

Discussing and planning care for people approaching the end of their life

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Introduction

The National End of Life Strategy¹ and National Institute of Health and Care Excellence (NICE) Quality Standard² recommend that, as the end of life approaches, patients have open and honest discussions with healthcare professionals^{1,2} and are given the opportunity to plan aspects of their care in accordance with their needs and preferences.^{1–3} Despite evidence that discussions and better planning of care can improve the patient's quality of life⁴ and increase carer satisfaction,⁵ many patients continue to die without having had these discussions.^{6,7}

Guidance issued by the General Medical Council (GMC)³ is clear that every clinician has the responsibility to consider and act on end-of-life issues in appropriate patients. However, physicians are not always confident about how to initiate discussions about end-of-life issues.⁶ Here, we highlight ways to help engage patients and their families and/or carers in discussions about the end of their life and, when appropriate, to plan aspects of their care.³

Patients can be considered to be approaching the end of their life when they might die within the next 12 months because of a deterioration in a serious chronic health problem, including frailty, or they have a life-threatening acute event, or they have a serious underlying condition that puts them at risk of sudden death.³ However, the term 'end of life' if used in discussion with patients and families, usually erroneously, conveys a sense of dying being imminent. What is important in such discussions is the opportunity for sharing information about deteriorating health, their risk of dying at some point that remains uncertain and holistic assessment of unmet supportive and palliative care needs. This should, if the patient and family wish it, include future care planning.

Care planning for patients approaching the end of life

The process of care planning aims to promote shared decision-making through voluntary dialogue between healthcare professionals and the patient, or relative and/or nominated other if the patient lacks capacity to make decisions. It includes, but is not exclusive to, 'advance care planning' (ACP) that, in

Box 1. Royal College of Physicians prompt tool for post-take ward rounds.⁸

- > Does the patient have an advance care plan?
 - > Does the patient have a valid and applicable advance decision to refuse treatment (ADRT)?
 - > Does the patient fall into one of the following categories?
 - Advanced, progressive, incurable condition(s)
 - General frailty and coexisting conditions that mean they might be expected to die within the next 12 months
 - Existing condition(s) as a result of which they are at risk of dying from a sudden acute crisis
 - Life-threatening acute condition caused by sudden catastrophic event(s)
- If so, discuss preferences of treatment and place of care with the patient and their family.

the UK, refers to the voluntary process of discussions about future care between an individual (with capacity) and their care providers when deterioration and loss of capacity are anticipated.⁸ Key outcomes from ACP discussions include creating an advance statement or an advance decision to refuse treatments (ADRTs) and/or nominating a lasting power of attorney (LPA).

More broadly, discussions incorporating relevant medical information and individual preferences can help determine a care plan that outlines proposed appropriate actions for specific clinical situations. Most patients will not lose capacity and such discussions enable them to consider their views on benefits and burdens of treatments in advance of the situation arising. Care plans tailored to the clinical situations have been shown to be more helpful than advance statements or ADRTs when making decisions at the end of life.⁹

Identifying patients

Unless patients request discussions about end-of-life care, it falls to clinicians to identify which patients are approaching the end of their life and initiate discussions about end of life and their care preferences. Knowing when and how to do this can be a challenge.^{1,4} Systematically remembering to consider these issues, sometimes with the help of tools which identify patients with a high risk of dying, can be helpful.

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Tools

The CURB-65 score¹⁰ is one example of a tool that helps identify patients with community-acquired pneumonia who are most at risk of dying in the next 30 days. In conjunction with discussions about their acute treatment, those at high risk of not recovering should be offered the opportunity to discuss and consider their options and preferences for end-of-life care.

Tools including the Prognostic Indicator Guide (PIG)¹¹ and Supportive and Palliative Care Indicator Tool (SPICITTM)¹² help identify patients with chronic conditions who might be approaching the end of their lives. Given that it is not easy to recall all of this information, having a copy or link to these tools in an easily accessible place might be useful as a prompt and help to provide a structured way of identifying these patients.

