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Care of the dying adult

NICE guideline: short version

Draft for consultation, July 2015

This guideline covers the clinical care of adults (aged 18 years and over) who are in the last few days of life. It includes recognising when people are entering the last few days of life, communication and shared decision-making with the person who is dying. It also covers anticipatory prescribing, the role of assisted hydration, and the pharmacological management of pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions.

Who is it for?

- People who are dying, their families, carers and other people important to them.
- Healthcare professionals caring for people who are dying, in particular those working in primary care, care homes, hospices and hospitals.
- Commissioners and providers of care for people in the last days of life.

This version of the guideline contains the recommendations, context and recommendations for research. The Guideline Committee's discussion and the evidence reviews are in the [full guideline](#).

Other information about how the guideline was developed is on the [project page](#). This includes the scope, and details of the Committee and any declarations of interest.

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1 **1 Recommendations**

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

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

Some of the medicines recommended do not have a UK marketing authorisation specifically for pharmacological management of symptoms in the last days of life. This is indicated with a footnote in relevant recommendation.

2 **1.1 *Recognising when a person is in the last days of life***

3 These recommendations are intended to help healthcare professionals
4 recognise when a person might be entering the last days of their life, or if they
5 may be stabilising or recovering. It is recognised that it is often difficult to be
6 certain about whether a person is dying. The recommendations supplement
7 the individual clinical judgement that is required when making decisions about
8 the certainty of prognosis and how to manage any uncertainty.

9 1.1.1 If it is thought that a person may be entering the last days of life,
10 gather information on:

- 11 • changes in the physiological, social, spiritual and psychological
12 needs of the person
- 13 • current clinical signs and symptoms
- 14 • the person's medical history and the clinical context, including
15 underlying diagnoses
- 16 • the person's goals and wishes
- 17 • the views of those important to the person with respect to future
18 care.

19 1.1.2 Assess for signs and symptoms and any change that may suggest
20 a person is entering the last days of life, for example:

- 1 • agitation
 - 2 • available investigation results, such as renal function tests or
 - 3 radiological imaging
 - 4 • changes in communication (for example talking about the
 - 5 nearness of death)
 - 6 • Cheyne–Stokes breathing
 - 7 • decreasing level of Eastern Cooperative Oncology Group
 - 8 (ECOG) performance status, especially deterioration to level of 4
 - 9 • deterioration in level of consciousness
 - 10 • fatigue
 - 11 • loss of appetite
 - 12 • mottled skin
 - 13 • noisy respiratory secretions
 - 14 • progressive weight loss
 - 15 • social withdrawal.
- 16 1.1.3 Use the knowledge gained from the assessment and other
- 17 information gathered from the multiprofessional team, the person
- 18 and those important to them, to help determine whether the person
- 19 is:
- 20 • nearing death **or**
 - 21 • recovering.
- 22 1.1.4 Monitor for further changes in the person at least every 24 hours.
- 23 Use clinical judgement to update the person’s care plan when a
- 24 clinical or other change suggests that the person’s condition may
- 25 be deteriorating or could be stabilising or improving.
- 26 1.1.5 Seek advice from colleagues with more experience of providing
- 27 end of life care if there is uncertainty about whether a person is
- 28 entering the last days of life.

1 **1.2 Communication**

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

4 1.2.1 Establish the communication needs and expectations of people
5 who may be entering their last days of life, taking into account:

- 6 • whether they would like a person important to them to be
- 7 present when making decisions about their care
- 8 • their current level of understanding that they may be nearing
- 9 death
- 10 • their cognitive status and if they have any specific speech,
- 11 language or other communication needs
- 12 • how much information they would like about their prognosis.

13 1.2.2 Discuss the dying person's prognosis with them (unless they do not
14 wish to be informed) as soon as it is recognised that they may be
15 entering the last days of life and include those important to them in
16 the discussion if the dying person wishes.

17 1.2.3 Identify the most appropriate available multiprofessional team
18 member to explain the dying person's prognosis based on the
19 professional's:

- 20 • competence and confidence
- 21 • relationship and rapport with the person.

22 1.2.4 Provide the dying person, and those important to them, with:

- 23 • accurate information about their prognosis (unless they do not
- 24 wish to be informed), explaining any uncertainty and how this will
- 25 be managed, but avoiding giving false optimism
- 26 • an opportunity to talk about any fears and anxieties, and to ask
- 27 questions about their care in the last days of life
- 28 • information about how to contact members of the team involved
- 29 in their care

- 1 • opportunities for further discussion with a member of their care
2 team.

3 1.2.5 Explore with the dying person and those important to them:

- 4 • whether the dying person has an Advance Care Plan or has
5 stated preferences about their care in the last days of life
6 (including any anticipatory prescribing decisions or advance
7 decisions to refuse specific treatments)
8 • whether the dying person has understood and can remember
9 the information given about their prognosis.

10 1.2.6 Discuss the dying person's prognosis with other members of the
11 multiprofessional care team, and ensure that this is documented in
12 the dying person's record of care.

13 1.2.7 Sensitively address any requests from people important to the
14 dying person to withhold information from the dying person about
15 their prognosis.

16 **1.3 Shared decision-making**

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

19 1.3.1 Establish the level of involvement that the dying person wishes to
20 have in shared decision-making, and ensure that honesty and
21 transparency are used when discussing the development and
22 implementation of the dying person's care plan.

