Royal College of Physicians

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Acute care resource

End-of-life care in the acute care setting

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Who should read this resource?

Any and all hospital doctors who care for people approaching the end of their lives, including (but not limited to) acute medicine consultants, geriatricians, gastroenterologists, endocrinologists, cardiologists, respiratory physicians, ED physicians, ICU consultants, renal physicians, hepatologists, haematologists, oncologists and neurologists.

Background

The definition of the end of life (EOL) by the General Medical Council (GMC) is not confined to people identified as imminently dying, but also includes those who may be in their final weeks, months or year of life.[1] Patients who die from all but sudden causes, including those who die from dementia and frailty, heart failure, chronic obstructive pulmonary disease (COPD), cancer, liver or renal failure as well as other causes, may have a recognisable EOL care phase.

We know that these patients are well represented in acute centres, with one large study showing that about 30% of all hospital inpatients are in their last year of life.[2] The importance of EOL care is also highlighted by the Care Quality Commission (CQC), which includes EOL care as one of its eight key domains in healthcare inspections.

It can be difficult to deliver high-quality EOL care in acute environments, despite the commitment and willingness of staff to do so. Identifying that someone is approaching the end of their life is challenging, as is offering them and those close to them a conversation about treatment choices for the future and different options for care. As a result, people with long-term conditions can be admitted repeatedly to hospital, although this may not be what they would want if asked.

In acute settings, active treatment is often the default course of action, such that busy teams may find it difficult to pause and recognise that someone is dying until that person reaches their final hours or days. In an after-death survey of relatives, the quality of care for people dying in hospitals was rated worse than that in either hospices or the home.[3]

The majority of patients who express a preference would prefer to die at home, although this falls below 50% when missing data are included.[3,4] The percentage also decreases as disease progresses. At present, only 45% of people at the end of their life die in their usual place of residence,[5] and therefore we have some way to go to better support patients to achieve their choice.

We also need to make changes to address quality in EOL care. The 2015 report from the Parliamentary and Health Service Ombudsman highlighted how EOL care in hospitals can go badly wrong, with patients and their relatives left unsupported.[6]

The Leadership Alliance for the Care of Dying People (LACDP) produced the report *One chance to get it right: improving people's experience of care in the last few days and hours of life* in 2014.[7] This report offers a comprehensive approach to management of the dying patient in their final days and hours. We recognise, however, that EOL care should not be limited to this period.

This resource addresses issues regarding the care of the patient who has been identified as being at the end of their life, throughout the final year and months of their life. It aims to support the acute and general physician in improving the care and choices provided to people in the acute care setting, who are at the end of their life, or approaching the end of their life.

EOL care for patients should be individualised and those caring for them should recognise that every patient will have different priorities for how their EOL care is managed. Patients' choices are supported when there is excellent holistic care, and sensitive and honest communication with patients, families and between all members of staff and the teams caring for them in different settings.

