

The Royal College of  
Emergency Medicine

# **The RCEM End of Life Care Toolkit**

**December 2020**

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## End of Life Care Toolkit

The presumption in Emergency Medicine is that our aim is to prolong life, however, we should also recognise that alleviating suffering and prioritising quality of life is just as important. This may be because of sudden unpredictable events such as intracranial bleeds, or because of a deteriorating chronic disease such as COPD or heart failure.

The emergency department provides some unique challenges to the delivery of end of life care, not least an environment which has been described as volatile, uncertain, complex and ambiguous. The need for staff to constantly react to changing circumstances within the department, often of a time critical nature, adds another layer of challenge. It is especially important when dealing with patients and their families that we strive to provide to make as much time as possible to delivering empathetic care in an environment which is as calm as possible.

Providing end of life care in the ED should go beyond simply managing symptoms and should consider many other equally important facets of care, some of which will be unique to the ED. These can be represented by the end-of-life care jigsaw (see page 6). The jigsaw has the patient and their loved ones at the centre of the picture, surrounded by eight pieces of equal size and value, all of which should be considered for those identified as dying. This allows us to look holistically at the situation and involve the patient and their loved ones in decisions about their care wherever possible and appropriate, thus ensuring an individualised person-centred plan is achieved.

When it comes to dying, we only have one chance to get it right. The emergency department has a key role in making and documenting end of life decisions, ensuring the patient is less likely to come to harm on the wards due to inappropriate escalation.

As Emergency Physicians the decisions we make and treatments we initiate will set the narrative for deaths occurring in our ED, but we do not need to manage end-of-life care alone. Working as part of a team with our Trust's Specialist Palliative Care Team, Spiritual Leaders/Chaplains and Specialist Nurses in Organ Donation means we can streamline end-of-life care communication and delivery in our own EDs to provide compassionate and patient centred care. [1]

### Authors

Sarah Vince, Calvin Lightbody

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## Recognising an End of Life Trajectory

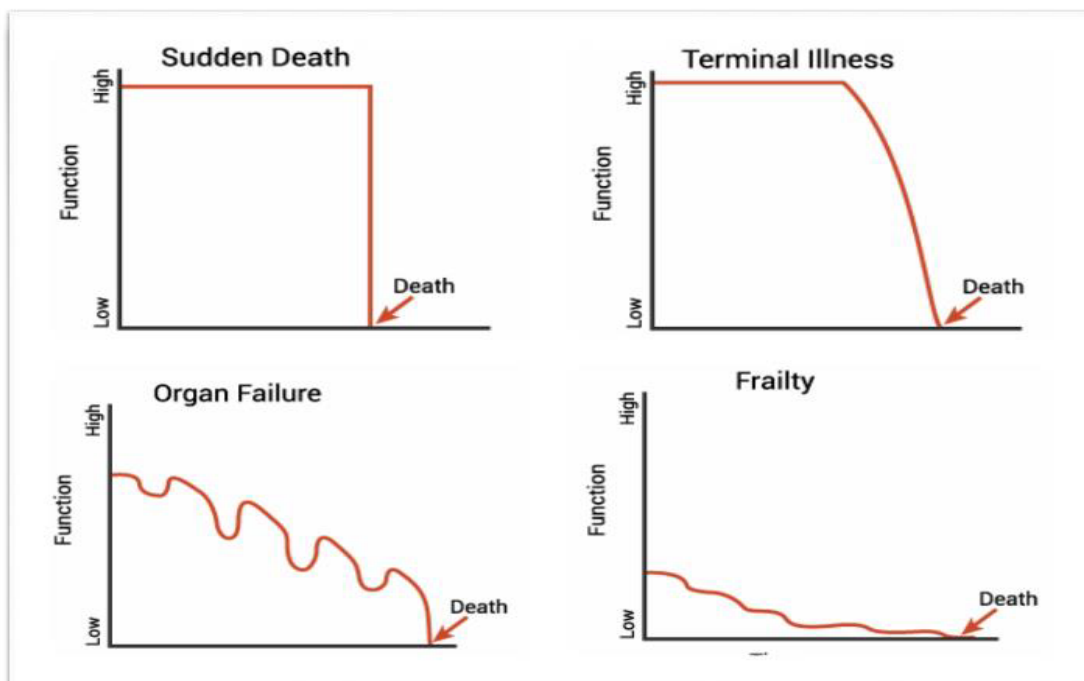
“How are things now compared to six months ago?”