23 1.3.2 As part of any shared decision-making process take into account:

- 24 • whether the dying person has an advance care plan or advance
25 decision in place
26 • the dying person's goals and wishes

- 1 • whether the dying person or those important to them have any
2 cultural, religious, social or spiritual preferences that should be
3 considered.
- 4 1.3.3 Identify a named lead healthcare professional, who is responsible
5 for encouraging shared decision-making in the person's last days of
6 life. The healthcare professional should:
- 7 • give their own contact details and also contact details for
8 relevant out-of-hours services to the dying person and those
9 important to them
- 10 • ensure that any agreed changes to the care plan are understood
11 by the dying person, those important to them, the
12 multiprofessional team and by others involved in the care of the
13 dying person.
- 14 1.3.4 Establish as early as possible the resources needed for the dying
15 person (for example, the delivery of meals, equipment, care at
16 night, volunteer support or assistance from an organisation) and
17 their availability.
- 18 1.3.5 In discussion with the dying person, those important to them and
19 the multiprofessional team, create an individualised plan of care.
20 The plan should include the dying person's:
- 21 • personal goals and wishes
- 22 • preferred care setting
- 23 • resources required
- 24 • preferences for symptom management
- 25 • anticipated care needs
- 26 • needs for care after death, if any are specified.
- 27 1.3.6 Record individualised care plan discussions and decisions in the
28 dying person's medical records and share the care plan with all
29 members of the multiprofessional care team.

- 1 1.3.7 Continue to explore the understanding and wishes of the dying
2 person and those important to them, and update the care plan as
3 required. Recognise that the dying person's ability and desire to be
4 involved in making decisions about their care may change as their
5 condition deteriorates or as they accept their prognosis.
- 6 1.3.8 Whilst it is normally possible and desirable to meet the wishes of a
7 dying person, when this is not possible explain the reason why to
8 the dying person and/or those important to them.
- 9 1.3.9 Ensure that shared decision-making is supported by experienced
10 staff at all times. Seek specialist advice if additional support is
11 needed.

12 **1.4 *Maintaining hydration***

- 13 1.4.1 Support the dying person to drink if they wish to and are able to.
14 Check for any difficulties, for example, swallowing problems or risk
15 of aspiration. Discuss the risks and benefits of drinking with the
16 dying person, the multiprofessional team and others involved in the
17 care of the dying person.
- 18 1.4.2 Offer frequent mouth care to the dying person and ensure that their
19 care plan includes the management of dry mouth if needed. Offer
20 as needed:
- 21 • lip care
 - 22 • help with cleaning their teeth or dentures, if they wish to
 - 23 • frequent sips of fluid.
- 24 1.4.3 Encourage people important to the dying person to help with mouth
25 care or giving drinks, if they wish to. Provide any necessary aids
26 (such as oral hygiene sponges) and give them advice on giving
27 drinks safely.

- 1 1.4.4 Review, preferably daily, with people at the end of life, the possible
2 need for clinically assisted hydration in those who are not currently
3 receiving it, respecting their wishes and preferences.
- 4 1.4.5 Discuss the risks and benefits of clinically assisted hydration with
5 the dying person and those important to them. Ensure that any
6 concerns raised by the dying person or those important to them are
7 addressed before starting clinically assisted hydration.
- 8 1.4.6 Advise the dying person and those important to them that, in the
9 last days of life:
- 10 • giving clinically assisted hydration may relieve distressing
11 symptoms or signs related to dehydration, but is unlikely to
12 prolong life or the dying process
 - 13 • death is unlikely to be hastened by not having clinically assisted
14 hydration.
- 15 1.4.7 When considering clinically assisted hydration for a dying person
16 take into account:
- 17 • whether they have expressed a preference for or against
18 clinically assisted hydration, or have any cultural, spiritual or
19 religious beliefs that might affect this, documented in their
20 advance care plan
 - 21 • their level of consciousness
 - 22 • any swallowing difficulties
 - 23 • their level of thirst
 - 24 • the risks of pulmonary oedema
 - 25 • whether recovery from dying is possible.
- 26 1.4.8 Consider a therapeutic trial of clinically assisted hydration for the
27 dying person who has distressing symptoms or signs that could be
28 associated with dehydration, such as thirst or delirium. Monitor at
29 least once a day for changes in these symptoms or signs, or for

1 any evidence of benefit or harm in people having clinically assisted
2 hydration:

- 3 • Continue with clinically assisted hydration if there are signs of
4 clinical benefit.
- 5 • Reduce or stop clinically assisted hydration if there are signs of
6 possible harm to the dying person, such as fluid overload,
7 significant discomfort at the infusion site, or if they no longer
8 want it.

9 1.4.9 For people who have already been started on clinically assisted
10 hydration (enteral or parenteral) before entering the last days of life,
11 review the risks and benefits with the person and those important to
12 them and consider whether to continue, reduce or stop clinically
13 assisted hydration as they near death.

14 **1.5 *Pharmacological interventions***

15 This section includes general recommendations for prescribing
16 pharmacological interventions for managing common symptoms in the last
17 days of life. Further information on prescribing is included [appendix A](#)
18 [Prescribing advice for non-specialist prescribers](#).

19 1.5.1 When it is recognised that a person may be entering the last days
20 of life, review their current medication and, after discussion and
21 agreement with the dying person and those important to them, stop
22 any previously prescribed medicines that are not providing
23 symptomatic benefit or may cause harm.

24 1.5.2 When involving the dying person and those important to them in
25 making decisions about symptom control in the last days of life:

- 26 • Use the dying person's individualised care plan to help decide
27 which medicines are clinically appropriate for the individual when
28 managing symptoms in the last days of life.
- 29 • Discuss the benefits and harms of any medicines offered.

