

View this article online at: [patient.info/doctor/end-of-life-care-pro](https://patient.info/doctor/end-of-life-care-pro)

## End of life care

See the related separate articles [Helping Patients Face Death and Dying](#) and [Palliative Care](#).

This article examines the terminal stage of palliative care; other articles cover symptom control in palliative care:

- [Pain Control in Palliative Care](#)
- [Nausea and Vomiting in Palliative Care](#)
- [Dyspnoea in Palliative Care](#)
- [Prescribing in Palliative Care](#)
- [Palliative Care of Heart Failure](#)

## Introduction

Population-based studies of preferences for place of death indicate that over 60% of people (including those who were not facing life-threatening illness at the time) would prefer to die at home<sup>[1]</sup>. The latter may require support and resources to help them to cope<sup>[2]</sup>. This can be a significant burden upon the Primary Healthcare Team in terms of time and emotion but it can also be most rewarding.

Whilst this has been an important driver for improving end of life care at home, the 'place of death' is not necessarily the highest priority for everybody. In a population-based study involving just under 10,000 adults across England, only 34% ranked 'dying in preferred place' as their top care-related priority. In addition they would change their mind if sufficient support from family, friends or social and medical professionals were not available. The need to be pain-free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care.

The Care Quality Commission (CQC) has found significant variations in the quality of care received by, for example, people of different ethnic background, sexual orientation and social background<sup>[3]</sup>. Despite this inequality, the UK ranks first for the quality of palliative care in 80 countries around the world<sup>[4]</sup>.

Terminal care is not just cancer care but other relevant diseases, which include [heart failure](#), [respiratory failure](#), [severe chronic kidney disease](#), [hepatic failure](#), as well as certain neurological diseases such as [multiple sclerosis](#) and [motor neurone disease](#), and [dementia](#). Each may bring its own challenges in terms of the provision of terminal care. Studies of end-stage [chronic obstructive pulmonary disease](#) (COPD) patients, for example, found that such patients tend not to ask for help actively and a discussion about support may need to be initiated by the healthcare worker<sup>[5]</sup> <sup>[6]</sup>.

## "One Chance to Get it Right"

"One Chance to Get it Right" was published in June 2014<sup>[7]</sup> <sup>[8]</sup>. It provides guidance in the care of dying people and is aimed at all clinicians everywhere - hospital and community. It was published by the Leadership Alliance for the Care of Dying People, which was established following an independent review of the Liverpool Care Pathway (LCP), commissioned by the UK government and chaired by Baroness Neuberger. Its members include the General Medical Council (GMC), NHS England, the Nursing and Midwifery Council and the Royal Colleges of GPs, Nursing and Physicians.

Five "Priorities of Care" are described and form the focus of care at the end of life. These are universal and applicable irrespective of the place where someone is dying - whether a hospital, their own home, a care home or a hospice.

"Good care for dying people ... is typified by looking at what that care is like from the perspective of the dying person and the people who are important to them, and developing and delivering an individualised plan of care to achieve the essentials of good care."

1. The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions 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, co-ordinated and delivered with compassion.

There are several tools to help identify people who may be nearing the end of their life, such as the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool [SPiCT]<sup>[9]</sup>. The Gold Standards Framework is a training programme supported by many authoritative bodies<sup>[10]</sup>. One of the key factors in managing terminal care is to institute such care at an appropriate time. This involves an estimation of prognosis. The Gold Standards Framework has developed a Prognostic Indicator Guide to assist in this process, which starts with asking three trigger questions<sup>[11]</sup>:

- Would you be surprised if the patient were to die in the next months, weeks or days?
- Do they have general indicators of decline - eg, reduced ability for self-care, repeated unplanned hospital admissions, spending more than 50% of their time in bed?
- Do they have specific clinical indicators - eg, cancer metastases, increased frequency of steroid courses (COPD)?

1% of the UK population will die every year; GPs are encouraged by the Dying Matters Campaign to identify their 1% of patients<sup>[12]</sup>. This benefits the individual and those close to them, as well as allowing appropriate care to be planned.

