

Guidance to support care for people in the last few days and hours of life and to facilitate completion of the individualised care record

The Leadership Alliance for Care of the Dying Person has 5 Priorities for Care

1. The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the person who is dying, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of the families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

(LACDP 2014)

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

- It can often be difficult to be certain that a person is dying, stabilising or even temporarily improving.
- Individual clinical judgement is needed to make decisions about the level of certainty of prognosis and how to manage any uncertainty.

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.

These should then be ideally recorded in the Individual Care Record for the Last Days of Life (ICRLDL).

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

- signs such as agitation, Cheyne–Stokes breathing, deterioration in level of

consciousness, mottled skin, noisy respiratory secretions and progressive weight loss

- symptoms such as increasing fatigue and loss of appetite
- functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal.

Again, please record this in ICRLDL.

Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering. If this is the case it may well be appropriate to stop using the ICRLDL.

- Avoid undertaking investigations that are unlikely to affect care
- Monitor for further changes in the person at least every 24 hours and update ICRLDL

Seek advice from colleagues with more experience of providing end of life care when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

Communication

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

- if they would like a person important to them to be present when making decisions about their care
- their current level of understanding that they may be nearing death
- their cognitive status and if they have any specific speech, language or other communication needs

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

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

- competence and confidence
- rapport with the person.

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

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

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

Explore with the dying person and those important to them:

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

Discuss the dying person's prognosis with other members of the multiprofessional care team.

Please ensure that the above is documented in ICRLDL.

Shared decision-making

- Establish the level of involvement that the dying person wishes to have and is able to have in shared decision-making
- Ensure that honesty and transparency are used when discussing the development and implementation of their care plan.
- Assess mental capacity.

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

- whether the dying person has an advance statement or an advance decision to refuse treatment in place, or has provided details of any legal lasting power of attorney for health and welfare
- the person's current goals and wishes
- whether the dying person has any cultural, religious, social or spiritual preferences.
- Record in ICRLDL

Identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life. The named healthcare professional should:

- give information about how they can be contacted and contact details for relevant out-of-hours services to the dying person and those important to them
- ensure that any agreed changes to the care plan are understood by the dying person, those important to them, and those involved in the dying person's care.

Providing individualised care

In discussion with the dying person, those important to them and the multiprofessional team, create an individualised care plan. The plan should include the dying person's:

- personal goals and wishes
- preferred care setting
- current and anticipated care needs including: preferences for symptom management and needs for care after death, if any are specified
- resource needs.

Record individualised care plan discussions and decisions in the dying person's Individual Care Record for the Last Days of Life and share the care plan with the dying person, those important to them and all members of the multiprofessional care team.

Seek further specialist advice if additional support is needed.

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.
- Offer frequent care of the mouth and lips
- Help with cleaning their teeth or dentures
- Frequent sips of fluid if they would like this

Assess daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences.

Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.

When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:

- whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment
- their level of consciousness
- any swallowing difficulties
- their level of thirst

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

Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium. This could be given subcutaneously.

For people being started on clinically assisted hydration:

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

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

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

Pharmacological interventions (please see Palliative Care Formulary on intranet for further information)

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

- Review current medicines
- Stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.
- Ensure that this is discussed with dying person and those important to them
- When considering medication for symptom control take into account preferences of the person and whether they are able to swallow
- 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, start 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. This should be 4 hourly in an inpatient setting.

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

Managing pain

Consider non-pharmacological management of pain in a person in the last days of life.

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

Managing breathlessness

Identify and treat reversible causes of breathlessness.

Consider non-pharmacological management of breathlessness, such as a fan. Do not routinely start oxygen to manage breathlessness.

Consider managing breathlessness with:

- an opioid or
- a benzodiazepine or
- a combination of an opioid and benzodiazepine.

Managing nausea and vomiting

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

Consider non-pharmacological methods for treating nausea and vomiting.

Managing 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. Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.

Consider non-pharmacological management of agitation, anxiety and delirium.

Treat any reversible causes.

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

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

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

Managing noisy respiratory secretions

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 non-pharmacological measures to manage noisy respiratory or pharyngeal secretions, to reduce any distress.

Consider a trial of medicine to treat noisy respiratory secretions if they are causing distress to the dying person. Tailor treatment to the dying person's individual needs or circumstances, using 1 of the following drugs:

- glycopyrronium bromide or
- hyoscine butylbromide or
- hyoscine hydrobromide.

When giving medicine for noisy respiratory secretions:

- Monitor for improvements, preferably every 4 hours, but at least every 12 hours.
- Monitor regularly for side effects, particularly delirium, agitation or excessive sedation when using atropine or hyoscine hydrobromide.
- Treat side effects, such as dry mouth, delirium or sedation

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).

Consider changing or stopping medicines if unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation, persist.

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.

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

Consider using the drug chart that accompanies the ICRLDL.

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

If anticipatory medicines are administered:

- Monitor for benefits and any side effects.
- Adjust the prescription as necessary and document in ICRLDL.