- 1 1.5.3 When considering medications for symptom control, take into
2 account:
- 3 • the dying person's preferences alongside the benefits and harms
4 of the medication
 - 5 • any individual or cultural views that might affect their choice
 - 6 • any other medicines being taken to manage symptoms
 - 7 • any risks of the medication that could affect prescribing
8 decisions, for example prescribing cyclizine to manage nausea
9 and vomiting may exacerbate heart failure.
- 10 1.5.4 Decide on the most effective route for administering medicines in
11 the last days of life tailored to the dying person's condition, their
12 ability to swallow safely and their preferences.
- 13 1.5.5 Consider prescribing different routes of administering medication if
14 the dying person is unable to take or tolerate oral medication. Avoid
15 giving intramuscular injections and give subcutaneous or
16 intravenous injections as appropriate for the setting.
- 17 1.5.6 Consider using a syringe pump to deliver medications for
18 continuous symptom control if more than 2 or 3 doses of any 'as
19 required' medication is needed within 24 hours.
- 20 1.5.7 For people starting treatment who have not previously been given
21 medications for symptom management, start with the lowest
22 effective dose and titrate as clinically indicated (for further
23 prescribing information see [appendix A Prescribing advice for non-
24 specialist prescribers](#)).
- 25 1.5.8 Ensure that plans are in place for regular reassessment, at least
26 daily, of the dying person's symptoms during treatment to inform
27 appropriate titration of medication.

1 1.5.9 Seek specialist palliative care advice if the dying person's
2 symptoms do not improve promptly with treatment or if there are
3 undesirable side effects such as unwanted sedation.

4 **Pain**

5 1.5.10 Be aware that not all people in the last days of life experience pain.
6 However, if pain is identified, manage it promptly and effectively,
7 and treat any reversible causes of pain, such as urinary retention.

8 1.5.11 Assess the dying person's level of pain and all possible causes
9 when making prescribing decisions for managing pain.

10 1.5.12 The management of pain in the last days of life should follow
11 principles of pain management used at other times, for example,
12 matching the medication to the severity of pain and following the
13 dying person's preferred route of administration.

14 1.5.13 Ensure that a dying person who is unable to effectively verbally
15 communicate that they are in pain, for example, someone with
16 dementia or learning disabilities, has a validated behavioural pain
17 assessment to inform their management.

18 **Breathlessness**

19 1.5.14 Consider non-pharmacological management of breathlessness in a
20 person in the last days of life.

21 1.5.15 Identify and treat reversible causes of breathlessness in the dying
22 person, for example pulmonary oedema.

23 1.5.16 Do not routinely start oxygen to manage breathlessness. Only offer
24 oxygen therapy to people known or clinically suspected to have
25 hypoxaemia.

26 1.5.17 Consider managing breathlessness with:

- 1 • an opioid¹ **or**
- 2 • a benzodiazepine¹ **or**
- 3 • a combination of an opioid¹ and benzodiazepine¹.

4 **Nausea and vomiting**

5 1.5.18 Assess for likely causes of nausea or vomiting in the dying person.

6 These may include:

- 7 • medicines that can cause or contribute to nausea and vomiting
- 8 • recent chemotherapy or radiotherapy
- 9 • any psychological causes
- 10 • any biochemical causes, for example hypercalcaemia
- 11 • raised intracranial pressure
- 12 • gastrointestinal motility disorder
- 13 • ileus or bowel obstruction.

14 1.5.19 Discuss options for treating nausea and vomiting with the dying
15 person and those important to them.

16 1.5.20 Consider non-pharmacological methods for treating nausea and
17 vomiting in a person in the last days of life.

18 1.5.21 When choosing medication to manage nausea or vomiting in a
19 person in the last days of life, take into account:

- 20 • the likely cause and whether it is reversible
- 21 • the side effects, including sedative effects, of the anti-emetic
- 22 • other symptoms the person may have
- 23 • the desired balancing of effects when managing other symptoms
- 24 • compatibility and drug interactions with other medicines the
25 person is taking.

¹ At the time of consultation (July 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. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

1 1.5.22 For people in the last days of life with obstructive bowel disorders
2 who have nausea or vomiting, consider:

- 3 • hyoscine butylbromide² as the first-line pharmacological
4 treatment
- 5 • octreotide² if the symptoms do not improve within 24 hours of
6 starting treatment with hyoscine butylbromide².

7 **Anxiety, delirium and agitation**

8 1.5.23 Explore the possible causes of anxiety or delirium, with or without
9 agitation, with the dying person and those important to them. Be
10 aware that agitation in isolation is sometimes associated with other
11 unrelieved symptoms or bodily needs for example, unrelieved pain
12 or a full bladder.

13 1.5.24 Treat any reversible causes of agitation, anxiety or delirium, for
14 example, fear and psychological causes, or certain metabolic
15 disorders.

16 1.5.25 Consider a trial of a benzodiazepine to manage anxiety or agitation.

17 1.5.26 Consider a trial of an antipsychotic to manage delirium or agitation.

18 1.5.27 Seek specialist advice if the diagnosis of agitation or delirium is
19 uncertain, if the agitation or delirium does not respond to
20 antipsychotic treatment or if treatment causes unwanted sedation.

21 **Noisy respiratory secretions**

22 1.5.28 Assess for the likely causes of noisy respiratory secretions in
23 people in the last days of life. Establish whether the noise has an
24 impact on the dying person or those important to them. Reassure
25 them that, although the noise can be distressing, it is unlikely to

² At the time of consultation (July 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. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

1 cause discomfort. Be prepared to talk about any fears or concerns
2 they may have.

