

Care of dying adults in the last days of life

Authors: Sarah Hodgkinson,^A Josh Ruegger,^B Antonia Field-Smith,^C Susan Latchem^D and Sam H Ahmedzai^E

ABSTRACT

Care of people in their last days of life should be based on compassion, respect and, wherever possible, on research evidence. Previously the Liverpool Care Pathway attempted to facilitate this but it was withdrawn after an independent government report found that its uncritical implementation could lead to poor care. This Concise Guideline overviews NICE Clinical Guideline (NG31), which addresses: recognising dying; communication and shared decision making; maintaining hydration; and pharmacological symptom control, including anticipatory prescribing. Doctors may need to change their attitudes to care of dying people and those important to them. Specific areas where practices will need to reflect the individualised approach to care are highlighted. Limitations of the guideline are discussed. Potential barriers to implementation include need for further training and 24/7 availability of specialist support to front-line clinicians.

KEYWORDS: End-of-life care, individualised care, recognition, communication, shared decision making, hydration, symptom control, anticipatory prescribing, training, palliative care, primary care

Introduction

In 2013, the Department of Health called for removal of the Liverpool Care Pathway, following criticism from the public, healthcare professionals and the media, and an independent review led by Baroness Neuberger,¹ highlighting several concerns:

- > recognition that a person was dying was not always supported by an experienced clinician and not reliably reviewed, even if there was potential for improvement or stabilisation
- > there may have been undue sedation from in judiciously prescribed symptom control medicines
- > hydration and some essential medicines may have been inappropriately withheld or withdrawn, with adverse consequences
- > care of dying patients was not evidence-based

- > the Liverpool Care Pathway had been widely misinterpreted and misused as a ‘tick-box’ exercise because of inadequate staff training, supervision and implementation.

The National Institute for Health and Care Excellence (NICE) Clinical Guideline NG31² on care of the dying adult in the last days of life has been developed to provide evidence-based guidance in this area applicable to all settings (including primary care) and addressing these concerns. It is complementary to the NICE guideline on patient experience³ (including communication), and to General Medical Council guidance on treatment and care towards the end of life (including nutrition and hydration).⁴ Its emphasis is on individualised care and a tailored, as against a ‘one-size-fits-all’, approach.

Scope and purpose

NG31 covers the clinical care of adults judged by a multiprofessional team to be in the last few (2–3) days of life, as distinct from other NHS policies and guidance labelled ‘end-of-life care’ covering the last year or so of a chronic condition. It is intended for:

- > people who are dying, their families, carers and others important to them
- > health and social care professionals, including those in primary care, care homes, hospices, hospitals and community care settings, including people’s own homes
- > commissioners and providers.

It is particularly aimed at healthcare professionals in all settings who do not have specialist level training in end-of-life care, but also provides baseline standards for specialist settings, such as non-NHS palliative care units and hospices.

Its scope includes:

- > recognition and review of when people are entering the last few days of life, including the possibility of recovery or stabilisation

Authors: ^Asenior research fellow, National Clinical Guideline Centre, London, UK; ^Bresearch fellow, National Clinical Guideline Centre, London, UK; ^Cspecialty registrar in palliative medicine (South West London and KSS training scheme), Royal Surrey County Hospital NHS Foundation Trust, Guildford, UK; ^Doperations director, National Clinical Guideline Centre, London, UK; ^Eemeritus professor of supportive care, Department of Oncology and Metabolism, University of Sheffield, Sheffield, UK

The National Institute of Health and Care Excellence (NICE) has accredited the process used by the Royal College of Physicians to produce the concise clinical guidelines published in *Clinical Medicine* with effect February 2010 to March 2018 (abstracted guidance) and July 2013 to July 2018 (*de novo* guidance). More information on accreditation can be viewed at: www.nice.org.uk/about/what-we-do/accreditation.

Box 1. Recommendations.**Recognising dying**

- 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.
- Assess for changes in signs and symptoms in the person and review any available investigation results that may suggest a person is entering the last days of life. Changes might include:
 - 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 social withdrawal.
- Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering.
- 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.
- Monitor for further changes in the person at least every 24 hours and update the person's care plan.

Communication and shared decision making

- 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 communication needs
 - how much information they would like to have about their prognosis
 - any cultural, religious, social or spiritual needs or preferences.
- As part of any shared decision making process take into account:
 - the level of involvement that the dying person wishes to have and is able to have
 - 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.
- Identify a named lead healthcare professional, who is responsible for encouraging shared decision making in the person's last days of life. They should provide their contact details as well as details for how to contact relevant out-of-hours services.
- 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 using honesty and transparency.