Finding the right time to identify patients

Any clinical encounter can potentially identify patients who might be approaching the end of their life. This includes outpatient reviews as well as during inpatient admissions. The Royal College of Physicians (RCP) recommends incorporating identifying these patients into 'routine practice' and has proposed a 'prompting tool' for use on the post-take ward round to help identify patients who might be approaching the end of their life (Box 1).⁸

Time constraints, lack of time to prepare for discussions and lack of availability of family or advocates can mean that these post-take ward rounds are not an ideal environment to undertake sensitive and appropriate discussions about the end of life and to plan care. However, this ward round can help flag that issues relating to an uncertain recovery or end-of-life care should be given consideration and followed up.

In an outpatient setting, identifying relevant transition points in disease could act as triggers for clinicians to incorporate routine consideration of care planning and end-of-life issues into outpatient practice. These might include recurrent unplanned admissions, decreased responsiveness to treatments without additional options¹² or a rapid change in functional status.¹³

Care planning discussions

Once patients are identified as potentially approaching the end of their life, clinicians should be prepared to have discussions that include planning their care. Successful conversations about care planning require preparation, attention to the content and style of discussion and follow up.¹⁴

Preparing for care-planning discussions

Taking time to prepare for conversations can reduce professional anxiety and ensure that care-planning discussions occur in an appropriate manner for the patient. Clinicians should be aware of relevant prognostic and disease-specific information and start to think about options and key decisions for the patients from a medical perspective.

Adequate preparation will require approaching patients to ascertain factors such as who they wish to be present and whether they wish to have these conversations with the current clinical team or defer them to discuss with their general practitioner (GP) or teams who provide their longer term care.

Consideration should be given to cultural needs; preferences relating to disclosure of information and attitudes to death and suffering might require specific support.¹⁵

Having a care-planning conversation

Communication

A successful care-planning conversation requires sensitive communication. This should be an active listening process with a balance of sensitivity, honesty and careful exploration of emotional reactions.

Key issues

Creating a successful care plan requires detailed examination of important issues. This is likely to include probing about patient and family expectations, explaining the balance and benefits of relevant medical options and ensuring that the thoughts of the patient or family are acknowledged and valued. Examples of the sort of issues that might require consideration are given in Table 1.

Care planning should ensure that relevant contact numbers are recorded and easy to find. This can help alleviate anxiety and increase the likelihood of help being sought in an appropriate way.

Involvement of family and/or carer

Providing that the patient does not object, involving family or carers is key and an important component of good end-of-life care. Including family members in the care-planning conversation should help ensure that they understand the situation, are familiar with the options and know how to seek appropriate help.

Recording, disseminating and using care plans

Recording and disseminating outcomes of care-planning discussions

Once discussions have occurred, it is important that discussions and plans are recorded in a way that is useful for patients, their families and healthcare professionals. Patients usually hold the

Key points

Timely identification of patients approaching the end of their life is an important skill

Clinical tools can support the identification of such patients

The General Medical Council requires clinicians to consider and act on end-of-life issues in appropriate patients

Sensitive discussions about planning future care can benefit patients and their families and/or carers

Written care plans of shared decision-making with patients and families can support clinicians and others in providing the most appropriate care for patients as they deteriorate and when they are dying

KEYWORDS: Care planning, capacity, shared decision-making, end of life, Royal College of Physicians (RCP) tool ■

Table 1. Examples of key issues that might require exploration.

Question and/or preference	Example of issues to consider
'I don't want that treatment anymore'	<ul style="list-style-type: none"> > What has led the patient to this decision? > What does the patient hope this will achieve (eg keep them out of hospital, not have 'invasive' treatment, etc)? > Do these need further discussion and/or clarification (eg are there misconceptions or other factors influencing the anticipated outcome)?
Or	<ul style="list-style-type: none"> > What symptoms and/or situations does the patient usually receive treatment for – are there other realistic ways to help manage these?
'I want this treatment again' eg non-invasive ventilation in patient with COPD and type II respiratory failure during infective exacerbation	<ul style="list-style-type: none"> > What would be the potential consequences of having/not having the particular treatment and is the patient aware and/or do they understand these? > Requests for treatment: clinician retains ultimate decision about whether it is appropriate – is the patient aware of this?
'I want to stay at home' eg patient with severe heart failure who has failed to offload fluid despite maximum tolerated treatment	<ul style="list-style-type: none"> > Why are they usually admitted to hospital? > Are hospital-based treatments likely to offer benefit? Explore from a clinical and broader patient or family perspective. > Are there other measures that can be taken to help support them and/or manage their symptoms? > Is additional care needed; eg is a Continuing Health Care Funding Assessment appropriate, should district nurses be involved? > If comfort is difficult to maintain at home, would they consider an alternative (eg community hospital, hospital, nursing home or hospice)?