3 1.5.29 Consider non-pharmacological measures to manage noisy
4 respiratory or pharyngeal secretions in people at the end of life, to
5 reduce any distress in the dying person or those important to them.

6 1.5.30 Consider a trial of medication to treat noisy respiratory secretions if
7 they are causing distress to the dying person or those important to
8 them. Tailor treatment to the dying person's individual needs or
9 circumstances, using one of the following drugs:

- 10 • hyoscine hydrobromide **or**
- 11 • atropine³ **or**
- 12 • glycopyrronium bromide³ **or**
- 13 • hyoscine butylbromide³.

14 1.5.31 When giving medication for noisy respiratory secretions:

- 15 • monitor for improvements at least every 12 hours
- 16 • monitor regularly for side effects, particularly delirium, agitation
17 or excessive sedation when using atropine or hyoscine
18 hydrobromide
- 19 • treat side effects, such as dry mouth, delirium or sedation (see
20 recommendation 1.4.2 on mouth care and 1.5.23 on delirium).

21 1.5.32 Consider changing or stopping medications if:

- 22 • noisy respiratory secretions continue and are still causing
23 distress after 12 hours **or**
- 24 • unacceptable side effects, such as dry mouth, urinary retention,
25 delirium, agitation and unwanted levels of sedation, persist
26 despite treatment.

³ At the time of consultation (July 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. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

1 **1.6 *Anticipatory prescribing***

2 1.6.1 Assess what medication the person might need to manage
3 symptoms likely to occur during their last days of life (such as
4 agitation, anxiety, breathlessness, nausea and vomiting, noisy
5 respiratory secretions and pain). Discuss any prescribing needs
6 with the dying person, those important to them and the
7 multiprofessional team.

8 1.6.2 Prescribe anticipatory medication as early as possible for people
9 with anticipated or changing needs for symptom control medication
10 in the last days of life. Ensure that suitable medications and routes
11 are prescribed as early as possible.

12 1.6.3 Use an individualised approach to prescribing anticipatory
13 medications for people who are likely to need symptom control in
14 the last days of life. Specify the indications for use and the dosage
15 of any medications prescribed.

16 1.6.4 When deciding which medications to offer as anticipatory
17 prescriptions take into account:

- 18 • the likelihood of symptoms occurring
- 19 • the benefits and harms of prescribing or administering
20 medications
- 21 • the benefits and harms of not prescribing or administering
22 medications
- 23 • the possible risks of sudden deterioration (for example,
24 catastrophic haemorrhage or seizures) for which urgent
25 symptom control may be needed.
- 26 • the place of care and time it would take to obtain medications.

27 1.6.5 When anticipatory medications are administered, monitor and
28 review the dying person's symptoms and any side effects daily, and
29 give feedback to the lead healthcare professional. Adjust the
30 individualised care plan and prescription as necessary.

1

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

2

3 **Implementation: getting started**

4 This section will be completed in the final guideline using information provided
5 by stakeholders during consultation.

6 To help us complete this section, please use the [stakeholder comments form](#)
7 to give us your views on these questions:

8 1. Which areas will have the biggest impact on practice and be challenging to
9 implement? Please say for whom and why.

10 2. What would help users overcome any challenges? (For example, existing
11 practical resources or national initiatives, or examples of good practice.)

12 **Context**

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

- 21 • recognition that a person was dying was not always made by an
22 experienced clinician and not reliably reviewed, even if the person may
23 have been improving
- 24 • the dying person may have been unduly sedated as a result of injudiciously
25 prescribed symptom control medication

- 1 • the perception that hydration and some essential medications may have
2 been withheld or withdrawn, with negative impact on the dying process.

3 These were not necessarily a direct consequence of following the LCP, but
4 due to poor implementation and without ensuring adequate staff training and
5 supervision.

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

12 The guideline is aimed at all healthcare professionals who might be involved
13 in the care of a person who is nearing death in any NHS setting. It is
14 specifically targeted towards non specialists (those working in primary care or
15 in care homes) and to healthcare professionals working in a wide range of
16 medical specialties in which people may die, but who do not have specialist
17 level training in end of life care. It will also be of value as providing a baseline
18 for setting standards of care in settings which specialise in care of dying
19 people, such as non-NHS palliative care units and hospices.

20 The process and timescale of dying varies widely, mostly because of the
21 underlying diseases responsible but also the person's robustness or frailty,
22 and their social setting. Some people can remain ambulant and largely self-
23 caring, and continue to take oral medication and drink and eat right up to the
24 point of dying. Others may die suddenly and unexpectedly following a
25 significant unintentional trauma. Some may never experience any of the
26 symptoms addressed in the guideline. Others, such as with progressive
27 neurological disorders, following stroke or with dementia may spend several
28 weeks or months in a gradual decline. Although the recommendations cover
29 those who are thought to be entering the last few days of life, it is
30 acknowledged that for the latter group, many of the principles of
31 communication, shared decision-making and pharmacological care can be

1 initiated long before that time. The guideline recommendations apply to
2 people at the end of life whether they are conscious or unconscious.

3 This guideline's aim is to provide a set of recommendations to guide
4 healthcare professionals to recognise better when a person is dying, how to
5 communicate and share decisions respectfully with the dying person and
6 those important to them, and how best to manage difficult symptoms in order
7 to maintain comfort and dignity without causing unacceptable side effects.