“Do you have any particular fears about what's happening?”

As clinicians we recognise four distinct patterns in end of life trajectory;

- **Sudden death**, end of life is abrupt with no preceding decline in function, for example trauma, myocardial infarction and subarachnoid haemorrhage.
- **Terminal illness**, where there has been a long history of illness, but a relative rapid decline at the end of life. Most cancers would follow this trajectory.
- **Organ failure**, decline is gradual but punctuated by exacerbations, after which return to baseline is never quite achieved. For example COPD or heart failure.
- **Frailty**, a slow steady decline, associated with extreme age or dementia. This group may present to the ED with a crisis such as sepsis that is likely to be terminal.

Patients and their loved ones may not appreciate the significance of their “new normal” and the implications of being increasingly bed bound, having a reduced appetite or being increasingly dependent on care for their activities of daily living. [2]



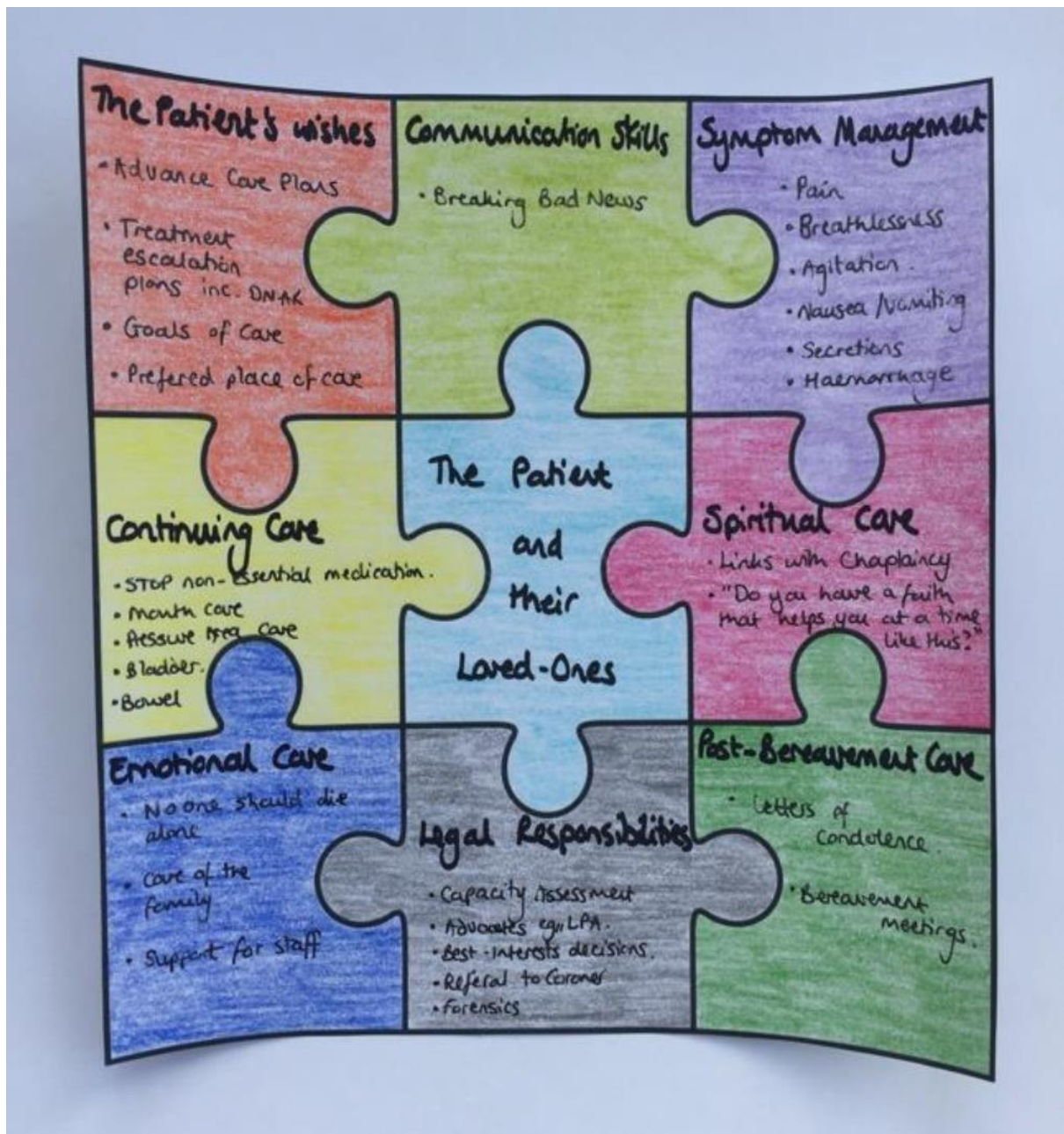
A cohort study from 2014 found that 1 in 10 inpatients in Scottish hospitals would die during that admission: 1 in 3 would die within a year of that admission with the exception of those over 85 years old, where half would die [3]. The imminence of dying for an individual can be difficult to predict. In the following situations, dying can reasonably be anticipated:

