# AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE





## **Comprehensive Care Standard**

## **End-of-life care: planning**

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 for planning end-of-life care.

Patients will require different end-of-life care depending on their individual needs, preferences and goals. When establishing a patient's goals for their end-of-life care, it is important to listen to what matters most to them and respectfully incorporate their needs and preferences into their care planning. See also resources for **shared decision making**.

Sometimes patients have preferences that cannot be safely met. Clinicians need to support patients and their families with open and honest communication about why this might be the case. Clinicians may be reluctant to discuss uncertain outcomes with patients, but acknowledging uncertainty can support realistic end-of-life discussions. For more information on goal setting, see Essential elements for comprehensive care – Essential element 2: Identifying goals of care.

## Deliver respectful and compassionate care

Every clinician has the responsibility to treat patients, their families and support people with respect and compassion. For most people, maintaining their **dignity** is of the utmost importance, and clinicians must seek to preserve the privacy of all patients. For some patients, respect could be as simple as supporting personal care activities, communicating empathically or providing privacy. Sometimes clinicians overlook simple formalities like calling a patient by their preferred name or ensuring patients are covered and clean. Respecting the patient's wishes without judgement and discrimination is essential to planning and delivering person-centred care.

## Individualise comprehensive care planning

Treatments for patients at the end of life should be of benefit, and all unnecessary treatments should be discontinued or avoided. Clinicians may not always agree with a decision made by a patient. However, provided patients have been given information about risks, benefits and options, they should be free to make choices that fit with their preferences and goals. It is important that care is provided continuously and collaboratively in line with the patient's current prognosis, agreed goals of care and the comprehensive care plan. For more information on care planning, see Essential elements for comprehensive care – Implementing the Comprehensive Care Standard: Develop a single comprehensive care plan.

The delivery of comprehensive care at the end of life should aim to achieve the agreed clinical and personal goals of care and address the ongoing comfort of the patient. This includes:

- Reducing risks of harm
- Anticipating and managing symptoms
- Preparing for a possible terminal catastrophe.

The process of delivering comprehensive care at the end of life should include relevant clinical disciplines working together in a multidisciplinary team to achieve end-of-life care that is compassionate and dignified, and which meets the goals that the patient and team set together. This may require multidisciplinary planning to coordinate a transfer to die at home, or in residential aged care or a hospice.



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#### Promote advance care planning

Advance care planning is a process of preparing for when a person no longer has the capacity to make and communicate decisions for themselves. The process includes discussion of a patient's values, preferences, and personal and family circumstances, and occurs in the context of their medical history and condition. When a patient's imminent death is anticipated, it is important to ascertain their wishes before they lose consciousness or the ability to communicate.

Early advance care planning can:

- Reduce the distress of substitute decision-makers by ensuring that the patient's wishes are known
- Improve comprehensive care coordination
- Enhance patient experience and family satisfaction
- Improve patient autonomy, confidence and agency
- Prevent futile interventions including cardiopulmonary resuscitation (CPR)
- Reduce healthcare costs through unnecessary interventions and transfers.

Other members of the multidisciplinary team, such as social workers and senior nurses, can play a valuable role in assisting patients with advance care planning. It is important for advance care plans or directives to be communicated to family members, and to the patient's general practitioner and the multidisciplinary team. Advance care plans can be shared through My Health Record. For more information on advance care planning, see the Advance Care Planning fact sheet and Advance Care Planning Australia.

#### Allocate a care coordinator

Identifying a person who takes overall responsibility for managing a patient's care is essential to ensure continuity, effective communication and best care coordination. The care coordinator may fill a designated position, or they may be the patient's admitting doctor, general practitioner, practice nurse, palliative care clinical nurse consultant, carer or family member.

From a patient perspective, a care coordinator is often valued as the 'go-to' person, acting as an information conduit between the patient, their family and support people, and other members of the multidisciplinary team. The care coordinator can help people process bad news and changes in prognosis, and explain what treatment can mean for the individual patient. A care coordinator can reduce the administrative burden on the patient and their family by assisting in accessing services they need and managing shared care arrangements.

A care coordinator should have good communication skills and a level of health literacy to be able to translate medical terminology into language that the patient, their family, carer and support people can understand.

#### Support spiritual and cultural needs

All patients should have access to spiritual care, regardless of their stated religion. People facing death can suffer from existential or spiritual pain that can cause great distress. Spiritual care is about trying to develop an understanding of the things that give meaning and value to a person's life and are important to the person. Some religions have particular prayers, blessings or rituals that are usually completed before death which should be identified and supported as required. Spirituality may overlap with religion for some people, while for others religion plays no part in their spiritual world view.

Some cultures and religions have special requirements for the body after death. For example, in some cultures, close family members are expected to wash and prepare the body for burial or complete rapid burial. Healthcare teams should try to accommodate special rituals that the patient requests in line with state legislation or special circumstances such as pandemics.

Resources for spiritual care are available through the **Spiritual Health Association**.



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### **Prevent futile interventions** including cardiopulmonary resuscitation

Patients should not be offered interventions, including CPR, that are not likely to provide benefit. For patients with an advanced illness or complex comorbidities, CPR may prolong inevitable death, increase family distress and extend patient suffering. CPR is generally an appropriate first aid response to unexpected cardiac arrest but this deterioration is unlikely to be reversible in patients with complex comorbidities. 1 Clinicians need to discuss the potential risks and benefits of performing CPR with the patient and their family so that they have realistic expectations of possible treatment. Patients, families and carers should be reassured that effective treatments will continue, and that care will continue although its focus may change.

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 ongoing handovers. Avoid ambiguous terms such as 'no heroic measures', in preference for clear statements such as 'not for CPR'.

### 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

#### References

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