8 **Recommendations for research**

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

12 ***1 Recognising dying***

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

17 **Why this is important**

18 It is difficult to determine when the dying person is entering the last few days
19 or weeks of life. The Committee are aware that predicting the end of life is
20 often inaccurate and that predictive tools and models are limited. The
21 Committee consensus was that some level of uncertainty in recognising death
22 is inevitable and that it is an on-going challenge, however it is vital to minimise
23 this uncertainty to ensure that it does not prevent key discussions between the
24 healthcare professional and the dying person and those important to them.

25 It is therefore important to identify how the uncertainty of recognising when a
26 person is entering the last days of life influences information sharing,
27 advanced care planning and the behaviour of healthcare professionals. This
28 question is designed as a mixed-methods approach (quantitative and
29 qualitative evidence to be obtained) and aims to explore how different

1 multidisciplinary team interventions (any different methods of giving feedback,
2 initiating end of life discussions, record keeping or updating care plans, versus
3 usual care) can reduce the impact of uncertainty on clinical care, shared
4 decision-making and communication, specifically on engaging the dying
5 person and those important to them in end of life care discussions. These
6 could be measured quantitatively (quality of life/patient or carer
7 satisfaction/changes to clinical care, identification and/or achievement of
8 patient wishes such as preferred place of death) or qualitatively (interviews or
9 focus groups with healthcare staff, the dying person or those important to
10 them). In addition the barriers and facilitators for the healthcare professionals
11 to manage this uncertainty to best support the dying person and those
12 important to them will be explored.

13 ***2 Agitation and delirium***

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

16 **Why this is important**

17 People who are entering the last days of life are prone to developing sepsis,
18 dehydration and various biochemical disorders which may predispose to the
19 development of delirium. This is characterised by altering levels of
20 consciousness, confusion and possibly hallucinations.

21 Many of the drugs used to control delirium are classed as sedatives, and it is
22 very difficult for inexperienced clinicians to reduce the manifestations of
23 delirium without causing undue sedation. It is self-evident that an
24 inappropriate large dose of sedative medication can compromise respiration
25 and a perceived risk of over-sedation is that the dying person's life may be
26 shortened because of the sedation itself.

27 Specialists in palliative care are knowledgeable about which drugs to use and
28 in which combinations, and know how to use the correct routes and frequency
29 to achieve reduction in delirium – and of any accompanying agitation – without
30 over-sedating the dying person. However most people who are dying are not
31 under the direct care of such specialists, although they may be called in for

1 advice out of hours when patients become agitated and this has resource
2 implications for specialist palliative care services.

3 The research will study how key drugs in UK palliative care practice
4 (benzodiazepines and antipsychotics) can be applied in a range of settings in
5 order to reduce delirium and agitation without causing undue sedation or
6 inadvertently shortening life. This is proposed to be conducted as a multi-arm,
7 multi-stage interventions at escalating doses.

8 ***3 Noisy respiratory secretions***

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

14 **Why this is important**

15 It is common to experience noisy respiratory secretions at the end of life
16 (reported in 23-92% of dying patients) and the 'death rattle' is a strong
17 predictor of death. The noise can cause considerable carer distress, both at
18 the time and possibly after death, due to concerns that the person may have
19 drowned or suffocated to death. For many years it has been the practice of
20 clinicians to administer subcutaneous anti-muscarinic agents in an attempt to
21 'dry up' secretions and relieve any distress primarily to carers and relatives
22 despite a lack of evidence of any beneficial effect to the patient or
23 improvement in distress levels.

24 Our review concluded that despite a recent Cochrane review, the evidence for
25 the efficacy of pharmacological interventions in managing respiratory
26 secretions is of low quality, and it is not clear whether any one drug is more
27 effective than another or whether drugs are more effective than non-
28 pharmacological approaches such as repositioning or oropharyngeal suction.
29 Most studies involved low numbers of patients and were primarily based on
30 cancer patients in hospices and so may not reflect the larger numbers of

1 patients dying with non-malignant diseases in hospitals and in community
2 care.

3 Anti-muscarinic agents have undesired side effects such as, dry mouth,
4 blurred vision or bladder retention, as well as a cost implication, and it is hard
5 both morally and economically to justify their continued use when the current
6 evidence does not support them and treatment is usually aimed at minimising
7 distress of people other than the dying person.

8 ***4 Anticipatory prescribing***

9 What is the clinical and cost effectiveness of anticipatory prescribing for
10 patients dying in their usual home on patient and carer reported symptoms at
11 end of life?

12 **Why this is important**

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

22 Following review of the available evidence uncertainty remains as to the
23 impact of anticipatory prescribing on outcomes such as preferred place of
24 death and symptom control, and also uncertainty as to the most appropriate
25 medications to be prescribed.

26 A cluster randomised controlled trial (randomised by GP practice) is proposed
27 to compare interventions of anticipatory prescribing (just in case boxes) with a
28 generic list of medications or anticipatory prescribing individualised to the
29 patient's expected symptoms, compared with reactive prescribing at the

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1 bedside after symptoms have occurred. Outcomes of interest include patient
2 and carer symptom ratings, patient rated quality of life and healthcare use.

3 **ISBN**

4

5

1 **Appendix A Prescribing advice for non-specialist** 2 **prescribers**

3 In the absence of evidence of efficacy from the evidence reviews conducted in
4 developing this guideline, the Committee felt that it was important to provide a
5 guide with suggestions for specific starting dosages for non-specialist
6 prescribers covering the pharmacological management of common symptoms
7 in the last days of life. Medicines for symptom management in adults in the
8 last days of life should be chosen for optimal efficacy with the least amount of
9 harm, taking into consideration the pharmacological actions of the drugs, their
10 known side effects, the individual needs of the dying person (for example,
11 starting doses may be reduced in frail elderly people and those with organ
12 failure or very low body weight) and the likely nearness of death.

