Advance care planning: ethical and clinical implications for hospital medicine

Advance care planning takes place 'in advance of' anticipated loss of capacity with the aim of informing the best interests judgments required when capacity is later lost. It is an ethically and clinically distinct subset of general care planning.

Daily decision making occurs 'now' in the acute medical setting; it is ethically and legally distinct and different from any form of care planning for the future.

While general care planning for the future is widely encouraged in order to try to achieve patients' preferences, especially in the context of end of life care, it is important to identify and find solutions for the clinical and ethical issues it raises: voluntariness, creating unrealistic expectations, conflicts of interest between patients and their families, individuals' preferences *vs* cost-effectiveness and justice. Advance care planning is a specific type of care planning for the future.

The primary aim of advance care planning by patients with capacity (as distinct from care planning in general) is to inform best interests judgments needed when patients later lack capacity, by recording their preferences and/or values in an advance statement. While acute inpatient care is unlikely to be the best time for advance care planning discussions, the knowledge of hospital specialists may be essential in enabling patients to be adequately informed to express true preferences. Patients may present a personal advance statement, possibly entitled 'advance care plan', or a document expressing preferences (but not specifically an advance statement), possibly entitled 'preferred priorities for care' or 'thinking ahead'. It is important that hospital staff recognize the significance of these. When appropriate, staff can use these to open conversations about advance care planning.

There is an important difference between the interpretation of the terms 'a choice' and 'a preference' in relation to patients' wishes regarding future treatment and care.

This article distinguishes 'decision making' now from 'care planning' for the future and explains briefly what is understood by care planning in a general sense, but it focuses primarily on the ethical and clinical issues of advance care planning as they impact on secondary care. While it reflects the National End of Life Care Programme (2011) guidance *Capacity, Care Planning and Advance Care Planning in life limiting illness*, produced in response to evident clinically significant confusion from both clinicians and patients, it also draws upon the comprehensive evidence-based guidance on advance care planning published by Royal College of Physicians (2009) and on the General Medical Council (2010) guidance *Treatment and care towards the end of life: good practice in decision making*.

Distinction between decision making (now) and care planning (for the future)

Decisions about treatment and care are made at the time when the treatment or care is clinically necessary. There is no legal or ethical mechanism whereby an effective decision could be made for a future time or circumstance (with the exception of a patient's advance decision to refuse a specified treatment, if valid and applicable). The well-understood processes for making decisions depend on whether or not the patient has capacity for the particular decision at the time it is needed; they are described in the General Medical Council (2008) guidance on consent, and in the code of practice for the Mental Capacity Act (Department for Constitutional Affairs, 2007) for patients who lack capacity.

In contrast, lack of clarity and misunderstanding of the ethical and legal issues of making plans for future health care have become clinically important, especially given the current promotion of care planning. Essentially a plan is only a plan – while it informs the decision to be made in future clinical circumstances it does not dictate what it must be, and it does not replace the decision-making authority and clinical responsibility of the clinician who is the decision maker when the decision is actually needed.

Where the patient retains capacity for the decision when it is needed, then the process is explicitly one of consent, so any pre-existing advance statement or advance decision to refuse treatment is not used, and any general care plan will be effectively overridden by the patient's current decisions about treatment and care.

But where the patient lacks capacity then the content of any advance statement or advance decision to refuse treatment, or general care plan agreed with the patient, must be taken into account in making the best interests judgment. It is essential that hospital doctors understand that when they are decision makers they are not bound by an advance statement (with the exception of a valid and applicable advance decision to refuse treatment) or by an

Dr Fiona Randall *is Consultant in Palliative Medicine, Earl Mountbatten Hospice, Isle of Wight Primary Care Trust, Newport, Isle of Wight PO30 2ER*

agreed 'care plan', although they will be informed by and take account of the values and preferences they express.

