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Advance care planning and clinical decision-making

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Abstract

Advance Care Planning has been defined as a process for individuals with decisional capacity to outline their values and reflect upon the meanings and consequences of serious illness scenarios in the months and years ahead. This process defines goals and preferences for future medical treatment and care, and addresses individuals' views across the physical, psychological, social and spiritual domains. It encourages individuals to identify a personal representative, and to record and regularly review any preferences so that these can be taken into account should they, at some point, be unable to make their own decisions. The internationally agreed definition has not incorporated patients with absent, diminished or fluctuating mental capacity at the time of making a decision about future care. This article discusses some of the clinical implications of this, and illustrates existing examples of best interests decision-making processes via a future care-planning approach. The article also highlights current definitions and discusses the need for a process that is concerned with 'what matters most' to patients, and is therefore not wholly focused on questions about future resuscitation attempts.

Keywords

Advance care planning; DNACPR; DNAR; Do Not Attempt Cardiopulmonary Resuscitation; future care planning; palliative care

Key points

- **Advance Care Planning as per its international definition is limited to capacious patients**
- **Several countries, notably Scotland and Wales, have now introduced terminology that also embraces future planning for those with diminished or absent mental capacity at the time of decision making**
- **There has been concern about the perceived unidirectional nature of advance care planning conversations and their being too strongly focused towards prioritizing DNACPR decisions. We outline other effective ways of documenting and communicating advance and future care planning decisions, including Advance Decisions to Refuse Treatment, Advance Statements and setting up Lasting Power of Attorney for Health and Welfare**

Introduction

Advance care planning in the context of palliative care when a natural and anticipated death is expected involves sensitive discussions about future scenarios and incorporating the views and preferences of the patient and those close to them.

Generalists and primary care clinicians who have known their patients for many years are often in a position to explore views on future resuscitation attempts, admission to hospital for interventions and investigations, prescribing anticipatory medications for home use, or even the location(s) a person might prefer to be cared for in the last days of their life.¹ The National Institute for Health and Care Excellence (NICE) quality standards on end-of-life care for adults state that people approaching the end of life should feel satisfied that they have been able to discuss, record and review their needs and preferences if they would like to do so.

In addition, the NICE guidelines on care of dying adults in the last days of life, state that healthcare providers should record individualized care plan discussions and decisions in a person's record of care; this care plan should be shared with the person, those important to them and all members of the multi professional care team. In recent years, there has been recognition that electronic patient records co-function as an important repository for the variety of advance and future care-planning decisions and documents that exist in each healthcare system.

Advance care planning sometimes over-focuses on 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) preferences and people's preferred place of care rather than utilising communicative approaches that alternatively focus in the first instance on what matters most to the person (see useful websites: 'What Matters Most charter').

Definitions

Advance care planning has been defined internationally as follows: ²

‘Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.’

This sets out that advance care planning requires *decisional mental capacity* at the time point(s) when a decision is required. However, it leaves out individuals for whom a future decision is required, but who, after careful assessment, are deemed not to be able to participate in decision-making. This includes individuals with diminished mental capacity, as well as infants and children.

Several countries have addressed this shortfall. In Scotland, the term *anticipatory care planning* has been used. In Wales, the term *future care planning* has been agreed as an umbrella term to capture both the advance care planning aspect (which, by the definition from the European Association for Palliative Care (EAPC), requires an individual to have decisional capacity at the outset), as well as best interest decisions for individuals who do not have decisional capacity regarding such aspects of their care at the start of a process.

The UK Mental Capacity Act provides a list of factors that decision-makers must consider when weighing up what may be in the person’s best interests. The Act makes it clear that decisions must not be made on the basis of an individual’s age, appearance or any aspect of their behaviour. Crucially, decision-makers must consider the individual’s past and present wishes as well as the beliefs and values that might have guided them had they had capacity.

Those pivotal in reaching a balanced decision are anyone named by the person who is engaged in caring for them, any registered Lasting Power of Attorney (LPA) for Health and Welfare, a nominated court-appointed deputy or, if a person has no family or significant others, an independent mental capacity advocate.

The term ‘future care plans’ has also been adopted by the Department of Health and Social Care for England and Wales in their 2022 document on the ‘Changes to Mental Capacity Act code of practice and implementation of liberty protection safeguards’ (see useful websites).

In the document they have introduced text on “future care plans” drawn up for a person who lacks the relevant capacity, emphasising that it should help inform a best interests decision.

Important definitions in clinical decision-making

Front-line clinicians should be familiar with the following terminology, which forms part of advance care planning, anticipatory care plans and future care planning approaches across the UK.

