

# Care of dying adults in the last days of life

NICE guideline

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## Context

Without an evidence-based approach to the care of dying people, there is a danger of placing tradition and familiar policies before the needs of individuals and families. The Liverpool Care Pathway (LCP) for the Care of the Dying Adult and its numerous local derivatives were widely adopted in the NHS and UK hospices until 2014. Although the LCP was designed to bring values of 'good' end of life care from the hospice movement to mainstream hospitals and elsewhere, it met with increasing criticism from the public, healthcare professions and the media. There were 3 main areas of concern:

- recognising that a person was dying was not always supported by an experienced clinician and not reliably reviewed, even if the person may have had potential to improve
- the dying person may have been unduly sedated as a result of injudiciously prescribed symptom control medicines
- the perception that hydration and some essential medicines may have been withheld or withdrawn, resulting in a negative effect on the dying person.

These were not necessarily a direct consequence of following the LCP, but often happened because of poor or indiscriminate implementation and a lack of staff training and supervision.

This guideline responds to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. It is focused on care needed when a person is judged by the multiprofessional clinical team to be within a few (2 to 3) days of death. This is different from other important NHS initiatives labelled 'end of life care' which are aimed at improving care for people in the last year or so of a chronic condition.

The guideline is intended for all healthcare professionals and other care providers who might be involved in the care of a person who is nearing death in any NHS setting. It is specifically aimed at non-specialists working in primary care or in care homes, and healthcare professionals working in a wide range of clinical specialties who do not have specialist level training in end of life care. It will also provide a baseline for standards of care in settings that specialise in caring for people who are dying, such as non-NHS palliative care units and hospices.

The ways in which people die and how long this takes varies widely, mostly because of the underlying diseases responsible but also the person's robustness or frailty, and their social setting. Some people remain mobile and largely self-caring, and can continue to take oral medication and eat and drink up until their death. Others may die suddenly and unexpectedly after a significant

trauma or catastrophic medical event. Some people may never experience any of the symptoms addressed in the guideline. People with progressive cardiac, pulmonary or neurological disorders, dementia, some forms of cancer or who have had a stroke may spend several weeks or months in a gradual or intermittent decline. Although the guideline focuses on the people who are thought to be in the last few days of life, for many people, especially those in a gradual decline, the principles of communication, shared decision-making and pharmacological care can be applied far earlier in their care. The recommendations apply to all people at the end of life, whether they are conscious or unconscious.

For some people who are entering the last days of life, mental capacity to understand and engage in shared decision-making may be limited. This could be temporary or fluctuating, for example it may be caused by delirium associated with an infection or a biochemical imbalance such as dehydration or organ failure, or it could be a permanent loss of capacity from dementia or other similar irreversible conditions. The guideline complements, but does not replace the healthcare professional and other's duty to comply with the Mental Capacity Act. It also makes clear the duties of the multiprofessional team regarding communication and involving those people important to the dying person.

This guideline provides recommendations to help healthcare professionals to recognise when a person is entering the last days of life or may have stabilised or be improving even temporarily; to communicate and share decisions respectfully with the dying person and people important to them; and to manage hydration and commonly experienced symptoms to maintain the person's comfort and dignity without causing unacceptable side effects.

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength of our recommendations, and has information about safeguarding, mental capacity and consent, and prescribing medicines (including 'off-label' use).

### 1.1 *Recognising when a person may be in the last days of life*

These recommendations are intended to help healthcare professionals to recognise when a person may be entering the last days of their life, or if they may be deteriorating, stabilising or improving even temporarily. It can often be difficult to be certain that a person is dying. The recommendations supplement the individual clinical judgement that is needed to make decisions about the level of certainty of prognosis and how to manage any uncertainty.

1.1.1 If it is thought that a person may be entering the last days of life, gather and document information on:

- the person's physiological, psychological, social and spiritual needs
- current clinical signs and symptoms
- medical history and the clinical context, including underlying diagnoses
- the person's goals and wishes
- the views of those important to the person about future care.

1.1.2 Assess for changes in signs and symptoms in the person and review any investigation results that have already been reported that may suggest a person is entering the last days of life. These changes include the following:

- signs such as agitation, Cheyne–Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions and progressive weight loss
- symptoms such as increasing fatigue and loss of appetite
- functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal.