End of life care is one of the themes of CQC inspection and UK practices are expected to have a palliative care register, regular palliative care meetings and a plan as to how they are finding their 1%, and to be aware of the Five Priorities of Care and show how they apply them <sup>[13]</sup> .

Clinicians must support adults approaching the end of their life to participate in decision making by having processes in place to establish the amount and type of information they would prefer <sup>[9]</sup> . They should also have systems to provide information in a way that meets their communication needs and preferences – for example, how it is given (verbally, on paper, by text, email, or other assistive technologies) and provision of professional interpreters. There should also be arrangements to review and anticipate their information needs and preferences as circumstances change.

#### **Editor's note**

[Dr Sarah Jarvis](#), 28th September 2021

#### **NICE quality standard on end of life care**

The National Institute for Health and Care Excellence (NICE) has updated its quality standard on end of life care <sup>[14]</sup> . They state that:

Adults who are likely to be approaching the end of their life should be identified using a systematic approach.

Adults approaching the end of their life should have opportunities to discuss advance care planning.

Adults approaching the end of their life should receive care co-ordinated between health and social care practitioners within and across different services and organisations.

Adults approaching the end of their life and their carers should have access to support 24 hours a day, seven days a week.

Carers providing end of life care to people at home should be supported to access local services that can provide assistance.

# Dying at home

For the patient wishing to die at home there must be adequate back-up. This usually means a close person such as a spouse, long-term partner, close relative or a team of people who are available 24 hours a day. Night sitter services are available but costly. The carer must be prepared to cope with the emotional and physical needs of the patient and these can be very demanding.

## Team approach

A multidisciplinary approach is often required to provide all the skills to care for adults approaching the end of their life. They may need support in <sup>[9]</sup> :

- Disease-specific questions, including symptom management, hydration and nutrition, and access to medication.
- Physical problems.
- Psychological problems.
- Social matters, including support and advice (for example, signposting advice on benefits, finance and third-sector, local or national support services).
- Support with activities of daily living, including access to equipment and rehabilitation services.
- Pastoral, religious and spiritual guidance.
- Cultural matters.

This team may include a GP, district nurses, perhaps Macmillan nurses, Social Services and often a minister of religion too. There should be a key worker who is the main point of contact for the patient, the family and the rest of the team. The key worker is often not the most senior member of the team but is the important person who liaises and who ascertains that nothing is left undone or duplicated.

If there is likely to be any problem out of hours, the local provider of unscheduled care should be informed. They should have a list of all terminally ill people. Adequate liaison may prevent unnecessary visits including, if the family agrees, waiting until the morning to certify death.

## Emotional needs

Death will come to us all but when it becomes imminent, emotions are bound to be strong.

Fear is common. How long will it be? What will it be like? Try to be honest with the patient and answer questions to the best of your ability, including being honest about uncertainties. Most people do want straight answers but you may need to signpost first that you are about to discuss some difficult questions. Don't be afraid to ask whether they would like to talk about what to expect and what is likely to happen.

Before the terminal stage and particularly whilst still of sound mind, unimpaired by drugs, the patient may have already considered their end of life care and how they want it to be managed. [Advance care plans](#), also called living wills or advance care directives, are the vehicle for this and should be taken into account if a person has lost [mental capacity](#)<sup>[9]</sup> .

Many people faced with death will turn to God either for the first time or as a return to lost faith. You may put them in contact with a minister of religion if required but do not attempt to influence someone in this situation.

They may also wish to make peace to end feuds with relatives or friends.

A conventional will should also be in place. If a conventional will has not been made then even at this late stage it should be done, as dying intestate is rarely desired.

## General debility

As death approaches, the patient will become weaker. They will need help in and out of bed and to the toilet. Sleep may be excessive. Appetite usually diminishes and weight falls. Be prudent in deciding if intensive nourishment is in the interest of the patient. Food dense in calories is often poorly absorbed and may produce diarrhoea and the distress of [faecal incontinence](#).