Advance Statements

An Advance Statement, also known as a ‘Statement of Wishes and Preferences’, allows individuals to record their ideas, wishes, feelings, beliefs, fears and values in case they later become unwell, are unable to communicate and need care or medical treatment. Such Advance Statements can exist in varying formats, including audio or video recordings. Advance Statements are advisory but they are not legally binding.

Advance Decisions

An Advance Decision to Refuse Treatment (ADRT) is sometimes referred to as an Advance Decision or living will, and in Scotland as an Advance Directive. It allows individuals to record and document treatments that they do not want to have in the future, in case they later become unable to make or communicate decisions for themselves. The ADRT will only become active if they cannot make or communicate a decision for themselves. ADRTs are legally binding in England, Wales and Northern Ireland. In Scotland, Advance Directives are not legally binding but should be taken into account by clinicians.

If valid and applicable, an ADRT has the same effect as a refusal made by a person with mental capacity, and clinicians must follow it, although they may refer any challenges to the Court of Protection. Failure to abide by a valid ADRT may meet the requirements for assault and battery.

Lasting Power of Attorney for Health and Welfare

An LPA allows individuals to give someone they trust the legal power to make decisions on their behalf in case they later become unable to make decisions for themselves. The person who makes the LPA is known as the ‘donor’ and the person given the power to make decisions is known as the ‘attorney’.

There are two different types of LPA in England and Wales: an LPA for Property and Financial Affairs, which covers decisions about money and property, and an LPA for Health and Welfare, which

covers decisions about health and personal welfare such as medical treatment, place of care, type of care given and day-to-day matters such as diet, how to dress and choice of daily routine.

An attorney cannot enforce that certain treatments be given but is able to refuse them on behalf of the donor. Furthermore, this can only happen if the donor has lost decisional capacity at the time when a specific decision has to be made. Clinicians should enquire whether someone has an LPA in place and what type of LPA it is. They should check that it is registered with the Office of the Public Guardian, and this information can be obtained online. Section 5 of an LPA for Health and Welfare form covers life-sustaining treatment and when reading the form, clinicians should check whether or not the attorneys have the power to make decisions about life-sustaining treatment.

Scotland uses the term Welfare Power of Attorney, and this covers decisions about health and personal welfare.

Do Not Attempt Cardiopulmonary Resuscitation forms

A DNACPR form is a document issued and signed by doctors and sometimes nurses, or allied healthcare practitioners, that advises healthcare providers attending not to attempt cardiopulmonary resuscitation (CPR).

DNACPR forms are not legally binding documents, and any decisions must be guided by an assessment of whether the initial reason for recording the DNACPR form is applicable to the situation at hand. For example, a person who is not dying from their cancer, but who is instead choking on food or suffering a sudden anaphylactic shock, may fully expect to have resuscitative measures put in place, even in the presence of a DNACPR form that has recorded a recommendation that they are not given CPR if and when they are dying from their metastatic lung cancer.

Scotland and Wales have national DNACPR policies that are openly accessible to the public, audited and regularly updated.

Treatment Escalation Plans (TEPs)

TEPs are paper and electronic components of a patient's clinical inpatient care record. They go further than DNACPR forms in that they document discussions and decisions involving life-sustaining treatments, for example pulmonary ventilation (invasive or non-invasive), cardiac resuscitation, renal replacement therapy, intravenous fluids and antibiotics.

The main aim of a hospital-based TEP is to ensure that an individual's goals of treatment are understood by all healthcare professionals during that *specific* hospital admission.³ TEPs also focus on acute care and immediate near-future decisions, whereas the process of advance care planning

tends to focus on decisions that last beyond a mere hospital inpatient stay; these can therefore be seen as two distinctive processes, but with common strands.

Good communication strategies

Sensitive and clear communication is one of the most important aspects of future care planning; a challenging task of conveying a topic that many still find difficult to talk about.

Examples of resources to support healthcare professionals in facilitating these conversations include the Royal College of Physicians' Second Conversation Project, the Serious Illness Conversation Project Cymru (introduced for professionals all over Wales) and the TalkCPR video resources (see useful websites and further reading).

It is important that such communications involve those close to the patient, are conducted in quiet undisturbed spaces and only happen if the patient is happy to carry on with such a conversation. Ideally, they should be offered to have a person they trust with them. Using checking questions or statements throughout the consultation, such as 'Are you ok for me to go on talking about this, or is it all a bit much right now?' or 'Let me know at any point if you want me to stop' can give the individual back a sense of control.