- In the event of "non-survivable" pathology e.g. massive SAH
- There is sustained and irreversible deterioration
- Maximal therapy within a defined ceiling of treatment, will not alter death as the eventual outcome
- The senior clinician and nurse looking after the patient agree that the patient is dying and a curative approach would be inappropriate.

There may also be clinical signs that death might be imminent, particularly if there is:

- Refractory / progressive bradycardia
- Mandibular movement with respiration
- Deeply mottled skin / cyanosed peripheries
- Noisy pharyngeal respiratory secretions (aka the "death rattle")

- [Indicators of Poor Prognosis – Northampton General Hospital](#)
- [Amber Care Bundle for those with an uncertain recovery](#)
- [St Mungo's blog post](#)





"Based on what you have told me about your husband, do you think he would want to receive any treatment to keep him alive longer, or would he prefer to only have treatment that ensures he's comfortable and free from pain?" [adapted from 4]

Communication is central to ensuring the best possible outcomes, explaining to the patient and their loved ones what is likely to happen next can be beneficial. This is not about taking away hope, instead, having an open and honest conversation and setting realistic expectations. This can help with letting-go rather than clinging-on, something that will make a "good" death more likely when the time comes. Communication skills at the end of life should not be just viewed as breaking bad news, it is also the opportunity to open up conversations about patients' wishes and priorities.

Answering the "how long have I/they got" question is fraught with difficulties. It is recommended that rather giving specific predictions we use ranges; hours to days, days to weeks or weeks to months.

When death does not appear imminent, but considered likely to during this admission, it is helpful to explore illness trajectory with the patient when possible, and their loved ones. The following questions might be used:

- What is your understanding of the current situation?
- How are things now compared with 6 months ago?
- Do you have any particular fears about what's happening?

Reflecting on the information gained will help with planning how best to proceed. It also means the patient/their loved ones are involved in the decision-making, their wishes can be respected and dignity can be preserved. About 10% of people will not want to have this conversation and we should respect that [3]. A substantial majority however will welcome it. Sometimes we may identify a patient who is frail but wants to go home. In this case make sure the patient is known to the GP as a patient approaching EOL.