13 **The tables were created by the Committee using the following** 14 **principles:**

- 15 • Standard prescribing principles should be followed, for example, BNF.
16 Prescribers should also be aware that some drugs within this guide are for
17 indications for which they do not have a UK marketing authorisation at the
18 date of publication. The prescriber should follow relevant professional
19 guidance, taking full responsibility for the decision. The patient (or those
20 with authority to give consent on their behalf) should provide informed
21 consent, which should be documented. For example, for doctors see the
22 General Medical Council's Good practice in prescribing and managing
23 medicines and devices for further information. Where guidance is given for
24 medications outside their licensed indications ('off-label use'), these drugs
25 are marked with a footnote.
- 26 • Please note that where medications have a least one licenced route of
27 administration for a given indication a footnote has not been provided. For
28 example hyoscine hydrobromide is licensed for treatment of respiratory
29 secretions by subcutaneous route, but not as a patch.
- 30 • General recommendations regarding pharmacological interventions
31 provided in section 1.5 are followed.

- 1 • The choice of route of administration may be determined by the setting as
2 well as the dying person's condition and preferences. For example
3 intravenous route may be applicable in hospitals but not in community or
4 hospice settings.
- 5 • The medications listed are suggestions reflecting the combined experience
6 and consensus of the Committee and reflect the medications considered in
7 the evidence reviews conducted for this guideline. Consider local
8 prescribing preferences, but the preferences of the dying person should be
9 respected.
- 10 • Specialist advice should be sought if there are uncertainties about how to
11 prescribe for individual patients (for example, renal impairment, concerns
12 about lack of response when titrating medications).

13 **Further information about these tables:**

- 14 • The order of symptoms presented below does not imply any greater
15 importance or priority of management but reflect how commonly these
16 symptoms occur at the end of life. Individual prescribing decisions should
17 always be based on the assessment of the dying person's symptoms (if
18 any).
- 19 • The medicines for each symptom are listed, providing licensed medication
20 first and then other non-licensed drugs are listed alphabetically, and not in
21 order of preference.
- 22 • Each pharmacological treatment should only be prescribed as part of an
23 individualised care plan; the drugs listed in the tables are not to be
24 considered as forming a 'package' of medicines that are all administered
25 together.
- 26 • The tables suggest starting doses for 'as required medication'. The
27 suggested maximum dosing and frequency of use is also listed. The
28 Committee recognises that for some dying people it will be appropriate to
29 use a syringe pump for symptom management, and the tables give
30 suggested starting 24-hour doses for medications to be used by this route.
31 Be aware of incompatibilities or other interactions that may occur when
32 medications are used in a pump.

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- 1 • The tables only cover drugs included within the review protocols for this
2 guidance, and do not cover other interventions carried out by specialists in
3 palliative care.
- 4 • The tables do not include guidance on prescribing 'palliative sedation' as
5 this was not included in the scope for this guideline.
- 6 • The tables do not include guidance on non-pharmacological interventions
7 which should be considered alongside pharmacological interventions.

8

1 **Table 1: Prescribing for the management of pain in adults in the last**
 2 **days of life**

| Is the dying person taking analgesics? | | | | |
|--|---|---|--|---|
| Type of analgesic | Yes | No – able to take oral medicines | No – unable to take oral medicines | |
| | | As required dose | As required dose | 24-hour starting dose |
| Non-opioids | Continue current medication using the route that the dying person prefers and can manage. Consider increasing dose up to the maximum dose of the medication if the dying person is still in pain. | Orally <ul style="list-style-type: none"> Ibuprofen 200-400 mg, up to 4 times a day and/or Paracetamol 1 g up to 4 times a day | Rectally <ul style="list-style-type: none"> Diclofenac 50 mg, up to 2 times a day Paracetamol 1 g, up to 4 times a day. <i>or</i> Intravenous infusion <ul style="list-style-type: none"> Paracetamol 1 g up to 4 times a day | Continuous subcutaneous infusion <ul style="list-style-type: none"> Diclofenac and ibuprofen: seek specialist advice. Paracetamol not given via continuous subcutaneous infusion |
| Opioids: | Continue current medication using the route that the dying person prefers and can manage. Consider increasing dose up to the maximum dose of the medication if the dying person is still in pain. Consider switching to a different opioid if there are unwanted side effects | Orally Oral Immediate Release morphine sulphate 2.5-5 mg by mouth, up to 2-4 hourly | Subcutaneously or intravenously Morphine sulphate 1.25-2.5 mg, up to 2-4 hourly | Continuous subcutaneous infusion Morphine sulphate 10–20 mg |
| Note: <ol style="list-style-type: none"> Assess need for laxative and anti-emetic treatment Monitor for unwanted sedation and other side effects that could impair the quality of the person's last days. Seek specialist palliative care advice early if the person's symptoms are not responding to medications. (See recommendations 1.5.8 and 1.5.9) The suggestions for prescribing for pain management in table 1 differ from the advice in the NICE guideline on opioids in palliative care (CG140) because that guideline is focused on managing pain in adults with advanced and progressive disease over a wider time frame. The prescribing suggestions in these tables are only for people in the last few days of life. | | | | |

