

KEY ACTIONS for clinicians

Comprehensive Care Standard

End-of-life care: clinical basics

The Australian Commission on Safety and Quality in Health Care has developed a series of fact sheets to support clinicians providing care to people who are nearing the end of life. This fact sheet focuses on issues when caring for a patient in the last days of life.

Delivering safe and high-quality end-of-life care is about shifting from a curative to a palliative approach to care. This means providing care that improves patient symptoms, focuses on comfort, and prepares the patient and the family for death.

Central to the clinician's role is monitoring patients and families at the end of a patient's life to respond to any questions, uncertainties and concerns they may have. Clinicians have responsibilities to both explain the normal aspects of the end of life, and to urgently escalate care to relevant teams or services, such as specialist palliative care services, if the patient experiences unrelieved suffering.

To improve the care provided to people at the end of life, clinicians should:

- Deliver care with kindness and compassion, and maintain patient dignity
- Share decision-making about end-of-life care
- Communicate openly and honestly with patients and families about prognosis
- Prioritise comfort measures, pain control and symptom management
- Review medications
- Consider time limits for trial therapies
- Avoid unnecessary monitoring and interventions
- Be aware of common risks of harm for patients at the end of life.

Deliver care with kindness and compassion, and maintain patient dignity

Every clinician has the responsibility to treat patients, and their families and support people with respect, kindness and compassion. The patient's **dignity** must be maintained at all times, and this requires frequent assessment, monitoring and reassessment, along with prompt responses to any concerns. Patients who are dying will often need more frequent rather than less frequent reviews, but those reviews should be clearly focused on improving the comfort and experience of the patient and their support people.

Share decision-making about end-of-life care

When it is unclear whether treating a clinical problem will be of benefit to a patient, a considered assessment of the benefits and burdens of any interventions is required.

Decisions about care delivered at the end of life should be guided by the preferences of the patient, and any advance care planning documentation. The risks and benefits of different care options should be explained to the patient, or their substitute decision-maker, and decisions about the care plan should be shared. Discussion between the patient, their carer and family, and the multidisciplinary team is essential when planning goals of care. Clearly conveying to the family the serious nature of the underlying disease that will cause death is crucial. This should be followed with a statement such as, "I cannot give you any specific treatment to make this illness go away, I am so sorry, but there is a lot we can offer to help manage your/your mother's symptoms".



Communicate openly and honestly with patients and families about prognosis

It can feel quite uncomfortable to talk with patients and their families about death and dying; talking about death goes against many cultural norms. Added to this, families often want to know exactly how long a patient might have before death, which can be extremely challenging to predict accurately.

Communicating with patients and families with honesty and compassion is critical, as is acknowledging the uncertainty in predicting the patient's trajectory. Patients and their families should be provided with the opportunity to freely talk about their preferences and worries when approaching the patient's end of life. This can reduce stress for patients, families and the workforce, and lead to greater readiness for the impending outcome.

An example of how a clinician could approach this discussion could be:

Many people expect doctors and nurses to know when the end of life will happen, but in truth we can often only give educated guesses. Many times those guesses are wrong. What I am sure about is ... and what I don't know is ...

Prioritise comfort measures, pain control and symptom management

Regular clinical assessment of patient symptoms and comfort is essential. Symptoms that cause discomfort can be resolved or reduced. Dying is a normal human experience, and while the circumstance for an individual patient can be unpredictable, generally deterioration in function and consciousness can be anticipated. Symptoms experienced by people at the end of life should be anticipated and managed.

Effective symptom control and pain relief are a priority for people near the end of life to live as well as they can for as long as they can. As a disease state progresses, clinicians should anticipate how a patient may deteriorate and prepare for the need for symptom control therapies (see Table 1).

Pressure area care, mouth care and eye lubrication are basic care tasks that can contribute to enhancing patient comfort, particularly when consciousness is declining. These components of care should be documented on the comprehensive care plan and updated as necessary. For more information, see the [components of a comprehensive care plan fact sheet](#).



