

## PRACTICE



## GUIDELINES

# Care of adults in the last days of life: summary of NICE guidance

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In 2013, the UK Department of Health called for the abolition of the Liverpool care pathway, which was designed to bring a standard of care for the dying from the hospice sector into other settings. This move was provoked by an independent review,<sup>1</sup> which showed that the pathway had been misused and misinterpreted as a tick box exercise. It called for individualised care plans and better staff training in all aspects of end of life care.<sup>1</sup> Care of dying people should be based on evidence and must be tailored to individual needs and wishes, rather than being protocol driven. This article summarises the most recent recommendations from the National Institute for Health and Care Excellence (NICE).<sup>2</sup>

## Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the committee's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are given in *italic* in square brackets.

## Recognising dying

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

- The person's physiological, social, spiritual, and psychological needs
- Current clinical signs and symptoms
- Medical history and the clinical context
- The person's goals and wishes
- The views of those important to the person about future care.

*[Based on moderate quality observational, diagnostic observational, and qualitative studies and the experience and opinion of the committee.]*

Assess for changes in signs and symptoms that may suggest a person is dying (especially multiple or progressive changes) and review any investigation results already reported. These may include:

- Signs such as agitation, Cheyne-Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions, and progressive weight loss
- Fatigue and loss of appetite
- Changes in communication, deteriorating mobility or performance status, or social withdrawal.

*[Based on moderate quality observational, diagnostic observational, and qualitative studies.]*

Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering.

Monitor for further changes at least every 24 hours and update the care plan.

*[Both of above points based on the experience and opinion of the committee.]*

## Communication

Identify the most appropriate team member to discuss prognosis with the dying person and those important to the person. *[Based on low quality qualitative and observational studies.]*

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

- Accurate information about the prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed

**What you need to know**

- Seek support from more experienced staff, including those in palliative care services, if you are unclear about any aspect of care of the dying adult, including the recognition of dying and symptom management
- Assess for and treat any reversible causes of distressing symptoms or signs in people in the last few days of life—for example, uncontrolled pain or dehydration causing agitation
- Regularly review the care plan (usually daily), discuss any changes with the dying person and those important to the person; make clear documentation in the medical notes

**What's new in this guidance?**

- Guidance on recognition of dying, with the uncertainty around this, and encouragement of open communication and shared decision making
- Maintaining hydration (including oral care) as a priority, and offering fluids up until the end of life, regardless of the care setting
- Emphasis on individualised prescribing for current and anticipated symptoms, avoiding undue sedation or other side effects

- An opportunity to discuss any fears and anxieties
- Information about how to contact members of the care team for further discussion, including details of out of hours services.

*[Based on low quality qualitative and observational studies and the experience and opinion of the committee.]*

Identify a named lead healthcare professional responsible for communication and shared decision making in the last days of life. *[Based on low quality qualitative studies and the experience and opinion of the committee.]*

Ensure that any agreed changes to the care plan are understood by the person, those important to the person, and others involved in care. *[Based on the experience and opinion of the committee.]*

The General Medical Council guidance on end of life care also provides advice on communication and shared decision making and is a useful resource for junior doctors.<sup>3</sup>

**Maintaining hydration**

Support dying people to drink (water, tea, fruit juice, or other favourite drink) if they wish and are able to. Check for any difficulties, such as swallowing problems and discuss the risks and benefits of continuing to drink. *[Based on the experience and opinion of the committee and co-opted experts.]*

Offer frequent care of the mouth and lips (including management of dry mouth) and encourage people who are important to the dying person to help with this. *[Based on the experience and opinion of the committee.]*

Assess, preferably daily, the person's hydration status, and review the possible need for starting or continuing clinically assisted hydration (for example, parenterally through the subcutaneous or intravenous route or enterally through a nasogastric tube), respecting the person's wishes and preferences. *[Based on the experience and opinion of the committee.]*

Advise that, in the last days of life, clinically assisted hydration may relieve distressing symptoms or signs related to dehydration but may cause other problems (such as fluid overload or local irritation at the infusion site). Explain that it is uncertain whether providing or withholding clinically assisted hydration could prolong or shorten the length of remaining life. *[Based on the experience and opinion of the committee.]*

Consider a therapeutic trial of clinically assisted hydration if the person has developed, or is at risk of developing, distressing symptoms or signs of dehydration, such as thirst or delirium, and oral hydration is inadequate. *[Based on very low to moderate quality randomised and non-randomised controlled trials.]*

For people receiving clinically assisted hydration:

- Re-assess preferably every 12 hours for changes in the symptoms or signs of dehydration and continue if there is clinical benefit.
- Reduce or stop if there are signs of harm to the dying person, or if the person no longer wants hydration.

*[Based on the experience and opinion of the committee and co-opted experts.]*

**Pharmacological interventions**

Owing to the lack of supporting evidence for the pharmacological management of symptoms in the last few days of life, this guidance can provide only limited recommendations on the use of specific drugs. Prescribers should follow local prescribing guidance and seek further advice from specialist palliative care if in any doubt.