- 1.1.3 Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering.
- 1.1.4 Avoid undertaking investigations that are unlikely to affect care in the last few days of life unless there is a clinical need to do so, for example, when a blood count could guide the use of platelet transfusion to avoid catastrophic bleeding.
- 1.1.5 Use the knowledge gained from the assessments and other information gathered from the multiprofessional team, the person and those important to them, to help determine whether the person is nearing death, deteriorating, stable or improving.
- 1.1.6 Monitor for further changes in the person at least every 24 hours and update the person's care plan.
- 1.1.7 Seek advice from colleagues with more experience of providing end of life care when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

## 1.2 *Communication*

Please also refer to the recommendations on communication in NICE's guideline on [patient experience in adult NHS services](#).

Healthcare professionals caring for adults at the end of life need to take into consideration the person's current mental capacity to communicate and actively participate in their end of life care (for more information see [your care](#)).

- 1.2.1 Establish the communication needs and expectations of people who may be entering their last days of life, taking into account:
- if they would like a person important to them to be present when making decisions about their care
  - their current level of understanding that they may be nearing death
  - their cognitive status and if they have any specific speech, language or other communication needs

- how much information they would like to have about their prognosis
- any cultural, religious, social or spiritual needs or preferences.

1.2.2 Identify the most appropriate available multiprofessional team member to explain the dying person's prognosis. Base this decision on the professional's:

- competence and confidence
- rapport with the person.

1.2.3 Discuss the dying person's prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.

1.2.4 Provide the dying person, and those important to them, with:

- accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism
- an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life
- information about how to contact members of their care team
- opportunities for further discussion with a member of their care team.

1.2.5 Explore with the dying person and those important to them:

- whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or an advance decision to refuse treatment or details of any legal lasting power of attorney for health and welfare)
- whether the dying person has understood and can retain the information given about their prognosis.

1.2.6 Discuss the dying person's prognosis with other members of the multiprofessional care team, and ensure that this is documented in the dying person's record of care.

### 1.3 *Shared decision-making*

The recommendations in this section cover shared decision-making in the last days of life. Healthcare professionals caring for adults at the end of life need to take into consideration the person's current mental capacity to engage and actively participate in shared decision-making on their end of life care (for more information see [your care](#)).

Please also refer to the recommendations on shared decision-making in NICE's guideline on [patient experience in adult NHS services](#).

- 1.3.1 Establish the level of involvement that the dying person wishes to have and is able to have in shared decision-making, and ensure that honesty and transparency are used when discussing the development and implementation of their care plan.
- 1.3.2 As part of any shared decision-making process take into account:
- whether the dying person has an advance statement or an advance decision to refuse treatment in place, or has provided details of any legal lasting power of attorney for health and welfare
  - the person's current goals and wishes
  - whether the dying person has any cultural, religious, social or spiritual preferences.
- 1.3.3 Identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life. The named healthcare professional should:
- give information about how they can be contacted and contact details for relevant out-of-hours services to the dying person and those important to them
  - ensure that any agreed changes to the care plan are understood by the dying person, those important to them, and those involved in the dying person's care.

### Providing individualised care

- 1.3.4 Establish as early as possible the resources needed for the dying person (for example, the delivery of meals, equipment, care at night, volunteer support or assistance from an organisation) and their availability.



- 1.3.5 In discussion with the dying person, those important to them and the multiprofessional team, create an individualised care plan. The plan should include the dying person's:
- personal goals and wishes
  - preferred care setting
  - current and anticipated care needs including:
    - preferences for symptom management
    - needs for care after death, if any are specified
  - resource needs.
- 1.3.6 Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multiprofessional care team.
- 1.3.7 Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.
- 1.3.8 While it is normally possible and desirable to meet the wishes of a dying person, when this is not possible explain the reason why to the dying person and those important to them.
- 1.3.9 Ensure that shared decision-making can be supported by experienced staff at all times. Seek further specialist advice if additional support is needed.