There has been concern about the perceived unidirectional nature of advance care planning conversations and their being too strongly focused towards prioritizing topics such as DNACPR and preferred place of death. Therefore, the UK End of Life Care Think Tank (supported by organizations including the Royal College of General Practitioners, Royal College of Nursing, Marie Curie and Macmillan Cancer Support) propose the What Matters Most Charter, based on four key principles (see box 1 below):

- 1. What matters most conversations are a voluntary process that can be discussed at any point in life**
2. Promote a culture of openness about living as well as possible for the whole of life, including living with life-limiting illness.
3. What matters most conversations centre on individuals and their significant relationships rather than being 'owned' by healthcare professionals.
4. To enable living well until death.

Practical guidance

Clinicians can sometimes focus primarily on completing tasks, including the need to document major decisions with regard to future care planning on designated forms on admission. It is the calibre of

the communication and the quality of the conversation that matter more, in both in-hours and out-of-hours situations.^{4 5 6} The value of a discussion can be significant and can be held over several consultations, not just one.

Survival to discharge after CPR is highly unlikely in certain conditions, such as sepsis or metastatic cancer, and offering CPR when not clinically indicated can cause harm. Clinicians should explicitly and clearly advise against attempting CPR where it is felt that this is likely to be unsuccessful and cause harm, explaining why it is not indicated as a medical treatment and is likely to be futile. Asking questions such as ‘Does your view on this topic differ significantly from what the medical team are thinking?’ can offer the individual and their significant others some room to express their own opinions or counter-views on future escalation measures. A key challenge during the coronavirus pandemic was the shift towards remote consultations, and how advance care planning conversations could be held, for instance, via video call. Practical solutions that some services came up with included sharing, with patient’s consent, their preferred video or app-based messaging contact methods,^{5 6 7} so that palliative care community workers could make contact via video messaging, for instance.

REFERENCES

1. Ali M, Capel M, Jones G, Gazi T. The importance of identifying preferred place of death. *Br Med J Support Palliat Care* 2019; 9: 84-91.
2. Rietjens J, Sudore R, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017; 18: 543-551.
3. Taubert M, Bounds L. Advance and future care planning: strategic approaches in Wales. *Br Med J Support Palliat Care* 2022; 0: 1-5.
4. Fritz Z, Slowther AM, Perkins GD. Resuscitation policy should focus on the patient, not the decision. *Br Med J* 2017; 356: 813-818.
5. Abel J, Taubert M Coronavirus pandemic: compassionate communities and information technology *BMJ Supportive & Palliative Care* 2020;10:369-371
6. Taubert M, Noble SIR, Nelson A What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners *BMJ Supportive & Palliative Care* 2011;1:13-18.
7. Taubert M, Norris J, Edwards S, Snow V, Finlay IG 2018. Talk CPR-a technology project to improve communication in do not attempt cardiopulmonary resuscitation decisions in palliative illness. *BMC palliative care*, 17(1), pp.1-12.

Further reading

Huber MT, Highland JD, Krishnamoorthi VR, Tang JW. Utilizing the electronic health record to improve advance care planning: a systematic review. *Am J Hosp Palliat Care* 2018; **35**: 532-541.

Mathew R, Sleeman KE, Dunhill H, et al. The second conversation project: improving training in end of life care communication among junior doctors. *Future Healthc J* 2019; **6**: 129-136.

Taylor RM, Gustin JL, Wells-DiGregorio SM. Improving do-not-resuscitate discussions: a framework for physicians. *J Support Oncol* 2010; **8**: 42-44.

Useful websites

Consultation (UK) June 2022: Changes to the MCA Code of Practice and implementation of the Liberty Protection Safeguards

<https://www.gov.uk/government/consultations/changes-to-the-mca-code-of-practice-and-implementation-of-the-lps> (accessed Sept 2022)

What Matters Most Charter, End of Life Care Partners Think Tank:

<https://www.whatmattersconversations.org/2020-charter>

British Medical Association. Best interest's decision making for adults who lack capacity toolkit.

<https://www.bma.org.uk/advice-and-support/ethics/adults-who-lack-capacity/best-interests-decision-making-for-adults-who-lack-capacity-toolkit> (accessed Sept 2022)

General Medical Council. Ethical implications towards the end of life. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/cardiopulmonary-resuscitation-cpr> (accessed Sept 2022)

TalkCPR. Information and videos for patients, carers and healthcare professionals about CPR.

<http://talkcpr.com> (accessed Sept 2022)