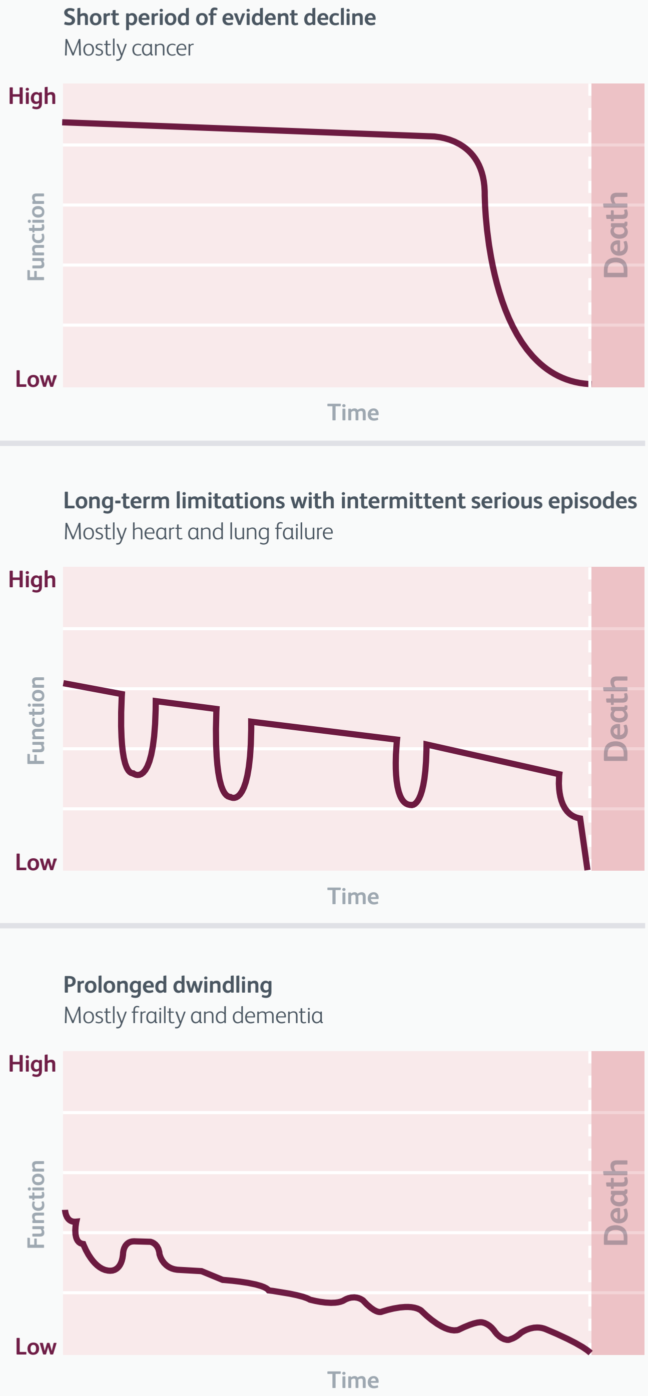
This is an area where solutions require changes of attitude and culture. Death should not always be equated with failure, but rather as a natural process. In the last year of life, people often receive care from a range of providers or in different settings, so solutions also require working with community partners and other care providers to ensure that the patient's care is well coordinated around their needs.

People in the last year of life

Most patients admitted acutely to hospital will be as a result of a deterioration of an underlying condition, or complications arising from its treatment. Indeed, up to one-third of hospital inpatients may die in the 12 months after admission.[2] Around 90% of patient deaths in England and Wales are from a previously diagnosed condition.[5]

Timely identification of patients who are in the last year of life is essential in order to plan and deliver the right care for them. Acute admissions are an opportunity to identify patients in time to make a real difference to their care in their last year, and to put things in place proactively to ensure that they receive care in line with their needs and preferences.

Estimating prognosis for the last months to years of life is inherently difficult, and all discussions must include this uncertainty, rather than presenting only the most optimistic prognosis. Various prognostic indicator tools have been developed to help doctors and healthcare staff to recognise when someone might be coming to the end of their life; most are based on illness trajectories for a cancer diagnosis, organ failure or long-term frailty (Fig 1).



Short period of evident decline
Mostly cancer

Long-term limitations with intermittent serious episodes
Mostly heart and lung failure

Prolonged dwindling
Mostly frailty and dementia

Fig 1 Living well at the end of life (adapted/reprinted with permission from the RAND Corporation, Santa Monica, CA, USA)[10]

Examples of prognostic guidance are the Gold Standards Framework Proactive Identification Guidance (PIG)[8] and the Supportive and Palliative Care Indicators Tool.[9] For those patients who either are older and frail or have an advanced progressive illness, factors that may aid prognostication include:

- a 'No' answer to the question 'Would I be surprised if the patient were to die in the next 12 months?'
- two or more unplanned hospital admissions in the past 6 months
- poor or deteriorating performance status
- persistent symptoms despite optimal therapy
- secondary organ failure arising from an underlying condition.