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

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

When considering drugs for symptom control, take into account:

- The likely cause of the symptom
- The dying person's preferences alongside the drug's benefits and harms
- Any individual or cultural views that might affect the person's choice
- Any other drugs being taken to manage symptoms
- Any risks of the drug that could affect prescribing decisions.

For people in the last days of life, consider non-pharmacological management of distressing symptoms or signs, such as facial fans or open windows for breathlessness, and repositioning or suction for noisy respiratory secretions.

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

Consider using a syringe pump to deliver drugs for continuous symptom control if more than two or three doses of any "as required" drugs have been given within 24 hours.

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.

**Shared decision making**

Take into account:

- Advance statements, advance decisions to refuse treatment, or a lasting power of attorney for health and welfare in those lacking capacity
- The person's current goals and wishes, and any cultural, religious, social, or spiritual preferences

[Based on low to moderate quality qualitative studies and the experience and opinion of the committee.]

[All above points based on the experience and opinion of the committee.]

**Managing pain**

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, such as urinary retention.

Follow the principles of pain management used at other times when caring for people in the last days of life using, when possible, the person's preferences for how it is given.

[Both of the above points based on the experience and opinion of the committee.]

**Managing breathlessness**

In a person who is not already on long term oxygen, do not routinely start oxygen to manage breathlessness. Offer oxygen therapy only to people known or clinically suspected to have symptomatic hypoxaemia. [Based on very low quality evidence from one randomised controlled trial.]

Consider managing breathlessness with an opioid, or a benzodiazepine, or a combination of an opioid and benzodiazepine. [Based on very low to moderate quality evidence from randomised and non-randomised controlled trials.]

**Managing nausea and vomiting**

Assess for, and if possible reverse, the likely cause (for example, metabolic disturbance, concurrent drugs). Consider the side effects, including sedation, of any drugs prescribed and compatibility and interactions with other drugs being used.

For people in the last days of life with obstructive bowel disorders who have nausea or vomiting, consider:

- Hyoscine butylbromide as the first line drug treatment
- Octreotide if symptoms do not improve within 24 hours of starting hyoscine butylbromide.

[Based on very low quality evidence from randomised controlled trials.]

**Managing anxiety, delirium, and agitation**

Treat any reversible causes of agitation, anxiety, or delirium, such as dehydration or uncontrolled pain. Be aware that agitation is sometimes associated with other unrelieved symptoms or bodily needs, such as pain or a full bladder.

Consider a trial of a benzodiazepine to manage anxiety or agitation, or a trial of an antipsychotic to manage delirium or agitation.

[Both points based on the experience and opinion of the committee.]

**Managing noisy respiratory secretions**

Assess for the likely cause and establish whether the noise has an impact on the dying person or those important to that person. Reassure them that it is unlikely to cause discomfort and may

be relieved by non-drug based interventions such as repositioning and suction.

Consider a trial of an antisecretory agent (glycopyrronium, hyoscine butylbromide, hyoscine hydrobromide, or atropine) to treat noisy respiratory secretions if they are causing distress to the dying person.

[Based on very low to moderate quality evidence from randomised controlled trials and cohort studies.]

Monitor at least twice daily and consider changing or stopping drugs if:

- Noisy respiratory secretions continue and are still causing distress after 12 hours, or
- There are unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation, and unwanted levels of sedation.

[Based on very low to moderate quality evidence from randomised controlled trials and cohort studies and the experience and opinion of the committee.]

**Anticipatory prescribing**

Individualise the approach to prescribing anticipatory or "just in case" drugs for people who will probably need symptom control in the last days of life.

[Based on the experience and opinion of the committee.]

Take into account:

- The likelihood of symptoms occurring
- The benefits and harms of prescribing or administering these drugs, or of not doing so
- The risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) and needing urgent symptom control
- The place of care and the time it would take to obtain the drugs.

[Based on moderate to high quality evidence from qualitative studies.]

If anticipatory drugs are given, monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional. Adjust the care plan and prescription as necessary. [Based on the experience and opinion of the committee.]

**Overcoming barriers**

Uncertainty in recognising when a person is entering the last days of life may be a barrier to good end of life care, especially when it is possible that the person may stabilise or recover. Honest communication about this uncertainty and the prognosis with dying people and those important to them is essential, although untrained clinicians may find these conversations difficult and uncomfortable. Seeking advice from other multi-professional team members who are more experienced in these situations and from palliative care specialists as recommended will help to resolve this difficulty. Training in

communication skills and shared decision making is needed to involve dying people and those important to them in their care. It may also be necessary to consult statutory<sup>4</sup> and GMC guidance<sup>3</sup> on the mental capacity act, because many adults in the last days of life lack capacity to make treatment decisions. The care setting should not be a barrier to implementing these recommendations—for example, with appropriate resources and training, clinically assisted hydration can be given in the community without the need for hospital admission.