Inevitably there will be a degree of uncertainty, but we should manage this and not let it interfere with doing the right thing.

## Managing Uncertainty

“The situation is serious, your mum is sick enough that she may die”

A more common scenario in Emergency Medicine is to be presented with a patient whose recovery is uncertain, for example frail older adults with sepsis or exacerbations of COPD. We recognise that there is a significant chance that they may not survive, but the situation has some potential for reversibility and is not without hope. In these circumstances we should acknowledge the uncertainty in discussions with the patient and their loved ones and involve them in decision making about their future. Our language needs to be clear and thus avoid euphemisms; the phrase “sick enough to die” is a simple and unambiguous way to convey the seriousness of a situation [5].

For example: “you have a very serious chest infection, I can see from the blood tests that we took from your wrist that your body is struggling to cope, and you are so sick that you may die. [Pause] I am hoping that with the antibiotics we are giving you, and with more of these nebulisers, we will see an improvement in your condition so we can get you well enough to get back home. If we don't see things improve with this treatment and you became more unwell, it is really important for me to know and understand what is important to you in these circumstances.....”

Sharing information about a poor prognosis is not easy. It is useful to establish what they want to know, for example; are they someone who likes all the detail, or just the headlines? [6]

Our brains are programmed to be disproportionately upset when we lose things, this is a cognitive bias known as loss aversion. With this in mind, we should phrase our conversations about ceilings of care and resuscitation status in a way that does not play to this bias. For example, instead of “there is nothing more we can do”, use “I am sorry to tell you that your wife is deteriorating despite our treatment, she is dying [pause]. I think it is time we change our focus of care and now concentrate on ensuring she is comfortable and is not distressed or in pain”.

Vulnerable groups, such as those with a cognitive impairment or learning disability, sometimes receive a poorer standard of care. We must pay particular attention to how we communicate, and be receptive to both verbal and non-verbal cues. Involving their loved ones and carers will help us understand how they take in information and express themselves, so we are best able to identify their needs and wishes. [7]

Breaking bad news over the telephone and from behind layers of personal protective equipment has been increasingly necessary during the Covid-19 pandemic; both situations challenge our communication skills because we lose the subtleties of facial expression and body language. If talking over the telephone, check now is a good time to talk, use short sentences at a slower pace and check understanding frequently, because just as they cannot see your body language, you cannot see theirs.



[RED-MAP Communication Tool \(Covid-19\)](#)  
[Evidence Based Advice for difficult conversations \(Covid-19\)](#)  
[RED-MAP Difficult conversations](#)  
[Communicating terrible news: St Emlyn's blog post](#)  
[ED Breaking bad news checklist \(Covid-19\)](#)  
[Phone conversations with relatives](#)  
[Caring for people with learning disabilities at the end of life](#)



## Understanding and Respecting the Patient's Wishes

"What do I need to know about you as a person to be able to care for you best today?"

"Given all that has been happening to you and your health what are your thoughts about what might lie ahead and how you would like to be cared for and treated?"

"If your mum could talk to me now, what would she tell me she wanted?"

As well as asking the patient or their family what their wishes are, we should try and establish if there are any existing decisions or statements of preference about end of life care and plan accordingly. This may be in the form of a community anticipatory care plan, an advanced directive (aka "living will"), a ReSPECT form, a Lasting Power of Attorney for Health and Welfare or documentation held by the patient's GP / care home / Electronic Palliative Care Coordination System (EPaCCS). Nominated decisions-makers (LPAs) can be really important in ensuring that a patient's final wishes are followed and should not just be viewed as a legal formality. Reassuring the patient that you are doing all you can to find their care plans and speak with their attorneys or family members is really important.

