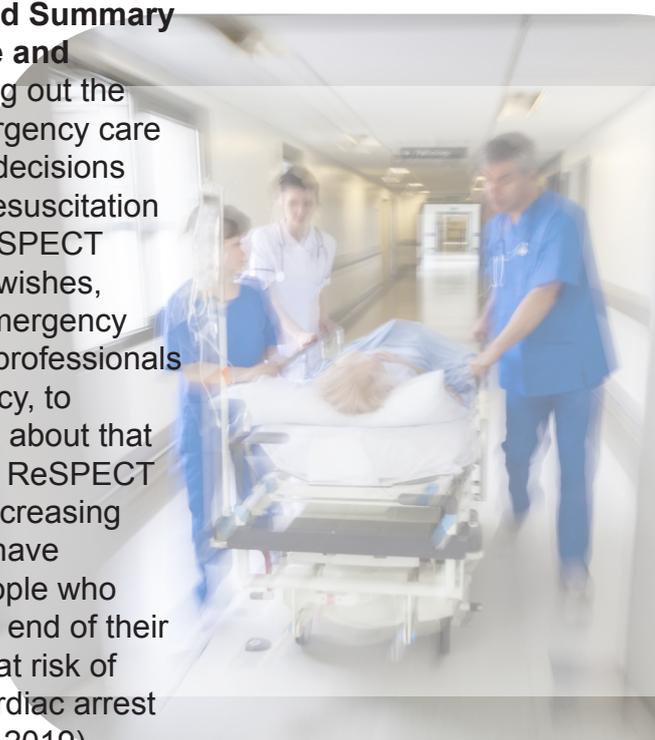
¹ [2013] UKSC 67

² *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB)

Following a report into the outcomes of in-hospital resuscitation, NCEPOD (2012) published national recommendations for an improved means of recording discussions and decisions relating to resuscitation and other levels of emergency care. It was recognised that whilst an individual may not be appropriate for resuscitation, other levels of acute care may be relevant. The term 'ceilings of care' was used to define and set out appropriate levels of urgent treatment for an individual, including resuscitation status. **Treatment Escalation Plans (TEP)** are commonly used to record ceilings of care, in hospital and community settings – these include admission to hospital, use of intravenous therapies, critical care treatments and resuscitation decisions. As part of ACP, individuals need to be involved with decisions regarding resuscitation and ceilings of care, so that these may be documented and followed in the event of the patient deteriorating.

ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

is a plan setting out the personal priorities for emergency care and treatment – including decisions regarding resuscitation (Resuscitation Council UK 2019). The ReSPECT provides details of patient wishes, with regards to levels of emergency treatments, to help health professionals responding to an emergency, to make immediate decisions about that person's treatment. Use of ReSPECT as part of ACP, will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest (Resuscitation Council UK 2019).



Although decisions regarding resuscitation and ceilings of care remain clinical decisions, made by senior clinicians, individuals need to be involved with decisions regarding resuscitation and ceilings of care. Individuals wishing to make advance planning to refuse life sustaining treatments, such as resuscitation, need to record these through ADRTs, which will be followed in the event of the patient deteriorating.