

# CME Palliative medicine

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## Advance care planning

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Advance care planning (ACP) is a process of discussion about future care between an individual, their care providers and often those close to them. It provides a framework for patients to inform decision making should they lose capacity.<sup>1</sup> ACP spans the documentation of conversations that happen as a part of good end-of-life care between patient and healthcare team regarding treatment preferences, goals and location of care, through to formal, legally binding advance decisions.

There are excellent national guidelines on ACP,<sup>1,2</sup> although significant effort will be required to implement them. Annually, 1% of the UK population dies, with only 15% dying suddenly.<sup>3</sup> Most people wish to die at home, yet over half will die in hospital. Ever greater medical interventions available to manage advanced, progressive disease broaden the options, and therefore decisions that patients and doctors must make.

### The End-of-Life Care Strategy

The End-of-Life Care Strategy (DH 2008) recognises that quality and choice in end-of-life care are far from equitable and sets out an ambitious, far-reaching agenda to address this (Table 1).<sup>4</sup> ACP is a key element within this, with the aim of fulfilling goals held by many patients including:<sup>4,5</sup>

- participation in decisions about treatment preferences

- preparation for death
- achieving a sense of completion
- being in familiar surroundings in the company of close family and friends.

### Palliative care provision

Most care is delivered by primary and/or secondary care teams who are not specialists in palliative care. Initiatives, such as the Gold Standards Framework<sup>6</sup> and Liverpool Care Pathway for the dying,<sup>7</sup> have been

implemented to support care in these settings (Table 2). The need for all health professionals to have skills in assessment, symptom management, communication and ACP for the end of life is now recognised<sup>4</sup> and is reflected in undergraduate curricula.

Specialist palliative care (SPC) is available for patients with complex needs (physical, psychological, social or spiritual) which cannot be met by their usual teams. Referral requires patient consent – hence discussion about the palliative nature of treatment. SPC services are available on the basis of need, rather than diagnosis, and include inpatient units (such as hospices), community and hospital advisory teams, daycare and outpatients.

### Starting the conversation

The role of the physician in ACP is established, but much remains to be learned in the key skills of prognostication, communication, goal setting and documentation (Table 3).

**Table 1. The main strands of the end-of-life strategy.<sup>4</sup>**

1	Promotion of public awareness and reducing taboos about death and dying
2	An integrated approach to planning, contracting and monitoring service delivery across health and social care as part of a strategic approach to commissioning
3	Identification of people approaching the end of life to be strengthened. NHS staff to have communication skills training so that they are equipped and confident in initiating conversations and supporting people approaching the end of life
4	All people approaching the end of life and their carers should have their needs assessed and have a care plan which records their preferences, including where they would wish to die
5	Ensure that care is well coordinated and can be accessed rapidly 24/7. Aim to avoid unnecessary emergency admissions to hospital: <ul style="list-style-type: none"> <li>• local registers for people approaching the end of life</li> <li>• health and social care working together</li> </ul>
6	Support the provision of high quality, integrated care across all settings: hospitals, community, care homes, sheltered and extra-care housing, hospices and ambulance services
7	Ensure that health and social care staff provide sensitive and culturally and spiritually responsive care during the last days of life and after death
8	Ensure health and social care organisations provide readily available information on all local services for those approaching the end of life
9	The needs of carers and families should be recognised, using a formal 'carers care plan' where appropriate
10	End-of-life care training should be commissioned and provided to ensure that relevant staff have the necessary competences

Research and data collection analysis are needed to underpin the above.

## Prognostication

Prognostication is difficult, even with well-defined disease trajectories, such as in many cancers and motor neurone disease (MND). It is even harder in progressive disease with a relapsing and remitting course, such as chronic heart failure and obstructive pulmonary disease. The question 'Would I be surprised if my patient died in the next 12 months?'<sup>28</sup> can help identify those with whom to start the conversation about end-of-life care. Other possible triggers include:

- a new diagnosis of a life-limiting condition
- a deterioration in prognostic markers
- a step change in treatment
- multiple hospital admissions

- admission to a care home, or
- whenever a thorough reassessment of the patient's needs is required.<sup>2</sup>

Within specialties, experienced physicians will usually be able to characterise a set of clinical features representing the onset of end-stage disease which can be used to guide decision making.

## Communication

Doctors may feel nervous about starting the conversation and patients may be waiting for the doctor to initiate this. There are perceived and real barriers to communication on both sides and facilitatory factors can be hard to achieve organisationally (Table 4). Many fear that addressing end of life will take away hope, and an approach of 'hoping for the

best, preparing for the worst' can be useful.