COPD = chronic obstructive pulmonary disease.

discussion record so that it is available to ambulance crews or other professionals if called urgently. Therefore it is important that they are familiar with the contents of the document. Local practices about how to identify that a person has a care plan relating to end-of-life issues vary considerably. If it is difficult to ascertain how this is done in your area, the local palliative care team should be able to help.

If another professional (eg GP) needs to follow up care-planning discussions, it might be helpful to correspond about key issues. One should remember that many hospitals letters are now routinely copied to patients and, thus, be mindful of this issue to ensure that patients do not receive potentially difficult information in an unexpected and unsupported manner.

Successful care planning is an iterative process; therefore, following up and amending care plans as the situation or preferences evolve is important.⁶

Using care plans to help clinical decision-making

Records of care-planning conversations can help decision-making in clinical encounters and it is important to check with a patient whether they have any care-planning records. When a patient retains capacity, their contemporaneous view is the most important. However, previously recorded care-planning discussions can help open up discussions, check preferences and flag what might be particularly important issues for that person. When somebody lacks capacity, any care-planning discussion should be considered when making a best-interest assessment.

Care plans do not always give clinicians a clear answer about what to do in a clinical situation, but do help clinicians to know what has been discussed and what seemed important at that time. Physicians must then judge their relevance and applicability to the current situation.

Conclusion

Effectively planning care for patients approaching the end of their life requires timely identification of their clinical condition, the potential to die soon and sensitive discussions about planning future care. Physicians should be encouraged to offer planning care in advance for patients who are likely to die because, when done appropriately, it can benefit both the patients and their families and/or carers. ■

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An innovative development programme for consultants to improve patient care in the last months of life

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Knowing is not enough: we must apply. Being willing is not enough, we must do

Leonardo Da Vinci

Introduction

Around half the annual 600,000 deaths in England occur in hospital, with an average of 30 days spent as inpatients during the last year of life, over several admissions.¹ Forty per cent of people who die in hospital may have no medical need to be there² and most would not choose to die in hospital if their care could be delivered in an alternative setting.³ Most people who die in the UK are managed by their general practitioner (GP), together with a range of hospital specialists without referral to specialist palliative care services.

Delivering patient-centred care in the last months of life and enabling people to die in a place of their choosing requires individuals and their families to know that they may be approaching the end of life in good time to be involved in decision-making, and for community support to be in place. Honest conversations about limits of medical treatment must be part of routine care if patients are to have time to consider their choices, as outlined in the General Medical Council (GMC) guidance *Treatment and care towards the end of life*.⁴ This

requires behavioural change in healthcare teams, influenced and led by consultants, acknowledging that clinicians are largely trained to cure or extend life.⁵ All physicians need to engage deeply in this challenging area of care and make it a routine part of their practice. Developing practice to embrace this requires more than the transfer of knowledge.

Senior doctors are accustomed to identifying their own learning needs. Recognising the need to change practice around palliative and end-of-life care (EoLC) may result from personal or professional experiences – good or bad – and the need to deliver enhanced curriculum requirements for trainees under their supervision.⁶

A range of learning opportunities is available, including e-learning,⁷ and local, regional and national training in EoLC.⁸ However, raising the bar in EoLC needs more than knowledge, and one-to-one work with specialist palliative care clinicians is a form of learning that is most highly valued.⁶ This may be a powerful way of learning, but is time intensive and palliative care clinicians do not always appreciate the issues in other specialties. This paper reports on an innovative development programme for senior clinicians that was designed and piloted in two trusts. Box 1 lists the questions to ask when evaluating EoLC.

Development programme in end-of-life care for senior clinicians

Led by consultants in palliative medicine, the pilot study used a range of methods including one-to-one work and action learning sets.

The aim was to enable consultants to identify their own learning needs, engage with the issues, undertake specific technical/clinical learning about palliative care and identify improvements in their own practice. Having increased their

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