Table 1: Possible symptoms at end of life and potential management strategies

Symptoms	Potential management strategies
Secretions including noisy breathing, wet respirations, terminal secretions ¹	<ul style="list-style-type: none"> ■ Position the patient to encourage postural drainage ■ Consider anticholinergic agents – but note that effectiveness varies ■ Provide explanation and support to family and friends ■ Suction the oral cavity
Swallowing difficulties	<ul style="list-style-type: none"> ■ Treat oesophagitis¹ ■ Consider corticosteroids¹ ■ Perform regular mouth care¹ ■ Alter patient positioning – sitting forwards often helps ■ Change essential medications to the subcutaneous route if possible¹ ■ Perform dietetic/speech pathology review – provided thickened fluids if desired and tolerated; patients may choose to drink thin fluids for comfort¹ ■ If patient is close to death and unconscious, cease oral fluids and start mouth swabs to moisten oral mucosa¹ ■ Provide support and guidance for caregivers¹
Pain	<ul style="list-style-type: none"> ■ Administer regular analgesia¹ ■ Perform regular assessments and review ■ Provide breakthrough or adjuvant analgesia¹ ■ If pain is not controlled, escalate to specialist palliative care¹ ■ Relieve obvious causes of pain (e.g. urinary retention, muscle spasm)¹ ■ Provide hot packs ■ Perform massage ■ Perform transcutaneous electric nerve stimulation if it has been of benefit ■ Consider other complementary therapies ■ Provide psychological support
Restlessness	<ul style="list-style-type: none"> ■ Perform pain and symptom assessment¹ ■ Provide support and explanation to caregivers¹ ■ Allow access to family, carers and other support people as indicated by the patient¹ ■ Ensure the patient is not experiencing urinary retention or faecal impaction¹ ■ If patient remains restless, escalate to specialist palliative care¹ ■ Consider anxiolytics¹ ■ Sedatives may be indicated¹ – seek specialist palliative care advice ■ Consider pet therapy ■ Provide comfort items ■ Change bed linen



Symptoms	Potential management strategies
Delirium	<ul style="list-style-type: none"> ■ Minimise medication burden ■ Maintain hearing aids and glasses where possible ■ Decrease day/night disruption ■ Provide explanation and reassurance for caregivers¹ ■ Create a familiar environment¹ ■ For moderate to severe delirium, consider low dose antipsychotic medication¹
Dyspnoea, shortness of breath ¹	<ul style="list-style-type: none"> ■ Open a window ■ Provide a simple fan in the room (unless airborne spread of pathogens is a concern) ■ Position the patient comfortably ■ Consider opioids ■ Consider anxiolytics if anxious ■ Promote a calm environment ■ Avoid bunching care activities
Bowel and bladder problems ¹	<ul style="list-style-type: none"> ■ Monitor, assess and document bowel and bladder function regularly ■ Consider indwelling catheter for urinary retention if identified, or to prevent pain and excoriation from incontinence ■ Provide suppositories or enemata if indicated ■ Consider motility agents ■ Consider aperients ■ Consider antispasmodics
Immobility ¹	<ul style="list-style-type: none"> ■ Use pressure-relieving devices ■ Perform appropriate pressure area care
Eye irritation	<ul style="list-style-type: none"> ■ Perform regular eye hygiene with moist swabs ■ Maintain lubrication
Dry mouth, lack of hydration ¹	<ul style="list-style-type: none"> ■ Perform frequent and meticulous oral hygiene to moisten the patient's mouth
Nausea and vomiting ¹	<ul style="list-style-type: none"> ■ Consider antiemetics or haloperidol ■ Consider prokinetics if appropriate ■ Offer small volumes of food and drinks more often if the person is still eating and drinking (e.g. gently use a syringe) ■ Assess for bowel obstruction – seek specialist advice



Ensure appropriate access to subcutaneous opioids and palliative medications

Reduced swallowing function is a normal part of dying. Clinicians should be prepared to convert oral analgesics to the subcutaneous route. When used appropriately, opioids will not expedite the dying process. Concerns about risks of addiction should not override a patient's comfort and they should have access to the treatment they require.