General care planning

The national End of Life Care Strategy (Department of Health, 2008) recommends that all patients (and also their carers) are offered a care plan. The terminology of care planning is familiar in nursing and social care. In contrast, the practice and language of doctors (and of the General Medical Council (2008) and health care law) pertains to decision making; as such it focuses first on selecting treatment options on the basis of overall benefit, then on consent for patients with capacity and on best interests judgments for patients lacking capacity.

The National End of Life Care Programme (2011) guidance makes clear that 'care planning' is applicable to patients with and without capacity. (This contrasts with advance care planning which is undertaken only by patients with capacity, any resulting advance statement being used only when capacity is later lost.) It also explains that care planning includes treatment strategies and is not confined to issues of nursing care or location of care; that it includes planning for 'immediate needs' and not just the future; that care planning is voluntary for the patient; that care plans which document 'the care and treatment actions necessary to meet a person's needs, preferences and goals of care' must have been agreed with the person receiving care or by those acting in the person's best interests.

Care planning for immediate needs must be a reference to decision making required 'now'. So the principles and process (ethically, legally and conceptually) must be those of decision making, namely consent or making a best interests judgment. Confusion may result from using the term care planning in lieu of decision making regarding current treatment.

The familiar term care plan, referring to a regimen of nursing care either on the ward or after discharge home, inclines us to think that care planning is about formulating this sort of care plan. Therefore broadening the concept to include medical treatment may cause confusion.

Distinction between a care plan for the future and a medical plan based on clinical appropriateness

There is a distinction between a medical plan to withhold or withdraw a treatment on the grounds that in those future circumstances it would be clinically inappropriate, and a care plan which the National End of Life Care Programme (2011) advises must be agreed with the patient or with those close to a patient who is lacking capacity. It is important that the doctors and other team members are clear about the ethical difference between the two plans, and in which category a particular patient's plan belongs.

In the context of end of life care a medical judgment or plan is sometimes made that in the event of a particular future deterioration in the patient's health certain treatments would not be clinically appropriate. An example is 'do not attempt resuscitation' orders made on the basis that there is no realistic prospect of successful cardiopulmonary resuscitation, so cardiopulmonary resuscitation is not offered, is discussed only if appropriate and is not attempted, as in the joint statement guidance (British Medical Association et al, 2007) and endorsed by the General Medical Council (2010) end of life care guidance. The basis of such medical judgments is lack of foreseen benefit, especially in the context of treatment harms and risks, so it should perhaps be described as a medical plan. If such a plan were considered a care plan then it could be made only with the patient's agreement (or that of those close to a patient who lacked capacity). This would be ethically unacceptable because doctors are not obliged to provide (and arguably ought not to provide) treatment which they consider is clinically inappropriate, which would include such treatment requested for the future, as the General Medical Council (2010) explains.

Even if a doctor records a medical plan that a particular treatment in future will or will not be clinically appropriate, when the time comes for that decision the doctor then clinically responsible for the patient will actually take the decision and bear responsibility for it.

Advance care planning

Advance care planning is about planning for future loss of capacity. In England and Wales advance care planning is directly related to the Mental Capacity Act 2005 which governs decision making for patients lacking capacity. The Adults with Incapacity Act (Scotland) 2000 applies in Scotland.

The General Medical Council (2010) defines advance care planning as: '

> **'The process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference….'**

It goes on to state that advance care planning seeks to create a record of the patient's values and preferences. Such a record is known as an 'advance statement'. Thus far this definition is unproblematic ethically.

However, the definition also states that the aim is:

> **'to *ensure* that care is planned and delivered in a way that *meets* their needs and *involves* and *meets* the needs of those close to the patient.' [author's italics]**

Two ethically problematic implications follow. The first is the implication that preferences will be met. This may give rise to unrealistic expectations in patients and their families, with possible attribution of blame on professionals who may also feel they have failed when preferences are not met because treatment or location of care requested were clinically inappropriate or not available within resource constraints.