### Care Planning and CPR Decisions

Note that a "Do Not Resuscitate" or DNACPR order only relates to CPR in the event of cardiac arrest. It does not proscribe / limit any other procedure or intervention and The RCEM End of Life Care Toolkit (December 2020)

therefore fails to address other important end of life issues. Patients at risk of deterioration and dying should have an individualised treatment escalation / limitation plan made to reduce their risk of being subjected to harmful over treatment [8]. This includes interventions that might be burdensome, futile or contrary to their wishes. When this is done, the patient is also more likely to have their palliative care needs addressed. The ReSPECT process (see link below) creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.

### Goals of Care

Any plan made for the patient should document what the goals of care are. These might be along the lines of "establish pain control" or perhaps "get home as soon as is practical". A decision regarding an appropriate escalation of care is also necessary; this should take into account the proposed benefits and be balanced against potential burdens of treatment, the patient's capacity to recover and the patient's values and wishes [9]. For this to take place, an understanding of the patient's pre-existing conditions and an assessment for the presence and degree of frailty is necessary. The Clinical Frailty Score is a useful tool for assessing and describing degrees of frailty, however, it is not suitable for assessing appropriateness of escalation to critical care in patients with stable long-term conditions (for example cerebral palsy), learning disabilities or autism and individualised assessment of frailty is required [10].

### Escalation of Care

If it would be inappropriate to admit the patient to the Intensive Care Unit then this should be documented. In some cases, transfer to High Dependency may also be inappropriate, particularly if this meant being subjected to treatments which were unlikely to be of benefit to the patient and in fact cause distress. Making and documenting these decisions in the ED means that the patient is less likely to come to harm on the wards due to inappropriate escalation.

### Preferred Place of Care

Someone's preferred place of care should also be considered. Very few people want to die in hospital and in certain circumstances, all be it a minority of cases for our ED population, we may be in a position to fulfil their wishes. Every ED should know how to access their local hospice and community palliative care team for those few patients that may be stable enough to transfer out of the hospital environment.

## Lack of Capacity

Once a patient is deemed to have lost capacity to make a decision about medical treatment, appropriate legal frameworks should be followed; in England and Wales the Mental Capacity Act (2005), in Scotland the Adults With Incapacity Act (2000), and in Northern Ireland the Mental Capacity Act (2016).

Have they written an Advance Decisions to Refuse Treatment? Have they appointed a Lasting Power of Attorney for Health and Welfare through the Office of the Public Guardian to make decisions on their behalf? If yes, decisions must be made accordingly. If not, we must make decisions in their **best interests**. To do this, we will need to look for any written statements of wishes and preferences and speak to family members to understand who they are as a person and what their priorities and preferences have been when they were involved in decisions about their care.

## Organ and Tissue Donation

One "end of life wish" that many of us have considered, discussed, and hopefully formally recorded, is that of whether or not we would want to be an organ/tissue donor after we have died. Consideration of organ/tissue donation should be a routine part of end of life care in the ED not simply to help those outside of our care awaiting vital organs, but as a way of honouring the end of life wishes of the patient in front of us.

Organ donation legislation differs throughout the UK:

The legislation (December 2015) for Wales is 'deemed consent'. This means that if the patient has not registered an organ and tissue donation decision (opt in or opt out), the patient will be considered to have no objection to becoming a donor. In England (May 2020) there is an opt out system which works on the understanding that all adults agree to become organ donors when they die, unless they have made it known that they do not wish to donate. From March 2021 Scotland will be adopting a similar 'opt out' system. In Northern Ireland the current legislation is to opt in to organ and tissue donation through the NHS Organ Donor Register and patients sharing their decision with their family.

The opportunity to donate organs is uncommon from the ED, as most donors die on an Intensive Care Unit. For any patient for whom a decision has been made to withdraw life-sustaining treatment, a discussion should be held with the Specialist Nurse for Organ Donation (SNOD) to consider suitability and see if they have recorded their wishes on the NHS Organ Donor Register. If the patient would be an appropriate candidate, a joint approach with a SNOD should be made to the loved ones, and not discussed without their expertise on hand to support.