End-of-life discussions

Evidence suggests that healthcare professionals are poor at initiating discussions with patients about EOL care, despite most patients wishing to be informed and involved in this.[11] A willingness to initiate these discussions should be demonstrated at a senior level and advanced communication skills training has been shown to help.[12]

Conversations should not centre on withholding specific treatments, such as cardiopulmonary resuscitation (CPR), but rather discussion about these treatments should be placed in the context of a conversation about the patient's illness and what will or will not be helpful (Box 1). It is important to check what conversations have already taken place, which might be recorded in an electronic palliative care coordination system or in an advance decision document. Bear in mind that the language healthcare professionals commonly use may, in itself, be distressing for patients and relatives.

A senior medical review should aim to include:

- an explanation to the patient that they may be in the last year of life, with limited reversibility of their underlying condition
- a review of current treatment and care, based on patient goals
- agreement with the patient on goals for further treatment, focusing on what can be done to support the patient to live well, but also on those interventions that are no longer helpful for that person; this may also include discussions about discharge to another care setting, and a plan for future deteriorations and whether these should result in readmission to hospital
- some people will choose the most active treatment on offer to them, including readmission to hospital, whereas others may prefer to avoid this.[1]

All discussions and treatment plans should be documented clearly in the medical notes with a treatment escalation plan (TEP), as part of personalised care and support planning, and communicated with colleagues as part of routine handover.[13] Discussions should also be offered to those identified as important to the patient, especially if there are concerns regarding the patient's current or future mental capacity. A patient with capacity has the right to refuse any treatment, even if this seems unwise to the people looking after them. They do not have the right to demand treatment that is not felt to be clinically appropriate.[1]

Box 1

Suggestions for starting a conversation about EOL care

- What do you understand about what is happening to you / your health?
- Do you want to talk about / have you thought about what will happen to your health in the future?
- Do you have any strong feelings about treatments that you would or would not want to receive?

Advance care planning

Some patients will wish to record the outcome of these discussions as part of the more formal process of advance care planning (ACP). This enables those close to the patient and professionals to follow a patient's previously expressed wishes regarding their care and treatment, should they lose capacity in the future. In addition to discussing healthcare decisions, this is also an opportunity to explore wishes about organ donation. Those close to the patient may also wish to know whether they have specific wishes for their funeral.

Options for recording an ACP range from a documented collection of preferences and values to completion of a legally binding advance decision/directive to refuse treatment (ADRT), or appointment of an attorney to make decisions on the patient's behalf. The Deciding Right website provides a useful suite of documents.[14] Guidance and documents which support the creation, recording and sharing of ACPs are also available from the Resuscitation Council UK (ReSPECT).[15]

For patients already identified as likely to be in the last year of life, previous assessments should also be sought, including outcomes from ACP discussions. This may be through speaking to the patient, those identified as important to them, or primary and palliative care colleagues. In some areas, it may be possible to use an electronic palliative care register to access key documents and patient information (see below).

Role of specialist palliative care

Following initial assessment, if the patient has complex symptoms or needs that are difficult to manage, referral to the specialist palliative care (SPC) team may be warranted. This may be for physical, psychological, spiritual or practical issues, either in the hospital or in the community.

> 'Bear in mind that the language healthcare professionals commonly use may, in itself, be distressing for patients and relatives.'

Communication and coordination of care

For those patients who recover and are well enough to be discharged to primary care, it is essential to document the following points in the discharge communication:

> the patient has been recognised as being at risk of dying in the next year
> outcomes from discussions about ACP, including patient preferences on place of care and death; and information on whether any do not attempt CPR (DNACPR) order is to remain in place, or be subject to further review
> a request that the patient is placed on the GP palliative care / end-of-life register
> information about SPC referral, if made
> information given to those close to the patient.

The NHS is promoting an electronic palliative care coordination system (EPaCCS)[16] to act as a register for key patient information, such as their treatment preferences and care plans, including any ADRT documents and DNACPR forms. It is anticipated that better access to key information will improve communication and coordination between professionals, and avoid unwanted or unnecessary treatments or interventions. Currently, there is wide variation across England and Wales in how far this system is embedded. Universal adoption and use of electronic registers is an important step towards effective coordination of care, and is essential to support patient choice at the end of life.