Timely communication with the patient's community pharmacist and general practitioner will enhance the transition of patients from the acute setting into the community and may avoid delays in accessing medication. It is important to advise the patient's general practitioner as soon as possible about the prescriptions required, and allow time for the hospital and community pharmacy to order any medications that are not in stock. Always educate, guide and support patients and caregivers about the use and potential effects of these types of medications.

Review medication

Medications should be reviewed and rationalised for patients approaching the end of life to ensure there is still an appropriate indication to use them, and their benefit outweighs the harm. Some medications, such as those prescribed for hypertension, hyperlipidaemia and osteoporosis, have limited value in people with a short life expectancy. Deprescribing, or discontinuation of medication, has a number of advantages including potentially reducing:

- Risks of adverse outcomes, such as falls or cognitive impairment
- Medication side effects, including cognitive effects and the impact of polypharmacy
- Complexity of care for patients who are on multiple medications or those who may no longer be able to comfortably swallow medication
- Costs to the patient and community.

When deprescribing, it is important to consider the risk of withdrawal and rebound syndromes, such as those observed with steroids, benzodiazepines, anticonvulsants and antidepressants (particularly selective serotonin reuptake inhibitors and tricyclic antidepressants). These syndromes can be avoided by either changing to subcutaneous administration or

reducing the dose over time under the supervision of a pharmacist. As with all changes to a patient's care, deprescribing must be discussed with the patient, and their carer and family, with decisions documented on the [comprehensive care plan](#) and communicated to the multidisciplinary healthcare team.

Consider time limits for trial therapies

If a trial therapy is initiated, it should be reviewed within 48 hours to assess its efficacy. If it is not providing benefit, consider whether it needs to be withdrawn. For clinicians who primarily aim to improve patients' health and function with interventions and therapies, providing care at the end of a patient's life can be a challenging time. Sometimes clinicians may feel instinctively tempted to keep providing therapies when there is no benefit for the patient. At these times, consultation with professional colleagues, self-reflection on the potential for safe and quality dying, and acknowledgement of one's own helplessness can be very helpful.

Avoid unnecessary monitoring and interventions

Clinicians need to ensure appropriate care is delivered at the end of life that aligns with the needs and preferences of the individual patient. Reducing unnecessary clinical activity, providing regular whole-person reviews, implementing a comprehensive care plan, monitoring the effectiveness of end-of-life care and completing associated documentation are important aspects of improving care. Patients, families and carers should be reassured that, although the focus may change, comprehensive compassionate care will continue. Families will likely have questions and concerns about the end of the patient's life. Clinicians must work in partnership with patients and families, exercising excellent communication and impeccable assessment, to deliver safe and quality end-of-life care.



Within hospitals, routine physiological observations are taken to identify the risk of potential deterioration, and to prompt a response when needed. This forms part of the monitoring plan required for all patients. When a patient has been identified as approaching the end of life, a different approach to the monitoring plan may be appropriate. At the end of life, it is often more appropriate to focus on regularly monitoring the patient's comfort and distress, and responding to any issues identified, as well as checking in regularly with the patient's carers and family to monitor and respond to their concerns or distress.

Be aware of common risks of harm for patients at the end of life

Patients nearing the end of life are at increased risk of the following adverse events:

- Delirium
- Pressure injury
- Medication safety incidents.

Screening for risks of harm should be done as soon as possible after the patient presents, given that adverse events such as falls and pressure injuries can happen quickly. In the last days of life, these complications can be minimised by clinical assessment and attending to basic care regularly, in alignment with processes and procedures that apply to immobile patients.

Helpful hyperlinks

[End-of-Life Essentials education portal](#)

[SA Health Safety and Quality: Prescribing guidelines for the pharmacological management of symptoms for adults in the last days of life](#)

[Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers](#)

Questions?



For more information, please visit:
safetyandquality.gov.au/our-work/comprehensive-care

You can also contact the Comprehensive Care project team at: mail@safetyandquality.gov.au

References

1. Therapeutic Guidelines Ltd. [Therapeutic guidelines: palliative care](#). Melbourne: Therapeutic Guidelines Ltd; 2016.

