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Advance care planning: the who, what, when, where and why

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Abstract

Advance care planning is an opportunity for patients to express their priorities for future care. NHS England has outlined a commitment to end-of-life care, advocating a shift towards more patient-centred care. The NHS is encouraging the workforce to engage patients in conversations about what is important to them, shifting the focus from ‘what is wrong with you’ to ‘what matters to you’. Traditionally, this was seen as the doctor’s role but this conversation can and should happen with the wider skilled medical workforce. The key to advance care planning is to have these conversations early on when patients have the capacity to discuss their preferences for care. Advance care planning can occur in any setting where the patient is comfortable to have the conversation, be that at home, in the GP surgery, in hospital or another setting. Patients with advance care plans are more likely to have their wishes respected, have fewer unwanted interventions, experience reduced transitions between care settings and are more likely to die in their preferred place of death. Healthcare professionals have a duty to offer advance care planning to patients nearing the last phase of life so that care can be delivered to honour individual needs at the end of life.

Key words: Advance; Care; End; Life; Planning

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Introduction

Advance care planning is an opportunity for patients to express their wishes and priorities for future care. The Royal College of Physicians’ (2018) *Talking about dying* report is an honest account of the challenges faced and the need for improvements when caring for patients in the last phase of life. The NHS *Long Term Plan* has outlined a commitment to end of life care, advocating a shift towards more patient-centred care. It emphasises the need to accommodate what is important to each individual patient (NHS England, 2019a).

In the context of an ageing population, there is a shift towards caring for patients with multimorbidity, frailty and dementia rather than single organ pathology (NHS England, 2019c). The uncertain disease course and prognosis calls for early conversations so that patients can communicate goals and preferences for future treatment before they lose capacity. This is to avoid making decisions in a crisis situation, which can cause distress for the patient, relatives, carers and clinicians (Brinkman-Stoppelenburg et al, 2014). Movements such as the international ‘What matters to you’ campaign aim to get patients and families talking about what is important to them, to shift the focus from ‘what is wrong with you’ to ‘what matters to you’ (NHS England, 2019b). These initiatives are working towards improving end of life care for patients, making sure patients are listened to and respected when they are most vulnerable. This article explores the practicalities of having these sensitive conversations.

Who should be doing advance care planning with patients?

Traditionally, the process of advance care planning was mostly practiced in palliative care. With the rapidly growing elderly and frail population, it would be impossible and inappropriate for palliative care alone to take on having these conversations (Brighton and Bristowe, 2016). The barriers to initiating advance care planning discussions are both psychological and practical. Some clinicians feel that they are not sufficiently trained and lack the skills required to navigate this topic (Fulmer et al, 2018). It has also been reported

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by many that they fear upsetting the patient or causing them to lose hope (Fulmer et al, 2018). Others feel that these conversations should only happen with the patient's 'regular' doctor or that they do not have sufficient time in their pressured schedules (Llewellyn et al, 2018).

In contrast to the concerns that clinicians harbour, evidence suggests that most patients value the chance to have conversations opportunistically and early on (Brighton and Bristowe, 2016). Hope does not need to solely relate to prolonging life but also refers to the hope of a good death, and maintained quality of life (Brighton and Bristowe, 2016). Patients have stated that they do not mind speaking with a doctor who they do not see regularly, as long as the doctor is sufficiently open and willing to have the conversation (Simon et al, 2015).

As well as doctors conducting these conversations, there are many nurses, therapists and allied healthcare professionals who are well equipped to engage a patient or carer in these discussions (Johnson et al, 2018). Members of the wider medical workforce are often able to spend more time with patients than doctors and often have more personal connections by seeing them regularly, sometimes in their own homes and with more focus on their general wellbeing rather than the diagnosis (Sævareid et al, 2019). Online platforms for recording advance care plans, such as Coordinate My Care (https://www.coordinatemycare.co.uk/), advocate that families start these conversations with loved ones or that individuals record advance care plans for themselves. The notion that these discussions can only happen with a doctor is outdated; the wider workforce and community need to give patients as much opportunity as possible to express their wishes for care.

What should advance care planning include?