## 1.4 *Maintaining hydration*

- 1.4.1 Support the dying person to drink if they wish to and are able to. Check for any difficulties, such as swallowing problems or risk of aspiration. Discuss the risks and benefits of continuing to drink, with the dying person, and those involved in the dying person's care.

- 1.4.2 Offer frequent care of the mouth and lips to the dying person, and include the management of dry mouth in their care plan, if needed. Offer the person the following, as needed:
- help with cleaning their teeth or dentures, if they would like
  - frequent sips of fluid.
- 1.4.3 Encourage people important to the dying person to help with mouth and lip care or giving drinks, if they wish to. Provide any necessary aids and give them advice on giving drinks safely.
- 1.4.4 Assess, preferably daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences.
- 1.4.5 Discuss the risks and benefits of clinically assisted hydration with the dying person and those important to them. Advise them that, for someone who is in the last days of life:
- clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems (see recommendation 1.4.9)
  - it is uncertain if giving clinically assisted hydration will prolong life or extend the dying process
  - it is uncertain if not giving clinically assisted hydration will hasten death.
- 1.4.6 Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.
- 1.4.7 When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:
- whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment
  - their level of consciousness
  - any swallowing difficulties

- their level of thirst
- the risk of pulmonary oedema
- whether even temporary recovery is possible.

1.4.8 Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate.

1.4.9 For people being started on clinically assisted hydration:

- Monitor at least every 12 hours for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm.
- Continue with clinically assisted hydration if there are signs of clinical benefit.
- Reduce or stop clinically assisted hydration if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.

1.4.10 For people already dependent on clinically assisted hydration (enteral or parenteral) before the last days of life:

- Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them.
- Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death.

## 1.5 *Pharmacological interventions*

Providing appropriate non-pharmacological methods of symptom management is an important part of high-quality care at the end of life, for example, re-positioning to manage pain or using fans to minimise the impact of breathlessness, but this has not been addressed in this guideline. This section focuses on the pharmacological management of common symptoms at the end of life and includes general recommendations for non-specialists prescribing medicines to manage these symptoms.

1.5.1 When it is recognised that a person may be entering the last days of life, review their current medicines and, after discussion and agreement with the dying person and those important to them (as appropriate), stop any previously

prescribed medicines that are not providing symptomatic benefit or that may cause harm.

1.5.2 When involving the dying person and those important to them in making decisions about symptom control in the last days of life:

- Use the dying person's individualised care plan to help decide which medicines are clinically appropriate.
- Discuss the benefits and harms of any medicines offered.

1.5.3 When considering medicines for symptom control, take into account:

- the likely cause of the symptom
- the dying person's preferences alongside the benefits and harms of the medicine
- any individual or cultural views that might affect their choice
- any other medicines being taken to manage symptoms
- any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

1.5.4 Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.

1.5.5 Consider prescribing different routes of administering medicine if the dying person is unable to take or tolerate oral medicines. Avoid giving intramuscular injections and give either subcutaneous or intravenous injections.

1.5.6 Consider using a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.

1.5.7 For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.

- 1.5.8 Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.
- 1.5.9 Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

## Managing pain

- 1.5.10 Consider non-pharmacological management of pain in a person in the last days of life.
- 1.5.11 Be aware that not all people in the last days of life experience pain. If pain is identified, manage it promptly and effectively, and treat any reversible causes of pain, such as urinary retention.
- 1.5.12 Assess the dying person's level of pain and assess for all possible causes when making prescribing decisions for managing pain.
- 1.5.13 Follow the principles of pain management used at other times when caring for people in the last days of life, for example, matching the medicine to the severity of pain and, when possible, using the dying person's preferences for how it is given.
- 1.5.14 For a person who is unable to effectively explain that they are in pain, for example someone with dementia or learning disabilities, use a validated behavioural pain assessment to inform their pain management.

## Managing breathlessness

- 1.5.15 Identify and treat reversible causes of breathlessness in the dying person, for example pulmonary oedema or pleural effusion.
- 1.5.16 Consider non-pharmacological management of breathlessness in a person in the last days of life. Do not routinely start oxygen to manage breathlessness. Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia.
- 1.5.17 Consider managing breathlessness with:

- an opioid<sup>[1]</sup> or
- a benzodiazepine<sup>[1]</sup> or
- a combination of an opioid<sup>[1]</sup> and benzodiazepine<sup>[1]</sup>.