Engagement in discussion will be determined by the degree of patient insight that death is near. For some patients, this will prove impossible while others will welcome the opportunity. Patients may wish to discuss some aspects of care but not others. Patients may initiate discussion themselves. The question 'How long have I got?' provides an opportunity to discuss progress and expectations and to set realistic goals, even if a precise answer is impossible and often inappropriate.

The most effective ACP is achieved when patient and physician work collaboratively. For this, preferred styles of decision making and information exchange need to be aligned. Clinicians have been found to underestimate patients' desire for information and discussion but to overestimate patients' desire to make decisions.<sup>9</sup> Informed ACP requires the doctor to know the medical facts, treatment options and the local resources and services available, and to communicate them effectively to the patient. Patients may choose a supportive or palliative care approach if this is presented to them as a positive choice.

ACP is best viewed as a process, with time between discussions for reflection and clarification of questions. Conversations may continue with other healthcare professionals. Once bad news has been absorbed, concerns can be elicited and addressed, and individual priorities, preferences and goals identified. The patient

**Table 2. Tools to support end-of-life care.**

Gold standards framework <sup>6*</sup>	<ul style="list-style-type: none"> <li>• GP-based system to streamline and improve the organisation and quality of care for patients in the last year of life</li> <li>• Inclusion criteria: all patients who might reasonably be expected to die in the next year</li> <li>• Three central processes:               <ul style="list-style-type: none"> <li>– identification of patients needing supportive/palliative care</li> <li>– assessment of needs, symptoms, preferences and priorities</li> <li>– care planning</li> </ul> </li> <li>• ACP, symptom relief and home support are priorities and targets for quality improvement</li> </ul>
Liverpool Care Pathway <sup>7**</sup>	<ul style="list-style-type: none"> <li>• A framework for good practice and documentation, to support and record good clinical care and judgement</li> <li>• Must be supported by appropriate education and training in end-of-life care, with regular review</li> <li>• Transfers best practice for care of the dying from a hospice environment to other care settings</li> <li>• Care plan determined by individual patient and family/carer needs</li> <li>• Inclusion criteria: patients in the last days of life, with advanced progressive disease with no reversible cause, and multiprofessional team agreement that the patient is dying</li> <li>• Includes proactive prn prescribing for common end-of-life symptoms, including pain, nausea and vomiting, excessive respiratory secretions and agitation</li> <li>• Addresses spiritual care and carers' needs</li> <li>• Not a one-way street – a small proportion of patients improve and the LCP can be discontinued</li> <li>• Subject to national audit every two years – National Care of the Dying Audit Hospitals<sup>**</sup></li> </ul>

\*Further information available at [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)  
 \*\*Further information and current version of the LCP available at [www.mcpcil.org.uk](http://www.mcpcil.org.uk)  
 ACP = advance care planning; GP = general practitioner; LCP = Liverpool Care Pathway; prn = as required.

**Table 3. Communication with the patient.**

'I think that the best physician is the one who has the providence to tell the patient according to his knowledge of the present situation, what has happened before, and what is going to happen in the future.' *Hippocrates (470–410 BC)*

'I must say that when my Mum was in hospital the doctors don't give you a lot of information at all. My Mum was in 10 days. I never knew what was wrong with her. I'm not one for asking questions but I used to say "What's wrong with her? No one ever came up to me to say "Oh, your Mum's got this or your Mum's got that". On the death certificate, it's got 'heart failure'.'<sup>13</sup>

must feel in control of the timing, place and pace of discussion with the option to stop at any time.

### Documentation

Documentation of discussions is essential. Currently, most patients are content with recording a verbal statement but a minority may wish to draw up a formal legal document.<sup>1</sup>

### Legal framework

The Mental Capacity Act (MCA) 2005<sup>10</sup> provides the framework for decision making when patients lack capacity – a common consideration in end-of-life care. Doctors are expected to be conversant with the act<sup>10</sup> and the Code of Practice.<sup>11</sup> The legal status of advance statements and decisions, and the role and responsibilities of lasting powers of attorney are clearly explained.

### Advance statement

An advance statement is a general statement regarding wishes, preferences,

beliefs and goals that an individual makes in order to clarify decision making should they lose capacity in the future. For example, 'When my MND progresses such that I need increasing admissions and my ability to communicate is limited, I would like the emphasis to be on comfort care at home rather than on life-sustaining medical interventions'. Another example is the Preferred Priorities for Care document.<sup>12</sup> While not legally binding, such statements must inform best interests decisions.