In its most basic form, advance care planning should cover the question 'what matters to you?'. Macmillan Cancer Care provides detailed advice regarding the questions and considerations one should have when approaching advance care planning (Macmillan UK, 2019). In the *Talking about Dying* report, 'The Conversation Project' at Bath University Hospital was described, which produced a free pamphlet for patients on advance care planning called *Planning Ahead* (Royal College of Physicians, 2018). Coordinate My Care (https://www.coordinatemycare.co.uk/) is an online platform used in London with a comprehensive set of questions used for advance care planning. The main questions which can be considered are summarised in Table 1.

An advance care planning discussion does not need to include all the points suggested. It is important with any of these conversations to go at the pace of the person making the care plan. If too much information is given to a patient, or they are pushed into talking

Table 1. Questions used for advance care planning
Does the patient have capacity for a care plan discussion?
Who is participating in the care plan discussion (professional/patient/lasting power of attorney/next of kin/other)?
What is the patient/family's understanding of the situation?
What care will be offered?
What ceilings of care will there be?
Any advance decision to refuse treatment?
What is their preferred place of care?
Discussion and plan regarding hospital admission avoidance
What is their preferred place of death?
Additional requests (cultural/religious/spiritual)
Details of nutrition and hydration plan
Any other wishes which the patient would like to discuss

about things they are not comfortable with, then it is likely that this will have a negative effect (McCabe et al, 2010). Some patients are not equipped to plan for hypothetical scenarios because of varying degrees of understanding or cognition (Mullick et al, 2013). In such situations, conversations should focus on individual feelings, beliefs and what is important to them.

Sensitivity to a patient's religious or cultural beliefs is necessary as this can heavily influence the choices they make and affect how the patient and family behave in the lead up towards death (Mullick et al, 2013). By being aware of these differences healthcare professionals will be more able to cater to the patient's and sometimes the family's needs in these difficult times. Public Health England recognises the crucial role of religion and has produced a resource on the importance of faith at the end of life (Public Health England, 2016).

When is it best to do advance care planning?

Advance care planning can never be done too early, as long as the patient is willing to have the conversation. Ideally discussions should take place when the patient still has capacity. In cases when the patient no longer has capacity, a proxy decision maker, usually the next of kin or family member can make a care plan on their behalf. When advance care planning is left too late and patients have surrogate decision makers, they are far more likely to have aggressive intervention at the end of life (Brighton and Bristowe, 2016). The Gold Standards Framework question of 'would you be surprised if the person died in the next year?' is a useful trigger for these discussions (Gold Standards Framework, 2019). Patients who have dementia or other debilitating conditions may lose capacity earlier than their last year of life and advance care planning should be initiated earlier on in the disease course. Some patients want to set out their wishes for future care even if they are not obviously nearing the last phase of life.

NHS England advises that, for severely frail patients, their preferences and needs around end of life care should be fully understood (NHS England, 2019c). Equally if a patient is unwell enough to require palliative care input, advance care planning may be appropriate (Brighton and Bristowe, 2016). Patients who have a 'do not attempt cardiopulmonary resuscitation' order or a treatment escalation plan should also have advance care planning as this allows the patient to explain what treatments and care they do want, rather than just crude indicators of what they do not want.

In the final stages of life, many patients experience numerous transitions between care settings. These transitions can be physically and psychologically detrimental (Hanratty et al, 2012). Many of these transitions involve admissions to hospital. Patients with life-limiting conditions, significant deterioration in their health or recurrent admissions, some of which may be inappropriate, should trigger consideration of whether advance care planning would be appropriate (Mullick et al, 2013). Advance care planning should also be kept in mind when patients require a move to a care home (Brighton and Bristowe, 2016).

Patients with an advance care plan may change their minds and perspectives when they are put into different situations. It should be emphasised to patients that this discussion is ongoing and can be revisited at any time with any proficient healthcare professional. Potential triggers are summarised in Table 2.

Where should advance care planning happen?