## Managing nausea and vomiting

1.5.18 Assess for likely causes of nausea or vomiting in the dying person. These may include:

- certain medicines that can cause or contribute to nausea and vomiting
- recent chemotherapy or radiotherapy
- psychological causes
- biochemical causes, for example hypercalcaemia
- raised intracranial pressure
- gastrointestinal motility disorder
- ileus or bowel obstruction.

1.5.19 Discuss the options for treating nausea and vomiting with the dying person and those important to them.

1.5.20 Consider non-pharmacological methods for treating nausea and vomiting in a person in the last days of life.

1.5.21 When choosing medicines to manage nausea or vomiting in a person in the last days of life, take into account:

- the likely cause and if it is reversible
- the side effects, including sedative effects, of the medicine
- other symptoms the person has
- the desired balancing of effects when managing other symptoms
- compatibility and drug interactions with other medicines the person is taking.

- 1.5.22 For people in the last days of life with obstructive bowel disorders who have nausea or vomiting, consider:
- hyoscine butylbromide<sup>[1]</sup> as the first-line pharmacological treatment
  - octreotide<sup>[1]</sup> if the symptoms do not improve within 24 hours of starting treatment with hyoscine butylbromide<sup>[1]</sup>.

### Managing anxiety, delirium and agitation

- 1.5.23 Explore the possible causes of anxiety or delirium, with or without agitation, with the dying person and those important to them. Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.
- 1.5.24 Consider non-pharmacological management of agitation, anxiety and delirium in a person in the last days of life.
- 1.5.25 Treat any reversible causes of agitation, anxiety or delirium, for example, psychological causes or certain metabolic disorders (for example renal failure or hyponatraemia).
- 1.5.26 Consider a trial of a benzodiazepine to manage anxiety or agitation.
- 1.5.27 Consider a trial of an antipsychotic medicine to manage delirium or agitation.
- 1.5.28 Seek specialist advice if the diagnosis of agitation or delirium is uncertain, if the agitation or delirium does not respond to antipsychotic treatment or if treatment causes unwanted sedation.

### Managing noisy respiratory secretions

- 1.5.29 Assess for the likely causes of noisy respiratory secretions in people in the last days of life. Establish whether the noise has an impact on the dying person or those important to them. Reassure them that, although the noise can be distressing, it is unlikely to cause discomfort. Be prepared to talk about any fears or concerns they may have.

- 1.5.30 Consider non-pharmacological measures to manage noisy respiratory or pharyngeal secretions, to reduce any distress in people at the end of life.
- 1.5.31 Consider a trial of medicine to treat noisy respiratory secretions if they are causing distress to the dying person. Tailor treatment to the dying person's individual needs or circumstances, using 1 of the following drugs:
- atropine<sup>[1]</sup> or
  - glycopyrronium bromide<sup>[1]</sup> or
  - hyoscine butylbromide<sup>[1]</sup> or
  - hyoscine hydrobromide<sup>[1]</sup>.
- 1.5.32 When giving medicine for noisy respiratory secretions:
- Monitor for improvements, preferably every 4 hours, but at least every 12 hours.
  - Monitor regularly for side effects, particularly delirium, agitation or excessive sedation when using atropine or hyoscine hydrobromide.
  - Treat side effects, such as dry mouth, delirium or sedation (see recommendations [1.4.2](#), [1.5.9](#) and [1.5.23](#)).
- 1.5.33 Consider changing or stopping medicines if noisy respiratory secretions continue and are still causing distress after 12 hours (medicines may take up to 12 hours to become effective).
- 1.5.34 Consider changing or stopping medicines if unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation, persist.

## 1.6 *Anticipatory prescribing*

- 1.6.1 Use an individualised approach to prescribing anticipatory medicines for people who are likely to need symptom control in the last days of life. Specify the indications for use and the dosage of any medicines prescribed.
- 1.6.2 Assess what medicines the person might need to manage symptoms likely to occur during their last days of life (such as agitation, anxiety, breathlessness,



nausea and vomiting, noisy respiratory secretions and pain). Discuss any prescribing needs with the dying person, those important to them and the multiprofessional team.