Maintaining hydration

- 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.
- 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.
- Assess, preferably daily, the dying person's hydration status, and review the possible need for starting or continuing clinically assisted hydration, respecting the person's wishes and preferences.
- 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.
- Consider a therapeutic trial of clinically assisted hydration if the person has or is at risk of distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and if oral hydration is inadequate.

(continued)

Box 1. (*Continued*) Recommendations.

- > For people on clinically assisted hydration (enteral or parenteral):
 - monitor, at least every 12 hours, for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm
 - review the risks and benefits of continuing clinically assisted hydration with the person and those important to them
 - continue if there are signs of clinical benefit and reduce or stop if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.

Pharmacological management

- > Consider the underlying cause of any distressing symptoms and treat any reversible problems, for example full bladder causing agitation or pain.
- > Consider non-pharmacological management of any symptoms in the last few days of life, such as fans to reduce the perception of breathlessness or repositioning to manage respiratory secretions
- > 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.
- > For people starting treatment, who have not previously been given medicines for symptom management, begin with the lowest effective dose and titrate as clinically indicated.
- > Regularly reassess, at least daily, the dying person’s symptoms during treatment to inform appropriate titration of medicine.
- > 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.
- > Pain
 - Follow the principles of pain management used at other times when caring for people in the last days of life. For example, use both non-opioids and opioids at the lowest dose possible to match the severity of pain and balancing against side effects such as sedation, and using the dying person’s preferences for how it is given.
- > Breathlessness
 - Do not routinely start oxygen to manage breathlessness. Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia.
 - Consider managing breathlessness with:
 - an opioid
 - a benzodiazepine (particularly if there is associated anxiety)
 - a combination of an opioid and benzodiazepine.
- > Nausea and vomiting
 - When choosing medicines to manage nausea and vomiting in the last few days of life, take into account:
 - the likely cause and if it is reversible
 - the side effects, including sedation, of the medicine
 - the desired balancing of effects when managing other symptoms
 - compatibility and drug interactions with other medicine.
- > Anxiety, delirium and agitation
 - Explore the possible causes of anxiety or delirium, with or without agitation, with the dying person and those important to them and treat any reversible causes if appropriate such as metabolic disorders.
 - Consider a trial of a benzodiazepine to manage anxiety or agitation.
 - Consider a trial of an antipsychotic medicine to manage delirium or agitation.
- > Noisy respiratory secretions
 - 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.
 - 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 one of the following drugs:
 - glycopyrronium bromide
 - hyoscine butylbromide
 - hyoscine hydrobromide
 - atropine.

(continued)

Box 1. (Continued) Recommendations.

- When giving medicine for noisy respiratory secretions:
 - Monitor for improvements, preferably every 4 hours, but at least every 12 hours.
 - Avoid using atropine or hyoscine hydrobromide for people who are at risk of developing delirium, agitation or excessive sedation.
 - Treat side effects, such as dry mouth, delirium or sedation.
- 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) and/or there are unacceptable side effects.

Anticipatory prescribing

- 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.
- Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person's needs change.
- 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, or conversely, the risks of not doing so
 - 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.
- 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.

- communication and shared decision making with the dying person and those important to them, to ensure individualised care
- maintaining hydration and oral care, including assisted hydration
- pharmacological management of pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation and noisy respiratory secretions.
- anticipatory prescribing.

This Concise Guideline highlights key recommendations of particular relevance to non-specialists (Box 1) from a total of 72 in NG31.

Limitations of the guideline

In several areas evidence was either lacking (eg management of anxiety, delirium or agitation), of low, or very low quality (eg management of pain, nausea and vomiting), and/or methodologically flawed. Recommendations were then based on expert opinion and consensus (see original guideline for research recommendations).

An individualised approach to pharmacological management is recommended, rather than 'blanket' prescribing of several drugs. Clinicians should follow local prescribing guidelines where available and seek specialist palliative care advice if symptoms are not improving or there are unacceptable side effects.

The evidence for clinically assisted hydration varied from moderate to very low quality. The recommendations (including consideration of a therapeutic trial) reflect this limitation. For humane reasons, oral drinking should be encouraged and supported if it is considered safe.

The particular challenges of prognosis, symptom assessment and management, and individualised care for people with

dementia, cognitive impairment or learning difficulties are acknowledged, along with the importance of the Mental Capacity Act⁵ in guiding care.

Implications for implementation

There are many examples of people receiving high-standard care in the last days of life by physicians and multiprofessional teams. However, recognising and discussing uncertainty and prognosis, which are essential first steps, remain challenging for many doctors and some will need extra training. The ability to support shared decision making may require change in long-standing attitudes and practices, with careful consideration of the dying person's current mental capacity to engage and participate in discussions. Doctors should adapt practices to ensure regular shared documentation and review of goals and wishes for current and anticipated care needs, with respectful involvement of those important to the patient. Training in these aspects of effective communication skills may need extra resources.