Urinary incontinence is often followed by faecal incontinence. This is distressing for the patient, unpleasant for the carer and adds to their burden. Pads, waterproof under-sheets, etc, are useful. As well as the unpleasantness, incontinence is a danger to the integrity of skin and in this condition, if it breaks down, it may never heal again. A urinary catheter may be required but do not be too eager and discuss the options with all parties first.

Immobility, poor circulation and inadequate nutrition all predispose to [pressure ulcers](#). Frequent turning, sheepskin to lie on and ripple mattresses are all to be considered. Turning can sometimes be very painful but necessary.

## Pain and distress

See also the separate [Pain Control In Terminal Care](#) article.

Pain is what patients fear most although, in reality, other features such as dyspnoea may be more distressing. There is a very wide range of other problems that will be encountered and most patients will experience a number of them. These can include <sup>[15]</sup> <sup>[16]</sup> :

- [Insomnia](#)
- Anorexia
- [Constipation](#)
- Sweating
- Nausea
- Dyspnoea
- [Dysphagia](#)
- Neuropsychiatric symptoms
- Vomiting
- Urinary symptoms
- [Dyspepsia](#)
- Paresis

- Diarrhoea
- Pruritus
- Dermatological symptoms

The hospice movement has done much to further knowledge about the management of pain and distress in terminal care. The doctor should be confident in their ability to manage pain and this should be transmitted to both patient and carers.

- Keep to oral medication for as long as possible.
- Try to avoid injections.
- Patches for drugs such as fentanyl are expensive but may be useful. Syringe drivers can be valuable.
- Let others, including patient or carers, decide to increase the dose if required but keep a general overview to ensure that a rational regime is in place.
- If doses are too far apart the pain becomes severe and debilitating and requires a very high dose to suppress it. Hence, the patient spends half the time distressed by uncontrolled pain and the other half sedated by heavy medication.
- In the terminal stages decide what routine drugs can be stopped.
- The central anxiolytic action of the opiates is very important and drugs including benzodiazepines, tricyclic antidepressants and phenothiazines can enhance the effect. Despite their effect of suppressing the respiratory drive, they can also be valuable in alleviating some of the distress of dyspnoea of respiratory or cardiac failure but they should be used with care.

Palliative care may require sedation for symptoms other than pain, such as involuntary movements or delirium, although the cause, such as medication, dehydration or hypercalcaemia, should be identified and treated if possible<sup>[17]</sup>. Sedation is frequently required<sup>[18]</sup>. A Cochrane review demonstrated that palliative sedation did not hasten death<sup>[19]</sup>.



As death approaches, the amount of time spent drowsy or comatose increases, the lucid time decreases and increases in medication are usual with increased dose and frequency. This is usual and the clinician should not be unduly concerned or surprised when it happens.

## Ethical Issues

There are many ethical issues surrounding end of life care, from the ethics of removing intravenous feeding to assisted dying.

In order to assist clinicians with these difficult issues, the General Medical Council (GMC) has published guidance "Treatment and care towards the end of life: good practice in decision making" <sup>[20]</sup> . While the document should be read in its entirety, salient points are as follows:

- Care should be equitable. Capacity and human rights legislation should be borne in mind.
- All reasonable steps should be taken to prolong a patient's life but there is no absolute obligation to prolong life irrespective of the consequences for the patient or the patient's views.
- Every adult patient should be presumed to have the capacity to make decisions about their care and treatment unless proved otherwise.
- If an adult patient lacks capacity, the decisions made on the patient's behalf must be based on whether treatment would be of overall benefit (including the option not to treat) in consultation with those close to the patient.
- Different decision-making paths should be followed for patients who have capacity and those who do not (full details are provided in the GMC guidance).

Decisions about palliative sedation and the role of food and fluid intake in the prolongation of life are ethically complex. A systematic review found inconsistencies in approach and calls for multicentre, prospective, longitudinal and international studies to help inform the process <sup>[21]</sup> .

Sometimes patients or relatives may request the health professional to end a tragic last phase<sup>[22]</sup> . Repeated requests are difficult to deal with. One study found that the response was variable and called for healthcare professionals to share the experience of troubling cases and of moral conflict and to be supported and heard in a non-judgemental environment<sup>[23]</sup> .