1.6.3 Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person's needs change.

1.6.4 When deciding which anticipatory medicines to offer take into account:

- the likelihood of specific symptoms occurring
- the benefits and harms of prescribing or administering medicines
- the benefits and harms of not prescribing or administering medicines
- the possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed
- the place of care and the time it would take to obtain medicines.

1.6.5 Before anticipatory medicines are administered, review the dying person's individual symptoms and adjust the individualised care plan and prescriptions as necessary.

1.6.6 If anticipatory medicines are administered:

- Monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional.
- Adjust the individualised care plan and prescription as necessary.

To find out what NICE has said on topics related to this guideline, see our web page on [end of life care](#).

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<sup>[1]</sup> At the time of publication (December 2015), this medication did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

## Implementation: getting started

This section highlights 3 areas of the care of dying adults in the last days of life guideline that could have a big impact on practice and be challenging to implement, along with the reasons why change is happening in these areas (given in the box at the start of each area). We identified these with the help of stakeholders and Guideline Committee members (see [section 9.4 of the manual](#)). The section also gives information on resources to help with implementation.

### *The challenge: recognising dying and communicating effectively*

See recommendations [1.1.2](#), [1.2.1](#), [1.3.1](#) and [1.3.7](#).

Poor communication and not recognising that people are dying were key themes identified by a Parliamentary and Health Service Ombudsman's investigation into complaints about end of life care, [Dying without dignity](#). Correctly recognising that a person is in the last days of life may allow opportunities for shared decision-making and prevent unnecessary interventions. Good communication of a dying person's prognosis improves their end of life care and the bereavement experience of those important to them. It can help to ensure that the dying person's expressed wishes are considered and to avoid misunderstandings and unnecessary distress.

### Recognising dying

Recognising dying can be challenging for health and care professionals. There is often uncertainty about how long a person has left to live and the signs that suggest that someone is dying are complex and subtle.

### Communication

Some health and care professionals are uncomfortable discussing how long someone has left to live, and sometimes do not have the skills and confidence to give difficult news or talk about the dying process. Adequate training and continued support is important to help health and care professionals to communicate sensitively and effectively.

### Shared decision-making

Effective shared decision-making can help to ensure that people get the right care in the last days of their life. Health and care professionals can help to achieve this if they have the right communication skills, and have a good rapport with the dying person and those important to them.

## What can health and care professionals do to help?

- Refer to the Leadership Alliance for the Care of Dying People's report, [One chance to get it right](#), for information on existing training for different types of professionals and commissioning advice.
- As part of face-to-face learning or joint sessions, use training programmes and guidance to help develop communications skills such as:
  - e-Learning for Healthcare's [end of life care for all \(e-ELCA\)](#). Relevant sessions include:
    - ◇ Assessment of dying phase and after-death care (02\_14)
    - ◇ "What will it be like?" – talking about the dying process (03\_26)
    - ◇ Discussing 'do not attempt CPR' decisions (03\_30)
  - Royal College of Nursing's [Getting it right every time](#)
  - General Medical Council's guidance [Treatment and care towards the end of life: good practice in decision-making](#)
  - Skills for Care's [end of life care learning materials](#)
  - National Cancer Action Team's [advanced clinical communication skills course](#)
  - National Council for Palliative Care's guide for carers, families and friends of dying people [What to expect when someone important to you is dying](#)
  - Courses and events provided by voluntary sector organisations such as [Living Well Dying Well](#)
- Encourage health and care professionals to keep their skills updated as part of their continuing professional development.

### *The challenge: maintaining hydration*

See recommendations [1.4.4](#), [1.4.5](#) and [1.4.7](#).

The independent [Review of the Liverpool Care Pathway for dying patients](#) highlighted a lack of understanding of the role of hydration during end of life care, which may have contributed to poor care. This guideline aims to ensure that hydration is maintained in the last days of life when needed, to prevent or minimise unwanted symptoms such as dehydration or delirium. When this is not possible by drinking, clinically assisted hydration can be beneficial in some circumstances.