The members of the committee were Sam H Ahmedzai (chair), Adrian Blundell, Maureen Carruthers, Susan Dewar, David Edwards, Mike Grocott, Adam Firth, Annette Furley, Gwen Klepping, Diana Robinson, Joy Ross, and Cheryl Young. Co-opted members of the committee were Abdallah Al-Mohammad, Lynn Bassett, Arun Bhaskar, Julie Hendry, Julian Hughes, Ian Mursell, Sarah Nightingale, Mark Thomas, and Elizabeth Toy. The technical team at the National Clinical Guideline Centre included Kate Ashmore, Ella Barber (until February 2015), Tamara Diaz, Lindsay Dytham (until December 2015), Katharina Dworzynski (until February 2015), Elisabetta Fenu, Antonia Field-Smith, Lina Gulhane, Alexander Haines, Sarah Hodgkinson, Bethany King, Susan Latchem, Josh Ruegger, and Eleanor Samarasekera (until May 2015).

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Who-we-are/Policies-and-procedures/code-of-practice-for-declaring-and-managing-conflicts-of-interest.pdf): SA has received payments from the National Institute for Health Research as national specialty lead for cancer research outside the acute hospital and an Health Technology Assessment research grant (effectiveness of early palliative care for advanced non-small cell lung cancer patients); Prostate Cancer UK research grant (development and validation of an online holistic needs assessment and care plan for prostate cancer patients); Medical Research Council research grant (clinical trial of saracatinib for bone cancer pain); royalty fees from Oxford University Press (Textbook of Supportive Care in Respiratory Disease); lecture fees for annual University of Amsterdam masterclass on palliative care. The authors' full statements can be viewed at [www.bmj.com/content/bmj/351/bmj.h6631/related#datasupp](http://www.bmj.com/content/bmj/351/bmj.h6631/related#datasupp).

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## Further information on the guidance

### Methods

The committee comprised two palliative medicine physicians (including the chair), a general practitioner, two patient representatives, a critical care consultant, a geriatrician, a care home representative, a specialist palliative care pharmacist, a palliative nurse, a community matron, and a district community nurse. The committee followed standard National Institute for Health and Care Excellence (NICE) methods during the development of this guideline.<sup>5</sup> The group developed clinical questions, collected and appraised clinical evidence, and evaluated the cost effectiveness of proposed interventions through literature review.

Many of the drugs recommended in this guideline, although commonly used at the end of life, do not have a UK marketing authorisation for that indication. The prescriber should follow relevant professional guidance, such as guidelines from the General Medical Council,<sup>6</sup> taking full responsibility for the decision.

Qualitative meta-synthesis was undertaken for several reviews in this guideline, using centre approved methodology to appraise the quality of these studies ([www.nice.org.uk/guidance/NG31/evidence](http://www.nice.org.uk/guidance/NG31/evidence)).

Evidence for outcomes from included studies was evaluated and presented using an adaptation of the GRADE toolbox (<http://gradeworkinggroup.org>). The quality elements for interventional, observational, and qualitative studies were adapted for diagnostic studies.

The draft guideline went through a rigorous review process, in which stakeholder organisations were invited to comment; the group took all comments into consideration when producing the final version of the guideline.

NICE has produced three versions of the guideline: a full version, a summary version known as the "NICE guideline," and a version for patients, their families and carers, and the public ([www.nice.org.uk/guidance/NG31/informationforpublic](http://www.nice.org.uk/guidance/NG31/informationforpublic)). These versions are available from the NICE website. Updates of the guideline will be produced as part of NICE's guideline development programme.

A formal review of the need to update a guideline is usually undertaken by NICE after guideline publication.

### Guidelines into practice

- How well do I consider uncertainty in recognising when a person may be dying, stabilising, or improving; and how effectively do I communicate this uncertainty to the person, those important to that person, and to the multi-professional team?
- How often do I consider the hydration needs of a person who may be in the last days of life; and how do I communicate with the person, those important to the person, and the multi-professional team when modifying the care plan to meet those needs?

### Future research

The committee identified some priority areas for research:

- Given the uncertainty of recognising when a person is entering the last days of life, how can multi-professional teams reduce the impact of this uncertainty on clinical care, shared decision making, and communication with the person and those important to the person?
- What is the best way to control delirium, with or without agitation, in the dying person, without causing undue sedation and without shortening life?
- In people thought to be in the last few hours or days of life, do antisecretory anti-muscarinic drugs (used alongside nursing interventions, such as repositioning and oropharyngeal suction) reduce noisy respiratory secretions and patient, family, and carer distress more effectively, without causing unwanted side effects, than nursing interventions alone?
- For patients dying in their usual place of residence rather than a hospital or hospice, what are the clinical and cost effectiveness of anticipatory prescribing with regard to patient and carer reported symptoms?

## How patients were involved in the creation of this article

Committee members involved in this guideline included lay members who contributed to the formulation of the recommendations summarised here.