Last weeks and days

On average, one person dies every minute in the UK, and around 75% of these deaths could be anticipated. Fewer than 50% of people in the UK now die in acute hospitals, and many have multiple conditions. Bereaved carers report that the quality of care in hospitals is lower than that at home or in hospices.[3]

Identifying death as a possible outcome

Identifying that a patient may be ill enough to die during this episode of care is clinically complex and fraught with uncertainty, particularly in patients with organ failure or long-term frailty.[17,18] The Gold Standards Framework PIG[8] and SPICT tool[9] give condition-specific guidance to help identify patients who may be approaching the end of their life (also see Box 2). Identifying the possibility of imminent death enables patients to achieve a comfortable death in their place of choice, and allows those important to them a chance to know that the patient is dying and to prepare accordingly. Failure to communicate that somebody is 'sick enough to die' is a major source of complaints in the NHS.[6]

Box 2

Factors that may indicate that dying is imminent in a patient with a progressive underlying condition with limited/no reversibility

> Bedbound
> Drowsiness, impaired cognition
> Difficulty taking oral medications
> Reduced food and fluid intake
> Increasing symptom burden

Box 3

Priorities for care of the dying person[7]

1. The possibility of death is recognised and communicated clearly; decisions are made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control (eg pain relief) and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

Clinicians should navigate an approach to address reversible problems that are compromising quality of life, while prioritising the patient's comfort and wishes in parallel. Sensitive open communication between professionals, patients and carers is important, ensuring a shared understanding of current disease status and shared decision making about the goals of treatment and care. The RCP's *Talking about dying* publication is an excellent resource in this respect.[19] Several conversations may be required before the patient and those close to them are able to appreciate this.[20] Decisions should be led by a senior clinician in collaboration with the team caring for the patient, seeking advice from palliative care teams if needed.

Managing the dying patient

In response to the independent review of the Liverpool Care Pathway, *More care, less pathway*,[21] an alliance of 21 organisations involved in delivering or ensuring high-quality EOL care (the LACDP) set out a new approach to the care of dying people in England, entitled *One chance to get it right*.[7] This approach identifies five priorities in the care of the dying patient and will support good care, even if the patient does not actually die (Box 3).

The individualised plan of care should take account of the patient's expressed wishes, including regarding preferred place of care and death. Resources at home vary across the country, but often include 24-hour availability of district nursing services, coordination with ambulance services, community-based palliative care rapid-response teams, hospice-at-home teams, care-home-based palliative care inreach projects, extended-hours pharmacies and palliative care coordination centres. Likewise, palliative care teams in hospitals are increasingly delivering 7-day face-to-face services backed by overnight palliative care telephone advice. For those patients for whom it is necessary to remain in hospital for the last days of life, bed managers should be informed so they can identify single rooms for privacy and to allow family and those close to the patient to remain with the patient as long as desired. These services allow patients to be cared for in the best possible environment, be that in hospital or at home.

Timely discharge for those who wish to die at home

Rapid discharge checklists have been developed to facilitate the timely, coordinated discharge of patients who wish to die at home. Community nurses and the patient's GP will be the main professional carers and will be responsible for ongoing coordination of care following discharge. A comprehensive handover is essential, and the GP should be contacted directly at or before discharge and have information sent to them to facilitate smooth transfer of care between care settings.

The community nurse can provide care and equipment, such as a hospital bed and commode. A package of care is usually required, often funded through the NHS and accessed rapidly via fast-track Continuing Healthcare funding. Oxygen may be needed if the patient is hypoxic and this should be ordered urgently. Some areas of the country have access to additional domiciliary palliative care nursing services, through either the Marie Curie community nursing service or the local hospice, providing up to 24-hour carer presence in the home.