Unlike organ donation, almost everyone can donate tissues after death. Tissues such as tendons, skin, corneas and heart valves can be life transforming to recipients. They can be retrieved up to 24-48 hours after death. Discussing and providing information about tissue donation should be a normal part of post bereavement care. The [National Referral Centre](#) (0800 432 0559) are able to offer guidance about individual referrals and support departments with relevant resources.

- [Hospital Anticipatory Care Plan – NHS Lanarkshire](#)
- [Respect Form](#)
- [Organ Donation: identification and referral guide](#)
- [Guidance on DNACPR Decision making](#)
- [Guidance on Best Interests Decision Making](#)



At the end of life there can be troubling and distressing symptoms that we are able to alleviate with simple measures and treatments.

### Non-pharmacological techniques for symptom management

- **Breathlessness:** The feeling of air moving over their face can provide great relief, so opening a window or introducing a fan to the room can be refreshing. Fans, however, should be avoided in infectious diseases, such as Covid-19, because of the risk of dispersing infectious droplets.
- **Acute Haemorrhage:** Using dark coloured towels to absorb the blood can reduce the visual and psychological impact on the patient and any family present.
- **Agitation:** Nurse in a calm, quiet, low stimulation environment. Look for and address causes of pain or distress, such as a full bladder, full rectum or wet bed. Playing someone's favourite music through a relative's smart phone can have a soothing and calming effect.
- **Respiratory Secretions:** Repositioning may settle the noise of uncleared secretions as can gentle suction to the oropharynx. Secretions are rarely troublesome to the patient themselves; simple reassurance can go a long way in alleviating the family's distress.
- **Pain:** Explanations to facilitate understanding of the nature of the pain and the nature and expectations of treatment often allow patients to cope better. [11] Covering open wounds or sores can provide relief, as does splinting fractures.

### Pharmacological therapies

Most Trust's will have easy to navigate algorithms for common symptoms such as pain, breathlessness and agitation that can be incorporated into ED care. These symptoms should be anticipated and appropriate prescriptions made so nursing staff are able to treat symptoms as they arise.

For example

- MORPHINE 2mg s/c, hourly PRN – for pain and / or breathlessness
- MIDAZOLAM 2mg s/c, hourly PRN – for anxiety / agitation

- HYOSCINE BUTYLBROMIDE 20mg s/c, maximum of 6 doses in 24hrs – for secretions
- LEVOMEPRMAZINE 2.5mg (two point five) s/c, 8 hourly PRN – for nausea
- HALOPERIDOL 2mg s/c, 12 hourly PRN for agitation / delirium

In some cases where patients have expressed a wish not to spend their last days in hospital, it may be possible to discharge a patient home (or to a care home) from the emergency department. As well as ensuring that the patient will have the appropriate level of family and community support, departments should consider whether they have the ability to dispense any anticipatory medication, with the appropriate safeguards, that might be needed, be 'in-hours' or 'out of hours'.

At the end of life there can be troubling and distressing symptoms that we are able to alleviate with simple measures and treatments.

- [Pre-emptive Prescribing – Brighton and Sussex University Hospitals](#)
- [Uncontrolled blood loss – Northampton General Hospital](#)
- [Covid-19 Lung Disease – Scottish Palliative Care Guidelines](#)
- [Managing breathlessness \(Covid-19\)](#)



If the patient is identified as near the end of life, stop all non-essential medication, blood tests and physiological observations as they are an unnecessary burden.

Food and drinks should be offered if a patient is awake enough to swallow, though appetite is normally lost as death approaches. Thirst may be troublesome, so oral fluids can offer relief, and clinically assisted hydration can be considered (intravenous or subcutaneous) if the oral route does not relieve their symptoms. A dry mouth is a common and distressing problem which is easy to remedy with basic mouth care interventions. Before commencing clinically assisted hydration it is important to check that a patient does not have an advanced decision which specifically refuses it. Spending time with family members, to explain the loss of appetite and thirst as death approaches, may help to allay anxiety that their loved one in 'dying of thirst'.