The Gold Standards Framework (2019) suggests five key steps for advance care planning:

1. Think
2. Talk
3. Record
4. Discuss
5. Share.

Patients may be more likely to start thinking and talking when at home in the community, but patients are mostly happy to have these conversations in any setting, providing the person

Table 2. Potential triggers to revisit an advance care plan
Patient or family wishes to discuss plans for end of life
Rockwood frailty score 7–9
Would you be surprised if the patient died in the next year?
Diagnosis of a progressive life-limiting illness or that of a condition which is likely to result in a loss of capacity or a deterioration in condition
Recurrent admissions
Patient already has a do not attempt cardiopulmonary resuscitation order and a treatment escalation plan discussed
Change in personal circumstances, eg move to care home
Referral to palliative care

having the discussion is knowledgeable and able to talk with them (Simon et al, 2015). Time is reported as a significant barrier in preventing these conversations from occurring in primary and secondary care (Fulmer et al, 2018). However, time spent with a patient when they are able to express their wishes can save multiple hours down the line when clinicians and relatives are caught trying to make difficult and sometimes inappropriate decisions on the patient's behalf.

In primary care, when appointment times are short, time may need to be specifically assigned to have these conversations. In the hospital setting, staff have the benefit of seeing patients and families over many days. This can provide an opportunity to have an in-depth discussion which can be revisited over the inpatient stay and also back in the community with their primary care team. Outpatient clinics offer another opportunity to initiate or review an advance care planning discussion in the context of discussing treatment for their condition (Mullick et al, 2013).

Advance care planning does not need to happen in a medical environment or be done by medical professionals alone. The majority of people who have started an advance care planning conversation preferred to do so with their family rather than healthcare professionals (Musa et al, 2015). Carers in a patient's care home are well placed to have an advance care planning discussion. They have the benefit of knowing the patient well and often have more time than medical staff. Doctors should be training and empowering non-medical colleagues to initiate these conversations so that they are no longer the remit of the medical professionals alone and patients can talk about their wishes on a more regular basis in an environment that suits them.

Why is advance care planning so important for patients?

Qualitative and quantitative data show the significant benefits of advance care planning both for patients and their families (Brinkman-Stoppelenburg et al, 2014). Patients' quality of life is reported to be significantly improved for those with advance care plans compared to those without and they are more likely to have a reduction in transition between care settings (Kernick et al, 2018). An analysis of data from Coordinate My Care shows that 71% of patients with an advance care plan on record died in their preferred place of death (Callender et al, 2017).

The bereavement process for the families is also improved when the patient has had advance care planning (Mullick et al, 2013) because it often removes the burden of the families worrying whether they have made the right decisions for their loved ones. It also reduces the likelihood of conflict between families and between the medical team and the relatives (Mullick et al, 2013). Clinicians and healthcare staff benefit from patients having an advance care plan as it helps them to know which treatments are appropriate and gives the team a better understanding of who the patient is and what their priorities are.

Key points

- Advance care planning should be available for all patients nearing the last phase of life.
- Advance care planning conversations can be initiated by a variety of skilled healthcare professionals, ranging from doctors and nurses to therapists and carers.
- The conversation should be based around what is important to the patient and be as detailed as the patient is comfortable with.
- Advance care planning can never be done too early as long as the patient is comfortable discussing their wishes.
- Advance care planning should ideally be initiated when the patient has capacity. If they no longer have capacity, a care plan can be discussed in the patient's best interests with a designated proxy decision maker.
- Advance care planning conversations can occur in any setting where the patient is comfortable, eg community or hospital setting.
- Advance care planning facilitates respect for patients' preferences for care at the end of life.
- Advance care planning can improve the end of life experience for patients and their families.

Curriculum checklist

This article addresses the following requirements from the general internal medicine stage 1 training curriculum:

- The patient as central focus of care
- Care of older people living with frailty
- Managing end of life and applying palliative care skills.

Conclusions

Advance care planning in an essential part of patient care, facilitating respect and dignity for patients as they are nearing the end of life. Patients should be considered for advance care planning while they still have capacity so that their preferences can be recorded. Advance care planning can be a very in-depth process and should be explored in detail with an individual and anyone else they want to involve. It can never be done too early but it is often left too late. These conversations can take place in any environment which is involved with the patient's care and by a wide variety of healthcare professionals. Clinicians have a duty to ask patients 'what matters to you' and accommodate their individual wishes as much as possible.

Conflicts of interest
The authors declare that they have no conflicts of interest.

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