Many countries have legalised Medical Assistance in Dying (MAID) or are thought likely to do so in the near future<sup>[24]</sup> . Where it is legal, palliative care physicians are involved in 90% of cases, although many palliative care bodies believe that palliation and assisted dying are incompatible<sup>[25]</sup> .

MAID remains illegal in the UK.

## **Caring for the carer<sup>[26]</sup>**

Caring for a loved one who is dying is a very demanding time. The emotional turmoil, compounded perhaps by lack of sleep, takes its toll. Seeing one's parent, sibling or spouse changing from a strong and independent person to becoming a frail, dependent, incontinent and perhaps, at times, confused shadow of their former self is most distressing. It can produce feelings of anger or guilt. Someone who has never even changed a nappy may have difficulty coping with a relative who is doubly incontinent or, if they are already frail themselves, they may struggle with heavy lifting.

Carers, like the patient, need to know what to expect. For example, they may find the "death rattle" of terminal breathing or Cheyne-Stokes breathing most distressing.

All attention is on the dying patient. Do not forget the needs of those who care.

Remember practical details too like who should be called in case of need and what to do when death occurs. They should not find themselves, in ignorance, dialling 999/112/911.

Have they spoken with the patient about practical details including funeral arrangements and where the will is lodged? When you certify the death, speak with the carers to let them know that you care about them too. Arrange to see them in the surgery some time after the funeral or for them to see their own doctor if they are not your patient. Usually it is a busy time until the funeral and it is after everyone has left and the flowers have died that the emptiness appears.

Whilst their needs may be challenging, carers should be seen in a positive light as an invaluable resource. They are often the best person to assist the health professional in making decisions about the care of the dying patient.

While it is recognised that carers need practical, psychological and financial support, there is a considerable lack of evidence as to what interventions are likely to be most helpful, and further research needs to be done in this area.

## **Death in the young**

When an old person dies it is often an emotional time, although one can rationalise a degree of satisfaction at the end of "a good innings". When a young adult, an adolescent or a child dies, emotions are compounded and the impact is enormous both for the family and the professionals involved<sup>[27]</sup>. Whilst it is important to ensure adequate bereavement support is available for the family and carers of a child who has died, it is also important that professionals involved have an opportunity to debrief with colleagues<sup>[28]</sup>.

## **Conclusion**

Care at the beginning of life has been removed from the hands of most general practitioners but care at the end of life exemplifies the benefits of the continuity of care and continuing responsibility that are the cornerstone of general practice.

Care of the dying at home is time-consuming, difficult and demanding. Your surviving patients will judge you on how you managed the entire episode. It is the ultimate in holistic care. Show competence and compassion and it will also be hugely professionally rewarding.

Death is not a failure of modern medicine but as inevitable as ever it was.

---

## Further reading

- [Improving supportive and palliative care for adults with cancer](#); NICE Cancer Service Guideline, March 2004
- [Advance Care Planning](#); Palliative Care Wales
- [Quinn KL, Detsky AS](#); Medical Assistance in Dying: Our Lessons Learned. JAMA Intern Med. 2017 Sep 1;177(9):1251-1252. doi: 10.1001/jamainternmed.2017.2862.

**Disclaimer:** This article is for information only and should not be used for the diagnosis or treatment of medical conditions. Egton Medical Information Systems Limited has used all reasonable care in compiling the information but makes no warranty as to its accuracy. Consult a doctor or other healthcare professional for diagnosis and treatment of medical conditions. For details see our [conditions](#).

Authored by:	Peer Reviewed by: Dr Colin Tidy, MRCGP	
Originally Published: 20/11/2023	Next review date: 17/03/2020	Document ID: doc_2565

---

View this article online at: [patient.info/doctor/end-of-life-care-pro](http://patient.info/doctor/end-of-life-care-pro)

Discuss End of life care and find more trusted resources at [Patient](#).



To find out more visit [www.patientaccess.com](http://www.patientaccess.com)  
or download the app



Follow us