The National End of Life Care Programme (2011) guidance on general care planning similarly implies that patients' preferences will be met. Furthermore, its definition of advance care planning stipulates the aim of recording 'choices about their care and treatment' as opposed to 'preferences'. The use of 'choice' implies that future treatment is a choice which it is up to the patient to make – but we know that patients cannot, either ethically or legally, require via an advance statement that in future a particular treatment or care regimen which is not judged to be in the patient's best interests would be provided, as the General Medical Council (2008) notes. This is once again because best interests judgments must include clinical appropriateness regarding the balance of clinical benefit to harm and risk. Resource constraints may also limit options. The only future choice that a patient can make is an advance decision to refuse a particular treatment.

The second problematic implication is that meeting the needs of 'those close to the patient' is part of the aim of advance care planning. A fundamental principle of the Mental Capacity Act 2005 is that decisions made must be based on the patient's best interests (as opposed to the interests of others such as those close to the patient). An inescapable ethical problem is the not infrequent conflict of interest between the patient's best interests and those of the family, especially in relation to place of care and death. The law protects the interests of the patient. However, as the code of practice explains (Department for Constitutional Affairs, 2007), 'interests' should be considered broadly to include any known values (especially those recorded in an advance statement) and the overall effects of decisions on the patient.

Outcomes of advance care planning

Under the terms of the Mental Capacity Act and for the purpose of aiding decision making when capacity is lost, a patient can make one or more of the following three recorded formal outcomes of advance care planning:

1. An advance statement recording preferences and values in relation to future care and treatment
2. Advance decisions to refuse treatment (which are legally binding if valid and applicable to the circumstances which then pertain)
3. Appointment of lasting powers of attorney for health and welfare and/or property and affairs.

These outcomes are voluntary – some patients will undertake the discussion but not wish to make any recorded outcomes.

Relationship of advance care planning to general care planning

Care planning is applicable to patients with and without capacity, whereas advance care planning is applicable only to patients with capacity for later use once capacity is lost. Care planning may be applicable to immediate needs, whereas advance care planning is about future needs or circumstances only.

Advance care planning is a specific subset of general care planning (but patients can achieve any of the three formal outcomes of advance care planning without a care planning discussion with health-care staff, although this is not advised).

An advance statement expressing the preferences of a patient following an adequately informed advance care planning discussion in anticipation of loss of capacity is clearly a more reliable guide when making best interests judgments than a general care plan, although the validity and applicability of both should be considered.

Advance care planning discussions: what information does the patient need?

Regarding future treatment options, in order to be adequately informed to express a preference the patient needs essentially the same information as would be needed to give consent for the treatment. In the context of end of life care this information will often entail discussion of future illness scenarios and how a treatment is likely to affect symptoms and the timing and mode of death. So, as the Royal College of Physicians (2009) recommends, professionals instigating advance care planning discussions need to have enough knowledge of the patient's disease, the treatment options, and the benefits, harms and risks of those options, similarly to the requirements for seeking consent. Regarding place of care and death, patients need honest information about the care they are likely to need and the resources available in each location.

Advance care planning as a hospital intervention?

The Department of Health (2009) 'top ten' quality markers for end of life care include ensuring that patients are offered a 'care plan', and for acute hospitals the measure is that 'they offer care plans to all patients approaching the end of life.'

However, this goal is rather inconsistent with evidence-based guidance produced by the Royal College of Physicians (2009) which advises that advance care planning is best conducted when the patient is stable and as a series of discussions over time, and may not be appropriate just after diagnosis, or when acutely unwell requiring hospitalization. It recommends that 'Ideally, advance care planning discussions should be initiated in primary care or in the outpatient setting, before individuals become acutely unwell.'