Assess bladder and bowel dysfunction as this can be an easily ameliorated cause of distress.

Pressure sores develop quickly especially in the frail, they can cause significant pain and therefore should not be neglected even in those who are actively dying. The need for regular turns and the use of appropriate mattresses should be assessed and employed as indicated and tolerated.

- [Continuation of Care Form – Northampton General Hospital](#)
- [Taste for Pleasure](#)





*"Do you have a faith that helps you at a time like this?"*

*"Are there any spiritual rituals or customs you would like to have performed?"*

*"Are there pieces of jewellery or religious objects that should not be touched or removed?"*

Spirituality is an important part of life for many people, and providing spiritual support in death can be just as important to some people as good symptom control. People who do not hold a particular religious affiliation may also require pastoral support in times of crisis. [12] Asking about spiritual needs should be a routine part of end of life care in the ED.

EDs should make strong links with their hospital's Chaplaincy Team as they will be able to provide support to those of many different faith groups and also those with no faith.

Detailed knowledge or experience of someone's faith or culture is less important than a sensitivity to the fact that their needs may be different to our own. [13] We should be careful to avoid cultural stereotypes but remain confident that compassion, care and interest in someone's spiritual needs will transcend all faith groups and cultures.

- [Religion or Belief: a practical guide for the NHS](#) Pages 29-31



### No one should die alone

Proactive management of end of life care is essential both for patients and their families, this may involve the use of side-rooms as well as increased frequency of checks. For some with troubling symptoms that are being actively managed this may involve multiple checks times per hour, and for those with more stable symptoms, every few hours. Ask about worries or fears, taking time to listen and respond.

Many loved-ones need to feel helpful and to know their contribution is valued; involving them in tasks such as mouth care or hydration can be beneficial to all. [14] Others may see this type of task as a burden so no expectations should be placed on the family, but a simple invitation made so they know they are welcome to be involved if they and their loved one would like.

For those without family present, effort should be made for a member of staff to sit with them so they are not alone. Given the pressures in EM this may mean seeking help from outside the ED and asking for a member of staff to be released from other less acute areas of the hospital to sit with a dying patient. Resources such a video conferencing can be used to facilitate patients and families seeing and speaking to each other if circumstances prevent them being together in person.

Providing loved ones with keepsakes such as fingerprints, a print out of the ECG (heart beat in a bottle) or locks of hair, are often well received by families. [15] Like all aspects of care, this should be discussed with individuals beforehand, as for some, well intended actions such as providing a lock of hair, may not be culturally or spiritually appropriate.

It should be recognised that staff may need emotional support when caring for people at the end-of-life. This is already embedded in our consciousness after events such as a paediatric cardiac arrests where debriefs are a routine part of practice. We

[The RCEM End of Life Care Toolkit \(December 2020\)](#)

must be cognisant that we and our colleagues may find ourselves affected by more “run of the mill” cases, especially if there are similarities with our own personal circumstances or history. Staff should know what mechanisms are in place to support them if they find themselves in difficulty.

Displaying humanity and empathy are key behaviours; being able to embrace the patient's experience or walking in another person's shoes is considered vital to good patient experience. These situations often raise challenges to even the most experienced clinicians; having to control their own feelings and recognising the need to ‘step back’ and reflect. [16]

[Bereavement Pack Example](#)

[Support for Families – Northampton General Hospital](#)

[Information for families “Coping with dying” leaflet – NHS Lanarkshire](#)

[Support for Families Bereaved by Suicide](#)

[Debrief Toolkit – Royal Derby Hospital](#)

[Psychological first aid – NHS Scotland](#)



In our routine ED practice we work within the framework of various pieces of legislation, such as the Mental Capacity Act (2005) in England and Wales, The Adults With Incapacity Act (2000) in Scotland, and The Mental Capacity Act (2016) in Northern Ireland. We will be familiar with making an assessment of capacity for a specific decision and how to make a best interests decision in the absence of an appointed attorney. This is especially relevant for those who are at the end of life.