Practice varies widely in the use of clinically assisted hydration at the end of life. Healthcare professionals and people important to the dying person may believe that providing clinically assisted hydration will prolong dying, or that 'withholding' it will hasten death, but there is no evidence for this. Giving clinically assisted hydration may relieve distressing symptoms or signs relating to dehydration but it may also cause pain, discomfort or swelling at the infusion site. Healthcare professionals need to be confident that they can discuss the risks and benefits with the dying person or those important to them before starting clinically assisted hydration.

### What can healthcare professionals do to help?

- Use the General Medical Council's 2010 guidance on [End of life care: clinically assisted nutrition and hydration](#), which is a good starting point for practitioners.
- Use training programmes such as e-Learning for Healthcare's [e-ELCA](#) to improve their knowledge and skills in these areas. Relevant sessions include:
  - Discussing food and fluids (03\_31)

### What can commissioners do to help?

- Ensure that healthcare professionals in all care settings have access to the equipment needed for clinically assisted hydration.

### *The challenge: anticipatory prescribing*

See [recommendation 1.6.1](#).

Poorly controlled symptoms can lead to considerable distress for the dying person, and poor symptom control was a key theme identified by the Parliamentary and Health Service Ombudsman's investigation into complaints about end of life care, [Dying without dignity](#). An individualised approach to anticipatory prescribing should ensure that the drugs prescribed are appropriate to the anticipated needs of the dying person, and prevent distressing hospital admissions and waste of medicines.

Prescribers may need further training for individualised anticipatory prescribing because it may mean a change in practice. The [Review of the Liverpool Care Pathway for dying patients](#) found that a 'proforma' approach to prescribing led to over medication, and there was concern that inappropriate prescription and administration of medicines by inexperienced staff was taking place. The availability of resources may differ between regions as well as between hospital and community settings.

### What can healthcare professionals do to help?

- Use training programmes such as e-Learning for Healthcare's [e-ELCA](#) to improve knowledge and skills in these areas. Relevant sessions include:
  - Symptom management: last days of life (04\_23–04\_26)

### What can providers do to help?

- Ensure that healthcare professionals in all care settings and at all times have access to the medicines that may be needed and are able to get advice from colleagues with experience of end of life care if they need it.

### What can commissioners do to help?

- Develop agreements with local pharmacies to keep an agreed list of drugs in stock and provide community staff with details of local on-call pharmacies.

### *Need more help?*

Further [resources](#) are available from NICE that may help to support implementation.

- Annual indicators for use in the Quality and Outcomes Framework (QOF) for the UK. See the [process and the NICE menu](#).
- [Uptake data](#) about guideline recommendations and quality standard measures.

- The Royal College of Physician's [National care of the dying audit of hospitals](#) can help providers to audit their care against national standards and policies.

## Recommendations for research

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the [full guideline](#).

### *1 Recognising dying*

What can multiprofessional teams do to reduce the impact of uncertainty of recognising when a person is entering the last days of life on clinical care, shared decision-making and communication with the dying person and those important to them?

#### Why this is important

It may be difficult to determine when the dying person is entering the last few days or weeks of life. Predicting the end of life is often inaccurate, and current prognostic tools and models are limited. Some level of uncertainty in recognising when a person is entering the last days of life is likely and is often a challenge to planning care. However, it is crucial to minimise this uncertainty to ensure that it does not prevent key discussions between the healthcare professional and the dying person and those important to them.

It is therefore important to identify how the uncertainty of recognising when a person is entering the last days of life influences information sharing, advanced care planning and the behaviour of healthcare professionals. A mixed-methods approach (quantitative and qualitative evidence) is proposed that aims to explore how different multidisciplinary team interventions can reduce the impact of uncertainty on clinical care, shared decision-making and communication, specifically on engaging the dying person and those important to them in end of life care discussions. Multidisciplinary team interventions include any different methods of giving feedback, initiating end of life discussions, record keeping or updating care plans, compared with usual care. Outcomes of interest include quality of life, patient or carer satisfaction, changes to clinical care and identification and/or achievement of patient wishes such as preferred place of death. In addition the barriers and facilitators for the healthcare professionals to manage this uncertainty to best support the dying person and those important to them should be explored.

### *2 Agitation and delirium*

What is the best way to control delirium, with or without agitation, in the dying person, without causing undue sedation and without shortening life?