An ethically appropriate solution to this apparent inconsistency may be to avoid instigating advance care planning when the patient is unstable, to exercise great caution in instigating advance care planning in the inpatient acute setting, but to offer a more general care planning discussion and to liaise clearly with the GP upon discharge – highlighting those patients who are likely now to be at the end of life and so should be offered this sort of discussion.

Potential benefits of advance care planning for patients

The key benefit is that patients' previously stated considered preferences can be taken into account in making best interests judgments on their behalf when capacity is lost. Thus treatment and place of care is more likely to accord with their wishes. In addition, there is some evidence that advance care planning discussions with patients with long-term conditions or as part of end of life care can increase patient satisfaction, as reported in the Royal College of Physicians (2009) guidance.

Potential harms of advance care planning for patients

Contemplation of both lack of capacity and future unpleasant illness scenarios can be distressing for patients. As the Royal College of Physicians (2009) noted, some patients with terminal disease or serious illness requiring hospitalization may not feel ready or able to engage in advance care planning. Although advance care planning is voluntary for patients, this voluntariness is threatened by overzealous attempts to ensure that patients agree some sort of care plan in order to achieve the quality measures, particularly in the acute setting. Causing excessive distress, pressure or coercion constitutes a harm.

Patient confidentiality is threatened through a mistaken notion that the family's views are sought, or when professionals forget that the patient's advance statement can be shared with other health-care teams only if the patient consents.

If family are involved, patient and family may disagree regarding future treatment and place of care – although the patient's wishes take priority, conflict may result.

Failure to understand the importance and purpose of advance care planning in future decisions will lead to lack of adequate patient attention to the discussion and any resulting advance statement. There is also a real risk that the requirements for professional time, knowledge and skills, plus the unpleasant nature of much of the necessary information, will result in inadequately informed preferences being expressed and recorded. Expression of preferences without adequate information may be worse than no care planning or advance care planning at all.

Failure to update the advance statement as preferences change will lead to a wrong or misleading representation of the patient's wishes, thus misinforming later best interests judgments.

There is also a real risk of creating unrealistic patient expectations that preferences expressed will in future be met, this risk being increased by use of the term 'choice' rather than 'preference'. Current NHS stress on achieving the previously stated preferred place of death, also a Department of Health quality measure for acute hospitals, may lead to pressure on patients to express 'achievable' preferences, or moribund patients might be moved, contrary to their best interests, simply to achieve this location.

Broader ethical issues of care planning in a publicly funded health service

In the NHS the (more individualistic) value of meeting the preferences of individual patients must be balanced against the (more communitarian) ethical imperatives of cost effectiveness and just distribution of health-care benefits. However, the political rhetoric of choice, and law which states that patients lacking capacity must be treated according to their best interests, make it difficult to implement the essential consideration of cost-effectiveness and justice in decision making.

Too much emphasis on where – as opposed to how – we die may also adversely distort societal values. **BJHM**

KEY POINTS

- Advance care planning is a distinct subset of care planning for the future; it is specifically a discussion with a patient who has capacity, to inform and enable the patient to express preferences regarding treatment and care in order to aid decision making in the event of anticipated future loss of capacity.
- For the purposes of decision making when capacity is lost, patients can make any of three formal outcomes of advance care planning: an advance statement, an advance decision to refuse treatment, or a lasting power of attorney appointment for health and welfare decisions.
- Advance care planning is complex clinically, requires that the patient is adequately informed similarly to consent, and is voluntary for the patient; the quality marker for end of life care is therefore that it should be offered and not that it be achieved.
- Advance care planning can encourage communication of information, alongside its primary benefit of informing decision makers responsible for future best interests judgments regarding treatment and care on behalf of the patient.
- Despite this, advance care planning is associated with potential harms and risks especially in the acute setting; it should not be instigated or continued unless the professional judges that it is clinically appropriate in terms of benefit exceeding harm and risk.

Conflict of interest: Dr F Randall was a member of the working party of the National End of Life Care Programme which produced the 2011 guidance referred to in this article.

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