3

1 **Table 2: Prescribing for management of breathlessness in adults in the**
 2 **last days of life**

| Is the dying person already taking an opioid? | | | |
|---|---|--|--|
| Yes | No – able to take oral medicines | No – unable to take oral medicines | |
| | As required dose | As required dose | 24 hour starting dose |
| <p>Continue current medication using the route that the dying person prefers and can manage.</p> <p>Consider increasing dose up to the maximum dose of the medication if the dying person is still breathless.</p> <p>Consider switching to a different opioid if there are unwanted side effects</p> | <p>Orally Immediate release Morphine sulphate⁴ 2.5 – 5 mg, up to 2 - 4 hourly</p> | <p>Subcutaneously or intravenously Morphine sulphate⁴ 1.25 - 2.5 mg, up to 2 - 4 hourly</p> | <p>Continuous subcutaneous infusion Morphine sulphate⁴ 10 - 20 mg over 24 hours</p> |
| <p>If still breathless with opioid (despite dose increases and switching), consider adding a benzodiazepine</p> | <p>Orally</p> <ul style="list-style-type: none"> • Diazepam⁴ 2 - 5 mg, up to 3 times a day <p><i>or</i></p> <p>Orally or sublingually</p> <ul style="list-style-type: none"> • Lorazepam⁴ 0.5 - 1 mg, up to 4 times a day <p><i>or</i></p> <p>Buccally Midazolam⁴ 2.5 mg 4 times a day</p> | <p>Rectally</p> <ul style="list-style-type: none"> • Diazepam⁴ 2.5 – 10 mg up to 3 times a day <p><i>or</i></p> <p>Subcutaneously or intravenously</p> <ul style="list-style-type: none"> • Midazolam⁴ 2.5 - 5 mg, up to every 2 - 4 hours | <p>Continuous subcutaneous infusion</p> <ul style="list-style-type: none"> • Clonazepam⁴ 0.5 - 2 mg over 24 hours <p><i>or</i></p> <ul style="list-style-type: none"> • Midazolam⁴ 5 - 20mg over 24 hours |

⁴ At the time of consultation (July 2015), this medication did not have a UK marketing authorisation for breathlessness. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

Note:

- a) Assess need for laxative and anti-emetic treatment
- b) Monitor for unwanted sedation and other side effects that could impair the quality of the person's last days. Seek specialist palliative care advice early if the person's symptoms are not responding to medications. (See recommendations 1.5.8 and 1.5.9)

1

1 **Table 3: Prescribing for the management of nausea and vomiting in**
 2 **adults in the last days of life**

| Is the dying person already taking an antiemetic? | | | | |
|---|---|---|--|---|
| | Yes | No – and able to take oral medicines | No – but unable to take oral medicines | |
| | | As required dose | As required dose | 24-hour starting dose |
| First line | Continue current medication using the route that the dying person prefers and can manage. Consider increasing dose up to the maximum dose of the medication if the dying person is still experiencing nausea and/or vomiting. | Orally <ul style="list-style-type: none"> • Cyclizine 50mg up to 3 times a day <i>or</i> • Domperidone 10 mg 3 times a day <i>or</i> • Haloperidol 0.5 - 1.5 mg up to 3 times a day <i>or</i> • Metoclopramide 10 mg 3 times a day <i>or</i> • Prochlorperazine 5 mg up to 3 times a day | Buccally <ul style="list-style-type: none"> • Prochlorperazine 3 mg tablets Subcutaneously <ul style="list-style-type: none"> • Cyclizine 50 mg up to 3 times a day <i>or</i> • Haloperidol 0.5 - 1.5 mg up to 3 times a day <i>or</i> • Metoclopramide 10 mg up to 3 times a day | Continuous subcutaneous infusion <ul style="list-style-type: none"> • Cyclizine 150mg over 24 hours <i>or</i> • Haloperidol 1.5 - 3 mg over 24 hours <i>or</i> • Metoclopramide 30 mg over 24 hours |
| Second line - add or substitute with this if first-line treatment is ineffective or not tolerated | Continue current medication using the route that the dying person prefers and can manage. | Orally Levomepromazine ⁵ 6 - 6.25mg up to twice a day | Subcutaneously or intravenously Levomepromazine ⁵ 2.5 - 5 up to mg 12 hourly | Continuous subcutaneous infusion Levomepromazine ⁵ 6.25 - 25 mg over 24 hours |
| Note: <ol style="list-style-type: none"> Be aware that some anti-emetics are contraindicated or should be used with caution in certain people (for example, cyclizine in heart failure or in people with delirium, domperidone or metaclopramide in bowel obstruction, levomepromazine may lower seizure threshold) Be aware that cyclizine is prone to causing skin reactions by the subcutaneous route; and is not readily mixable in a syringe driver with other drugs. Monitor for unwanted sedation and other side effects that could impair the quality of the person's last days. Seek specialist palliative care advice early if the person's symptoms | | | | |

⁵ At the time of consultation (July 2015), this medication did not have a UK marketing authorisation for nausea and vomiting. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information for further information.

are not responding to medications. (See recommendation 1.5.8 and 1.5.9)

1 **Table 4: Prescribing for management of anxiety (with or without**
 2 **agitation) in adults in the last days of life**