### Advance decision to refuse treatment

An advance decision to refuse treatment (ADRT) states what a patient does not want to happen to them and must relate to a specific treatment and a specific circumstance. An ADRT comes into force when the patient loses capacity to consent to or refuse treatment. It is legally binding if constituted according to the conditions in the MCA and if it meets the specific clinical circumstances. An ADRT for life-

sustaining treatment must be in writing, signed and witnessed and state that it should be enforced even if life is at risk.

There are restrictions on an ADRT, for example:

- basic nursing care cannot be refused
- inappropriate treatment or an illegal course of action (such as euthanasia) cannot be demanded.

### Lasting power of attorney

An individual with capacity can appoint a lasting power of attorney (LPA) to make health decisions on their behalf if they lack capacity in the future. The LPA must be registered with the Office of the Public Guardian. This body is legally bound to act according to the best interests of the individual. Their jurisdiction extends only to decisions regarding life-sustaining treatment if this is expressly stated in the original application. A valid ADRT drawn up after the appointment of an LPA must be honoured.<sup>10</sup>

**Table 4. Barriers and facilitators to end-of-life care communication.**<sup>14–17</sup>

Barriers	<ul style="list-style-type: none"> <li>• Difficult subject matter</li> <li>• Variation in patient preferences for information and discussion</li> <li>• Perception that the doctor does not want to and/or have time for discussion</li> <li>• The doctor does not have time for discussion</li> <li>• Fear of removing hope, causing alarm and distress</li> <li>• 'Clinics are for balancing and monitoring medical treatment'</li> <li>• Emphasis on a curative model of care</li> <li>• Unfamiliar faces</li> <li>• Multiple healthcare teams</li> <li>• Unpredictability of illness</li> <li>• Inadequate communication skills of professionals</li> <li>• Delirium/confusion/fatigue/breathlessness</li> <li>• High incidence of depression</li> <li>• Language barrier and ambiguities</li> </ul>
Facilitators	<ul style="list-style-type: none"> <li>• Patient experience of family/friends who have died</li> <li>• Trusting ongoing relationship with doctor</li> <li>• Physician expertise in relevant specialty</li> <li>• Patient feeling cared for as a person</li> <li>• Doctor asks about end-of-life care skilfully</li> <li>• Patient had discussed end-of-life care with others previously</li> <li>• Patient experience of being very ill</li> <li>• Health system that expects doctors to have end-of-life discussions with patients</li> </ul>

### Sharing information

ACPs need to be accessible at the point of care, reviewed regularly and up to date. Up to a third of those with formal ACPs will change them over time due to evolving circumstances.<sup>1</sup>

Healthcare professionals also need to communicate with one another on the progress of discussions.

Patients are responsible for keeping and presenting formal ACPs. Ideally, there should also be a local repository for information, accessible to all healthcare providers and including emergency services. Locality palliative care registers are advocated to hold key patient data, note of advance decisions and preferred priorities of care.<sup>4</sup> Various models are being piloted.

### Conclusions

Many patients welcome open discussion of end-of-life issues at a time, place and pace suited to them, with the potential for their preferences and priorities to be

## Key Points

Hospital physicians, with their specialist knowledge of the course and timescales of advanced progressive disease, have a vital role to play in end-of-life care planning

Advance care planning (ACP) is a voluntary process whereby patients can express their preferences and goals for future care should they lose capacity

ACP is most effective when it develops collaboratively between patient and healthcare team, and is reviewed regularly in light of changing circumstances

Tools to support ACP are available and may or may not be used. However, they cannot replace open, honest, timely and sensitive discussion and sound clinical judgement

ACP may be a general statement of wishes and preferences regarding the direction and location of care and/or decisions regarding refusal/s of specific medical interventions (eg cardiopulmonary resuscitation, ventilation and artificial nutrition)

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identified and realised. The choice of others not to engage in this process must be respected.

All patients known to be dying should have a care plan in place. Some patients will also wish to record advance statements or draw up a formal ADRT. The skills and sensitivities required in ACP are subtle and complex, and training, experience and fine tuning are required. The current strategic focus on ACP is welcomed, but ACP must not become a tick box exercise in a target-oriented culture.

Hospital physicians have a vital role in identifying patients who have reached the last year of life, in initiating discussion and in communicating with the primary care team. As a voluntary process which progresses at the patient's pace, it is likely that ACP will

need to be supported in both primary and secondary care. Processes to support this collaboration between patient, carer and healthcare teams need to be developed and training in ACP made available.

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