After a patient has died, we also have specific legal responsibilities that will be less familiar to those working in other palliative care settings, specifically referral mechanisms to the Coroner or Procurator Fiscal and the preservation of evidence in forensic cases. These systems and recommendations will vary depending on the local systems and forensic pathology service.

- [Confirmation of Lasting Power of Attorney](#)
- [Guidance on Coronial Referrals](#)
- [Sudden Unexpected Death in childhood and Infancy](#)
- [Guidance on completion Medical Certificate Cause of Death \(MCCD\)](#)
- [Reporting Deaths to the Procurator Fiscal](#)



Bereavement meetings are offered by many EDs, where families are invited to return to meet senior clinicians as an opportunity to ask questions or seek clarification on events. It may be that information was not available on the day their loved one died, or that information was provided but the family were not able to take it in due to the distress of the situation. A number of methods have been adopted to offer this invitation; letters sent to the next-of-kin 4-6 weeks after the death has been shown to be a successful format. [17] Whilst there may be a low response rate to these invitations, each one has the potential to make a difference by the expression of care that is conveyed. [13]

- [Bereavement meeting SOP and Condolence Letter template – Northampton General Hospital](#)

## Additional training resources

<https://www.e-lfh.org.uk/programmes/end-of-life-care/>

Dawood M. End of life care in the emergency department. *Emerg Med J* 2020;37:273–278. doi:10.1136/emermed-2019-208632

<https://www.rcn.org.uk/professional-development/professional-services/end-of-life-care-and-wellbeing-for-the-nursing-and-midwifery-workforce>

## Departmental Audit Standards

- A departmental lead need for End of Life Care
- EoL Training for doctors and nurses covering, but not limited to
  - Communication skills
  - Mental Capacity legislation
  - Organ and tissue donation
  - Access to
    - Chaplaincy teams,
    - Specialist palliative care team/resources,
    - Hospice and community palliative care pathways
- Treatment escalation plan/anticipatory care plans alongside all DNAR decisions
- Guidelines available for management of common end of life symptoms
- Facilities for providing end of life care to patients and their families
  - A side room with a door to allow a quiet and private space to deliver end of life care
  - A relatives room that is private, quiet, has comfortable chairs/sofa, a phone, drinks and access to outside space. [18,19]
  - A viewing room
- An ED representative on the Trust's Organ Donation Committee
- Post bereavement care – Loved ones have a mechanism to ask follow-up questions after leaving the ED
- Systems in place to notify the GP & Medical Records department of a death within 1 working day.
- Governance:
  - Departmental Mortality Review to retrospectively look at the quality of care of those who die in the ED.
- Hospital M&M to examine if any harms were associated with treatment decision making (or lack thereof) e.g. review of cardiac arrest calls; was it appropriate for the patient to have been for full escalation?

## Key words

End of life care

Palliative Care

Bereavement

Sudden Death

Dying

Treatment Escalation Plan

DNACPR

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## **Review**

Usually within three years or sooner if important information becomes available.

## **Conflicts of Interest**

None

## **Disclaimers**

RCEM recognises that patients, their situations, Emergency Departments and staff all vary. This guideline cannot cover all possible scenarios. The ultimate responsibility for the interpretation and application of this guideline, the use of current information and a patient's overall care and wellbeing resides with the treating clinician.

## **Research Recommendations**

None

## **Key words for search**

End of Life Care, Emergency Department



**The Royal College of  
Emergency Medicine**

The Royal College of Emergency Medicine  
7-9 Breams Buildings

London

EC4A 1DT

Tel: +44 (0)20 7400 1999

Fax: +44 (0)20 7067 1267

[www.rcem.ac.uk](http://www.rcem.ac.uk)

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