3

| Is the dying person already taking anxiolytic medication? | | | |
|---|--|---|--|
| Yes | No – able to take oral medicines | No – unable to take oral medicines | |
| | As required dose | As required dose | 24-hour starting dose |
| Continue current medication using the route that the dying person prefers and can manage. Consider increasing dose up to the maximum dose of the medication if the dying person is still anxious. | Orally <ul style="list-style-type: none"> • Diazepam 2 - 5 mg up to 3 times a day <i>or</i> • Clonazepam⁶ 0.5 - 1 mg at night <i>or</i> Orally or sublingually <ul style="list-style-type: none"> • Lorazepam 0.5-1 mg up to 4 times a day | Subcutaneously or intravenously <ul style="list-style-type: none"> • Clonazepam⁶ 0.5 - 1 mg at night <i>or</i> • Midazolam⁶ 2.5-5 mg up to every 2-4 hour | Continuous subcutaneous infusion <ul style="list-style-type: none"> • Clonazepam⁶ 0.5 - 2 mg over 24 hours <i>or</i> • Midazolam⁶ 5 - 20mg over 24 hours |
| Note: <ol style="list-style-type: none"> If the dying person has associated delirium and becomes agitated, consider adding an antipsychotic (see table 5) Be aware that in some patients, benzodiazepines used alone may cause disinhibition and worsen delirium; if this occurs add an anti-psychotic. If the dying person becomes agitated and poses a danger to themselves and/or others, consider increasing benzodiazepine as well as adding an anti-psychotic. Monitor for unwanted sedation and other side effects that could impair the quality of the patient's last days. Seek specialist palliative care advice early if the patient's symptoms are not responding to medications. (See recommendations 1.5.8 and 1.5.9) | | | |

4

⁶ At the time of consultation (July 2015), this medication did not have a UK marketing authorisation for anxiety. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

1 **Table 5: Prescribing for management of delirium (with or without**
 2 **agitation) in adults in the last days of life**

| Is the dying person already taking antipsychotic medication? | | | |
|--|--|--|--|
| Yes | No – able to take oral medicines | No – unable to take oral medicines | |
| | As required dose | As required dose | 24 hour starting dose |
| <p>Continue current medication using the route that the dying person prefers and can manage.</p> <p>Consider increasing dose up to the maximum dose of the medication if the dying person is still experiencing delirium.</p> | <p>Orally</p> <ul style="list-style-type: none"> Haloperidol 1 – 2 mg 3 times a day <i>or</i> Olanzapine⁷ 2.5 - 5 mg 3 times a day <i>or</i> Risperidone⁷ 0.5 mg twice a day | <p>Orally (orodispersible)</p> <ul style="list-style-type: none"> Olanzapine⁷ 2.5 - 5 mg 3 times a day <i>or</i> Risperidone⁷ 0.5 mg twice a day <p>Subcutaneously</p> <ul style="list-style-type: none"> Haloperidol 1 – 2 mg 3 times a day <i>or</i> <p>Subcutaneously or intravenously</p> <ul style="list-style-type: none"> Levomepromazine 6.25 - 12.5 mg every 2 hours | <p>Continuous subcutaneous infusion</p> <ul style="list-style-type: none"> Haloperidol 2.5 - 5 mg over 24 hours <i>or</i> Levomepromazine 12.5 - 50 mg over 24 hours |
| <p>Note:</p> <ol style="list-style-type: none"> If the dying person has associated anxiety, or their symptoms are not responding to antipsychotics alone, consider adding a benzodiazepine (see table 4) If the dying person becomes agitated, consider adding or increasing benzodiazepine. Be aware that doses of anti-psychotics should be reduced for older and frail people. Monitor for unwanted sedation and other side effects that could impair the quality of the person's last days. Seek specialist palliative care advice early if the person's symptoms are not responding to medications. (See recommendations 1.5.8 and 1.5.9) | | | |

3

⁷ At the time of consultation (July 2015), this medication did not have a UK marketing authorisation for delirium. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information for further information.

1 **Table 6: Prescribing for the management of noisy respiratory secretions**
 2 **in adults in the last days of life**

| Is the dying person already on an antisecretory medication? | | |
|---|---|--|
| Yes | No As required dose | 24-hour starting dose |
| <p>Continue current medication using the route that the dying person prefers and can manage.</p> <p>Consider increasing dose up to the maximum dose of the medication if the dying person is still experiencing noisy respiratory secretions.</p> <p>Consider changing to an alternative agent after 12 hours if treatment is ineffective.</p> | <p>Subcutaneously</p> <ul style="list-style-type: none"> Hyoscine hydrobromide 400 micrograms every 6-8 hours <i>or</i> Glycopyrronium bromide⁸ 400 micrograms every 6-8 hours <i>or</i> <p>Transdermal</p> <ul style="list-style-type: none"> Hyoscine hydrobromide 0.5-1 mg patch(es) to be applied every 3 days <i>or</i> <p>Sublingually</p> <ul style="list-style-type: none"> Atropine⁸ 1% eye drops 1 - 2 drops, every 4-6 hours (NB: this is eye drops being used sublingually) <i>or</i> <p>Subcutaneously or intravenously</p> <ul style="list-style-type: none"> Hyoscine <u>butyl</u>bromide⁸ 20 mg up to every 6-8 hours | <p>Continuous subcutaneous infusion</p> <ul style="list-style-type: none"> Hyoscine hydrobromide 1200 micrograms over 24 hours <i>or</i> Glycopyrronium⁸ 600 - 1200 micrograms over 24 hours <i>or</i> Hyoscine <u>butyl</u>bromide⁸ 60 mg over 24 hours |
| <p>Note:</p> <p>a) Monitor for unwanted sedation and other side effects that could impair the quality of the person's last days. Seek specialist palliative care advice early if the person's symptoms are not responding to medications. (See recommendations 1.5.8 and 1.5.9)</p> <p>b) Note the differing formulation/routes for each of the hyoscine salts.</p> | | |

3

⁸ At the time of consultation (July 2015), this medication did not have a UK marketing authorisation for noisy respiratory secretions. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information for further information.