



Acute care resource

End-of-life care in the acute care setting November 2015

The period for end-of-life (EOL) care is approximately the last year of someone's life and includes, but is not limited to, their last few hours and days.¹

The definition of EOL care by the General Medical Council (GMC) is not confined to people imminently dying, but also includes those who may be in their final year, months, weeks or days of life. 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 more than 30% of hospital patients at any one time are in their last year of life.² The importance of EOL care is also highlighted by the fact that the Care Quality Commission (CQC) includes EOL care as one of its eight key domains in healthcare inspections.

Background

It can be difficult to deliver high-quality EOL care in acute environments, despite the willingness of staff to do so. Identifying that someone is approaching the end of life is challenging, as is offering them a conversation about treatment choices for the future. 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 has become 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. Finally, in an after-death survey of relatives, the quality of care for the dying in hospitals was rated worse than that in either hospices or the home.³

More than 80% of people express a preference to die at home.³ This percentage decreases as disease progresses, but remains over 50% even in advanced illness. At present, only 45% of people at the end of their life die in their usual place of residence,⁴ and therefore we have some way to go to better support patients in their choice. We also need to make changes to address quality in EOL care. The 2015 report from the Parliamentary and Health Service Ombudsman illuminated how EOL care in hospitals can go badly wrong, with patients and their relatives left unsupported.⁵

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 2014.⁶ 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 RCP acute care 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.

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The aim of this resource is to support the acute and general physician in improving the care and choices available to people at the end of life, or approaching the end of life, who are seen in the acute care setting. It is important to ensure that EOL care for patients is individualised and to recognise that every patient will have different priorities in how their EOL care is managed, rather than assuming that every patient will have the same needs or wishes. Excellent holistic care and communication are the most important aspects of ensuring that patients' choices are supported. This is an area where solutions require changes of attitude and culture. Death should not always be equated with failure, but is a natural anticipated outcome in some circumstances. Solutions also require working with community partners because, in the last year of life, people often move between settings, and they need their care to move with them.

People in the last year of life

In their last year of life, people will often move between different care settings. Most patients will be admitted acutely to hospital with deterioration from an underlying condition, or complications arising from its treatment. Of these, 30% will die in the 12 months after admission.² Around 90% of patients die from a previously diagnosed condition. 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. 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). One such prognostic indicator is the Gold Standards Framework Prognostic Indicator.⁸ 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.

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Fig 1 Living well at the end of life

(adapted with permission from the RAND Corporation, Santa Monica, CA, USA)⁷



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.⁹ A willingness to initiate these discussions should be demonstrated at a senior level; advanced communication skills training has been shown to help. 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 be helpful (Box 1). An example of useful language pointers to support such discussions from the Australian and New Zealand Intensive Care Society is available on the RCP website as an appendix.¹⁰

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.¹¹

All discussions and treatment plans should be documented clearly in the medical notes and communicated with colleagues as part of routine handover.¹² Discussions should also be offered to those identified as important to the patient. This should include situations where there are concerns regarding the patient's current or future mental capacity.

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 consent to the outcome of these discussions being recorded 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 advance care plan range from a documented collection of preferences and values to completion of a legally binding advance decision to refuse treatment (ADRT), or appointment of a lasting power of attorney (LPA) to make decisions on the patient's behalf. The Deciding Right website provides a useful suite of documents.¹³

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.

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) / allow natural death (AND) 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 identified as important to the patient.

Public Health England is currently implementing an electronic palliative care coordination system (EPaCCS)¹⁴ 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.

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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. At any one time, however, approximately 30% of hospital inpatients are in their last year of life² and many have multiple comorbidities. 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.^{15,16} Yet to ignore the possibility of imminent death may deny patients a comfortable death in their place of choice, and may also deny those important to them a chance to know that the patient is dying and to prepare accordingly. 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 those close to the patient is important, ensuring a shared understanding of current disease status, and shared decision making about the goals of treatment and care. 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. The Gold Standard Framework prognostic indicator guidance¹⁷ and SPICT tool¹⁸ also give condition-specific guidance to help identify patients who may be approaching the end of their life (also see Box 2).

Box 2 Factors that may indicate that dying is imminent

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

Managing the dying patient

In response to the Independent Review of the Liverpool Care Pathway, *More care, less pathway*,¹⁹ the LACDP, an alliance of 21 organisations involved in delivering or ensuring high-quality EOL care, set out a new approach to the care of dying people in England, entitled *One chance to get it right*.⁶ This approach identifies five priorities in the care of the dying patient and will support good care, even if the patient does not die as soon as might be expected (Box 3).

The individualised plan of care should take account of the patient's expressed wishes regarding preferred place of care and death. A range of resources is now available, including improving 24-hour availability of district nursing services, cooperation with ambulance services, community-based palliative care rapid-response teams, hospice-at-home teams, innovative care-home-based projects, extended-hours pharmacies and palliative care coordination centres. Likewise, palliative care teams in hospitals are increasingly delivering 7-day services backed by overnight palliative care telephone advice support. These services allow patients to be cared for in the best possible environment, be that in hospital or at home.

Box 3 Priorities for care of the dying person⁶

- 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 and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

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 by phone 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 should be put in place, 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 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, which can be very reassuring.

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.^{20,21} 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.

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

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

Symptom	Medication options	Starting dose
Pain > Normal renal function > Impaired renal function (eGFR <30 mL/min)	Morphine or equivalent Fentanyl or alfentanil	2.5 mg S/C, PRN, up to hourly 25 µg S/C, PRN, up to hourly 100 µg S/C, PRN, up to hourly
Agitation > No delirium > With delirium	Midazolam Add haloperidol or levomepromazine	2.5 mg S/C, PRN, up to hourly 0.5–1.0 mg S/C, PRN, up to hourly 12.5 mg S/C, PRN, up to hourly
Nausea > Alternative > Chemical cause	Cyclizine Levomopromazine Haloperidol	50 mg S/C, 8 hourly/PRN 6.25 mg S/C, 6 hourly/PRN 1.5–3.0 mg S/C, daily
Respiratory tract secretions > Alternative > Or	Hyoscine butylbromide Hyoscine hydrobromide Glycopyrronium	20 mg S/C, PRN, up to hourly 400 µg S/C, PRN, up to hourly 200–400 µg S/C, PRN, up to hourly
Breathlessness > Alternative	Morphine Midazolam	2.5 mg S/C, PRN, up to hourly 2.5 mg S/C, PRN, up to hourly

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

Professional development in EOL care

Physicians 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 End-of-life Care Audit (www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals) 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.

Recommendations for professional development in EOL care include the following.²²

- > 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 end-of-life care locally and nationally at the Association for Palliative Medicine’s website (www.apmonline.org).
- > The e-learning programme End of Life Care for All (e-ELCA) aims to enhance the training and education of the health and social care workforce (www.e-lfh.org.uk/programmes/end-of-life-care/).
- > Find advice and guidance on prescribing in palliative care by registering at www.palliativedrugs.com.

Box 4 Considerations regarding patients in their final year of life on post-take ward rounds or general ward rounds⁶

- > 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.

Box 5 Reflections and discussions following recent deaths²²

- > Was this death expected?
- > Were the patient’s priorities for end-of-life 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?

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