Similar attitudinal and practice changes will be required in the assessment of hydration status and requirement. Doctors will need to work with the multiprofessional team to ensure patients' wishes are respected (eg with continued drinking), as these may contrast with those of family members and some staff. Clinicians will need to become familiar with options for clinically assisted hydration, including subcutaneous infusions. These may require further training programmes.

Understanding and managing symptom control is a skill set often missing in general medicine, particularly among junior staff. 'One-size-fits-all' or 'blanket' prescribing proformas containing all commonly used medications for symptom

Box 2. Royal College of Physicians (RCP) end-of-life care audit, 2016

The RCP audit reported on 9302 deaths from 142 trusts in England.

- > **Common symptoms:** The audit found documented evidence that pain was controlled in 79%; agitation/delirium in 72%; breathing difficulties in 68%; noisy breathing/death rattle in 62% and nausea/vomiting in 55%.
- > **Hydration and swallowing:** The audit found that 67% of dying patients had an assessment of their ability to drink in the last 24 hours; 45% were supported to drink; and 39% were recorded as drinking on their last day of life. Clinically assisted hydration (CAH) was in place during the last 24 hours before death in 43% of patients overall but there was wide variation between hospitals in the assessment of patients' need for CAH.
- > **Access to specialist palliative care:** The audit found that 97% of participating trusts reported having their own specialist palliative care service but, while the majority offered round-the-clock telephone support, only 11% of trusts offered a 24/7 face-to-face visiting service. Furthermore, 26 trusts had no level of medical out-of-hours availability.

control, which were intrinsic to many local 'end-of-life care pathways', may have contributed to the concern regarding oversedation identified in the Neuberger review.¹ In spite of the lack of good-quality research evidence for prescribing in the last days of life, the guideline recommends an individualised approach, based on careful assessment of benefits and harms of each drug being added or withheld. This adaptation will require commitment by senior clinicians and trainees to careful assessment and frequent review of pharmacological symptom control. Specialist palliative care services will need to be more accessible for management of refractory symptoms or in cases where there are unacceptable side effects of medication.

Physicians may wish to review these topics as part of continuing professional development and revalidation. The following are links to training programmes and guidance.

e-Learning for Healthcare's end of life care for all (www.e-lfh.org.uk/programmes/end-of-life-care/). General Medical Council's guidance Treatment and care towards the end of life: good practice in decision-making.⁶ National Cancer Action Team's advanced clinical communication skills course (www.connectedonlinebookings.co.uk/). National Council for Palliative Care's guide for carers, families and friends of dying people. What to expect when someone important to you is dying⁷ courses and events provided by voluntary sector organisations such as Living well dying well (www.lwdwtraining.uk/courses-events/).

Measures of the experience of people important to the dying person, such as FAMCARE, may also be a useful benchmarking and monitoring tool.

There is variation across England in the use of clinically assisted hydration in the community setting. Written policies, education and training exist in some areas detailing options for certain trained staff to provide this subcutaneously or intravenously to dying people remaining at home. These could be replicated elsewhere.

Varied availability of specialist palliative care advice and 24/7 specialist bedside access remains a barrier to optimal care. This is the case for all multiprofessional team members. NICE is currently developing a service delivery guideline in this area.

Many of the recommendations in NG31 were reflected in the recently published organisational and clinical audit of the end-of-life care in hospitals, conducted by the Royal College of Physicians. The findings highlight both current variation and the challenge ahead (Box 2).⁸

Members of the committee

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). ■

Acknowledgements

The authors would like to acknowledge the support of the guideline Committee and technical team who contributed to the development of NG31, commissioned and funded by NICE.

References

- 1 Department of Health. *More care, less pathway. A review of the Liverpool Care Pathway*. London: DH, 2013.
- 2 National Institute for Health and Care Excellence. *Care of dying adults in the last days of life (NG31)*. London: NICE, 2015.
- 3 National Clinical Guideline Centre. *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE clinical guideline 138*. London: National Clinical Guideline Centre, 2012.
- 4 Council General Medical. *Consent: patients and doctors making decisions together*. Manchester: General Medical Council, 2008.
- 5 Acts of Parliament. *Mental Capacity Act: Chapter 9*. London: The Stationary Office, 2005.
- 6 General Medical Council. *Treatment and care towards the end of life: good practice in decision making*. London: GMC, 2010.
- 7 National Council for Palliative Care. *What to expect when someone important to you is dying*. London: NCPC, 2015.
- 8 Royal College of Physicians. *CEEU. National care of the dying audit for hospitals*. London: RCP, 2016.

Address for correspondence: Prof S H Ahmedzai, Department of Oncology and Metabolism, Medical School, University of Sheffield, Sheffield S10 2RX, UK.
Email: s.ahmedzai@sheffield.ac.uk