

KEY ACTIONS for clinicians

Comprehensive Care Standard

End-of-life care: last days of life

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 specific considerations for providing care in the last days of life. It has information to help you provide optimal care during this difficult time so that the interventions provided to patients focus on maintaining comfort, anticipating and managing symptoms, preparing for possible severe symptoms, stopping interventions that are not beneficial, and providing appropriate emotional and psychological support.

Identify that a person is in the last days of life

It is often difficult to predict when a person will die. A number of terms are used to describe this period, including actively dying, terminal phase or last days or hours of life. Triggers that may indicate a person has entered this phase are:

- Ongoing deterioration despite optimal clinical care
- Increasing difficulty swallowing or taking oral medications
- Increasing disinterest in food or fluid
- Profound weakness, decrease in function and being bed bound
- Drowsiness or sleeping for extended periods of time.

Perform appropriate clinical observations

It is important to recognise and respond to unresolved symptoms (see [End-of-life care clinical basics factsheet](#)) in the last days of life by continuing to observe the patient. Observations should remain routine but should be limited to those that will change the care plan. This may include symptom assessment,

and observation for signs of restlessness, agitation, or distress from pain or shortness of breath, as well as other indicators of discomfort. Physiological parameters should only be tracked if the results will affect care, such as monitoring blood sugar levels to prevent hypoglycaemic seizures. Care should focus on maintaining the comfort and dignity of the patient, and providing support to their family and carers.

Reducing unnecessary clinical activity and the associated documentation is an important aspect of improving end-of-life care. Clinicians need to ensure appropriate care is delivered at the end of life and prioritise the care that is needed for the individual patient.

A clinician should escalate care or initiate an appropriate medical review, potentially by specialist palliative care services, if they observe an increase in patient distress or if the patient's symptoms do not respond satisfactorily to prescribed measures such as 'as required' (PRN) medication. This action remains important even when a patient has an advance care plan in place that indicates that they are not to be resuscitated.

Anticipate and manage symptoms

For most patients and their families, the wish to die peacefully is their most important end-of-life goal of care. Although some patients have few symptoms while dying, some may require specialist support to ensure their symptoms are well controlled. All patients should have access to specialist palliative care advice (National Safety and Quality Health Service Standards action 5.16), and care plans should include instructions about managing possible symptoms, including sufficient analgesia, during the last hours.



Suffering is a multi-factorial human experience that may be eased by non-pharmacological interventions. Psychological and spiritual supports can offer enormous assistance to the suffering patient. Clinicians should be aware of the emotional demands that accompany care of the dying patient and be mindful of their own self-care. Referral to appropriate services should always be considered.

After appropriate assessment and consultation, administration of sedative agents may assist patients with intolerable, refractory, non-reversible symptoms. Palliative care advice should be sought before initiating sedation. Providing sedation during the terminal phase of end-of-life care may support refractory symptom management and is not intended as a measure to shorten life.

Prepare for emergencies at the end of life

Anticipating potential terminal catastrophes and planning appropriate clinical strategies is crucial in providing safe and high-quality end-of-life care. This planning aims to prevent distress for the dying patient and to minimise the anguish of family and support people in witnessing their loved one's suffering. Palliative care specialist services can be consulted to support care planning, especially when larger than usual doses of medications may be required. Potential terminal catastrophes that are a clinical emergency and appropriate management strategies are shown in Table 1.

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

Clinical emergency	Potential management strategies
Massive haemorrhage such as: <ul style="list-style-type: none"> ■ When a tumour erodes through a large blood vessel wall (e.g. an acute carotid blowout) ■ Epistaxis ■ Haematemesis ■ Melaena 	<ul style="list-style-type: none"> ■ Dark towels to camouflage blood loss ■ Appropriate dressings, such as pressure dressings or nasal tampons ■ Appropriate medicines, such as: <ul style="list-style-type: none"> – agents to decrease blood flow, including topical adrenaline, octreotide (for the gut) – coagulants such as antifibrinolytic agents, including tranexamic acid and aminocaproic acid – subcutaneous midazolam infusion
Respiratory distress	Appropriate medicines for severe dyspnoea, such as infusions of: <ul style="list-style-type: none"> ■ Subcutaneous opioids ■ Subcutaneous benzodiazepines such as midazolam
Status epilepticus	Appropriate medicines for epilepsy that can be given subcutaneously, such as midazolam or clonazepam
Ruptured viscera	Appropriate medicines such as: <ul style="list-style-type: none"> ■ Subcutaneous smooth muscle relaxants such as hyoscine butylbromide ■ Subcutaneous opioids ■ Subcutaneous midazolam infusion



Prevent futile interventions including cardiopulmonary resuscitation

Part of comprehensive care planning for patients at the end of life includes making decisions about interventions like cardiopulmonary resuscitation (CPR). Ideally, these decisions should be made proactively and early. They should be undertaken by the primary caring team, preferably during routine business hours, and not left to clinicians who do not know the person, in out-of-hours and/or emergency situations. If the patient is frail on admission, it may be important to establish these plans while developing the initial plan of care. While an advance care plan is used when patients cannot make decisions for themselves, it may be a good starting point for conversations about interventions at the end of life. If patients are requesting treatments that may be inappropriate, early consultation with other services may be indicated and beneficial. It may also flag additional needs such as further emotional or psychological support for patients, carers and families.

Patients should not be offered interventions, including CPR, that are not likely to provide any benefit. CPR is generally an appropriate first aid response to unexpected cardiac arrest but is unlikely to be helpful in patients with complex comorbidities.¹ For patients at the end of life, CPR may contribute to patient suffering, prolong inevitable death and increase family distress.¹ Clinicians need to discuss frankly the potential risks and benefits of performing CPR with the patient and their family so that they have realistic expectations of possible treatment.

Outcomes of decision-making discussions about CPR should be documented clearly on the patient's comprehensive care plan, communicated to the multidisciplinary team and flagged at all handovers. Clear instructions, such as 'not for CPR', need to be used, and ambiguous terms, such as 'no heroic measures', must be avoided. All relevant team members should be aware of any changes to the escalation plan for a patient. This should include after-hours staff. Patients, families and carers should be reassured that, although the focus of care may change, comprehensive care will continue.

References

1. Brindley PG, Beed M. Adult cardiopulmonary resuscitation: 'who' rather than 'how'. *Br J Anaesth* 2014;112(5):777-9.

Support carers, family members and loved ones

It is important for clinicians to demonstrate kindness and compassion towards carers, family members and friends of the dying patient.

Simple kindnesses can be comforting, such as verbally acknowledging the difficulties associated with witnessing a loved one at their end of life. Even simply asking the family members how they are, and listening to the response, can be helpful.

Some carers and family members may be unsure of how best to communicate with the dying patient, particularly if the patient is unresponsive. It can be helpful to inform family members that it is thought that the patient can hear, even if appearing unconscious, and they can continue to talk with the patient. Clinicians can softly speak to the unconscious patient when attending to care, thus modelling caring communication.

Carers and family members may benefit from the support provided by allied health professionals such as social workers or spiritual health practitioners. Access to these services should be facilitated where possible. Information on spiritual health is available through the [Spiritual Health Association](#).

Helpful hyperlinks

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

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