## Why this is important

People who are entering the last days of life may develop sepsis, dehydration and various biochemical disorders which may lead to the development of delirium. This is characterised by altering levels of consciousness, confusion and possibly hallucinations.

Many of the drugs used to control delirium are classed as sedatives. It can be difficult for inexperienced clinicians to reduce delirium without causing undue sedation. An inappropriately large dose of sedative medication may also compromise respiration. A perceived risk of over-sedation is that the dying person's life may be shortened because of the sedation itself.

Specialists in palliative care are knowledgeable about which drugs to use and in which combinations, and know how to use the correct routes and frequency to achieve reduction in delirium, and of any accompanying agitation, without over-sedating the dying person. However most people who are dying are not under the direct care of such specialists, although they may be called in for advice out-of-hours if the person becomes agitated and this has resource implications for specialist palliative care services.

The research should study how key drugs in UK palliative care practice (such as benzodiazepines and antipsychotics) can be applied in a range of settings in order to reduce delirium and agitation without causing undue sedation or inadvertently shortening life. This is proposed to be conducted as multi-arm, multi-stage interventions using escalating doses over 12-hours as clinically indicated.

## 3 Noisy respiratory secretions

In people considered to be in the last few hours and days of life, are antisecretory anti-muscarinic drugs (used alongside nursing interventions, such as repositioning and oropharyngeal suction) better at reducing noisy respiratory secretions and patient, family and carer distress without causing unwanted side effects, than nursing interventions alone?

## Why this is important

It is common for people to experience noisy respiratory secretions at the end of life and the so called 'death rattle' is a predictor of death. The noise can cause considerable distress for people important to the dying person, both at the time and possibly after death, because of concerns that the person may have drowned or suffocated to death. Clinicians may administer subcutaneous anti-muscarinic agents in an attempt to 'dry up' secretions and relieve any distress primarily to people important to the person despite a lack of evidence of any beneficial effect to the patient or improvement in distress levels.



The evidence for the efficacy of pharmacological interventions in managing respiratory secretions is of low quality, and it is not clear if any one drug is more effective than another or if drugs are more effective than non-pharmacological approaches such as repositioning or oropharyngeal suction. Most studies involved low numbers of patients and were primarily based on cancer patients in hospices and so may not reflect the larger numbers of patients dying with non-malignant diseases in hospitals and in community care.

Anti-muscarinic agents may have undesired side effects, such as dry mouth, blurred vision or urinary retention, as well as a cost implication, and it is therefore hard to justify their continued use given the limited evidence base.

A randomised controlled trial is proposed comparing antisecretory anti-muscarinic drugs and nursing care to nursing care alone. Nursing interventions include repositioning, mouth care and education and reassurance for those important to the dying person. Outcomes of interest are subjective and objective measures of reduction in noise level, reduction in distress to the dying person or those important to them and adverse effects.

## *4 Anticipatory prescribing*

What is the clinical and cost effectiveness of anticipatory prescribing for patients dying in their usual place of residence, on patient and carer reported symptoms at end of life?

### **Why this is important**

Anticipatory prescribing can provide access to essential medicines for symptom control at the end of life. Current best practice when it is recognised that someone is entering the final days of life recommends that medicines to manage pain, breathlessness, nausea and vomiting, and agitation are prescribed with authorisation for administration if clinically indicated when it is recognised that someone is entering the final days of life. Although their use is relatively widespread, there remains a need to investigate the clinical and cost effectiveness of this approach. Studies undertaken to date have been small-scale audit-type projects evaluating the use of anticipatory prescriptions and qualitative studies exploring the barriers to uptake.

Uncertainty remains as to the impact of anticipatory prescribing on outcomes such as preferred place of death and symptom control, and also uncertainty as to what should be prescribed.

A cluster randomised controlled trial (randomised by GP practice) is proposed to compare interventions of anticipatory prescribing ('just in case' boxes) with a generic list of medicines or

anticipatory prescribing individualised to the patient's expected symptoms, compared with reactive prescribing at the bedside after symptoms have occurred. Outcomes of interest include patient and carer symptom ratings, patient-rated quality of life and healthcare use.

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## *Accreditation*