Table 1 Anticipatory prescribing for the dying patient (refer to local guidelines)

Symptom	Medication options	Starting dose
Pain		
Normal renal function	Morphine or equivalent	2.5 mg S/C, 2- to 4-hourly/PRN
Impaired renal function (eGFR <30 mL/min)	Fentanyl	25 µg S/C, 1- to 2-hourly/PRN
	Alfentanil	100 µg S/C, 1- to 2-hourly/PRN
Agitation		
No delirium	Midazolam	2.5 mg S/C, hourly/PRN
With delirium	Add haloperidol	0.5–1.0 mg S/C, 2- to 4-hourly/PRN
	or levomepromazine	6.25 mg S/C, 4-hourly/PRN
Nausea		
Alternative	Cyclizine	50 mg S/C, 8-hourly/PRN
Chemical cause	Levomepromazine	2.5–6.25 mg S/C, 6-hourly/PRN
	Haloperidol	0.5–3.0 mg S/C, daily
Respiratory tract secretions		
	Hyoscine butylbromide	20 mg S/C, hourly/PRN
	or hyoscine hydrobromide	400 µg S/C, hourly/PRN
	or glycopyrronium	200–400 µg S/C, hourly/PRN
Breathlessness		
Alternative	Morphine	2.5 mg S/C, hourly/PRN
	Midazolam	2.5 mg S/C, hourly/PRN

eGFR, estimated glomerular filtration rate; PRN, as required; S/C, by subcutaneous injection.

For advice about the management of symptoms, including doses of medication in syringe pumps and opioid conversion, seek SPC advice.

Box 4

Considerations regarding patients in their final year of life on post-take ward rounds or general ward rounds[7]

- Does the patient have an advance care plan?
- Does the patient have a valid and applicable ADRT?
- Does the patient fall into one of the following categories?
  - has advanced, progressive, incurable condition(s)
  - has general frailty and coexisting conditions that mean they may be expected to die within the next 12 months
  - has existing condition(s), as a result of which they are at risk of dying from a sudden acute crisis
  - has a life-threatening acute condition caused by sudden catastrophic event(s).

  If so, discuss preferences for treatment and place of care with the patient and those who are important to them.

Clinical management of the dying patient

In the last days to weeks of life, the focus of care should be comfort based. Unhelpful investigations and ineffective treatments should be avoided or discontinued where the burdens outweigh the benefits. Medications to relieve pain, nausea, dyspnoea, agitation or troublesome respiratory secretions should be prescribed in anticipation. Most localities and trusts have advisory documents for anticipatory prescribing for dying patients. Table 1 provides examples of commonly used medications.

Patients who are already on oral opioids or anti-emetics may have their medication continued by subcutaneous infusion, if needed. Patients should be supported to eat and drink while they can. Decisions regarding assisted hydration and nutrition should be considered regularly on an individual patient basis.[1,22] Regular review and monitoring of the patient's clinical condition, the goals of and responses to treatment, the carer's concerns, and also signs of recovery are of paramount importance.

Box 5

Reflections and discussions following recent deaths[22]

- Was this death expected?
- Were the patient's priorities for EOL care (such as place of care and death) known?
  - If yes, were they adhered to?
  - If no, were there opportunities for ACP?
- Did the patient have an appropriate, individualised plan of care?

Professional development in EOL care

Physicians at all levels of training need the knowledge and skills to provide high-quality EOL care. This may be achieved through specific learning events, as well as through informal contact with expert colleagues and on-the-job learning. Using prompts (see Boxes 4 and 5) as part of the multidisciplinary team or board round discussion can promote learning through discussion across the team. Hospital teams should be encouraged to participate in the National Audit of Care at the End of Life[23] and review their local data at the end of the audit period, in order to evaluate the care that they provide to patients and to consider areas on which to focus for further improvement.

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> 'Physicians at all levels of training need the knowledge and skills to provide high-quality EOL care.'

Recommendations

for professional development in EOL care include the following.[24]

- Integrate palliative care into your daily practice – ask a member of your palliative care team to attend clinics, ward rounds and multidisciplinary team meetings, especially in areas with a high proportion of patients who require palliative care.
- Actively incorporate feedback from patients and carers to guide your professional development; for example, use patient or carer surveys or personal reflection.
- Refer to your local palliative care guidelines for quick reference and a stepwise management guide to common palliative care problems.
- Include at least one learning event on 'end-of-life care' within a 5-year continuing professional development (CPD) cycle.
- Find an up-to-date list of useful courses on palliative and EOL care locally and nationally at the Association for Palliative Medicine's website.[25]
- The e-learning programme End of Life Care for All (e-ELCA)[26] aims to enhance the training and education of the health and social care workforce.

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