

A decorative graphic consisting of three thick, overlapping curved bands. The outermost band is magenta, the middle one is purple, and the innermost one is blue. They are arranged in a semi-circular pattern, curving from the top left towards the bottom right.

# **Essential elements for safe and high-quality end-of-life care**

**National Consensus Statement**

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# Executive summary

The way people experience the end of their life is personal. It can be very different for each individual and their family, friends and carers. The way people respond to medical treatment at the end of their life also varies. This means there is potential for ambiguity and uncertainty for both the person at the end of their life and the healthcare services caring for them. The health care that people receive in the last years, months and weeks of their life can reduce the distress and grief associated with death and dying.<sup>4,9-11</sup>

End-of-life care should be relevant to a person's situation and preferences. The person's preferred place of care, and their psychosocial, cultural and spiritual care needs may change over time, and should be frequently assessed. The end of a person's life is not always straightforward, and it is likely that aspects of care will need to be revisited as the person's condition changes.

Effective communication and coordination of care is particularly critical at the end of a person's life. Systems should be employed that support collaboration and shared care between healthcare services including general practitioners, residential aged care facilities and providers, acute services, specialist palliative care services, and social care agencies. The aim is to maximise the likelihood that the person will be cared for and die in their preferred place and to optimise the coordination and delivery of end-of-life care.

The *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (the Consensus Statement) provides healthcare services with a best practice approach to caring for people who are approaching the end of their life. The Consensus Statement provides nine guiding principles that define safe and high-quality end-of-life care. These are followed by 10 essential elements that outline the key actions that should be applied by healthcare services providing end-of-life care.

Essential elements 1–5 describe how end-of-life care should be approached and essential elements 6–10 describe the organisational processes required for the effective delivery of safe and high-quality end-of-life care. However, the way the elements are applied will vary according to the local circumstances of the setting, the available resources, and the individual needs and preferences of the person receiving care.

# Background

The Consensus Statement was first released in 2015 and reflects the views of patients, consumers, carers, experts in the field, and the Australian Commission on Safety and Quality in Health Care (the Commission). It was derived from experts, published evidence, partnership with carers, consumers, representatives from public and private hospitals and healthcare services, professional colleges, state and territory health departments, and other government agencies.

Evidence supporting safe and high-quality end-of-life care has evolved since the original Consensus Statement. This second edition incorporates the findings of two rapid literature reviews<sup>8,12</sup> and additional consultation with the primary and community care sector, expert committees that advise the Commission and the Australian public.

## Purpose

The purpose of the Consensus Statement is to describe the essential elements for delivering safe and high-quality end-of-life care in Australia.

## Scope

The Consensus Statement applies to all services where health care is provided to people approaching the end of their life, including hospitals, hospices, residential aged care facilities and home settings.

The elements within the Consensus Statement are designed to apply to people regardless of their clinical condition. However, some population groups may have specific needs or considerations. These have been highlighted within the essential elements.

In some states and territories, an eligible person has the right to ask for medical assistance to end their life. Voluntary assisted dying legislation provides a legal framework for people who are dying to choose the manner and timing of their death. Specific requirements for voluntary assisted dying are not discussed in this document as each state or territory has, or is considering, legislation that regulates access. Healthcare services should familiarise themselves with the legislation in their jurisdiction and ensure patients and their families have access to appropriate information. People opting for voluntary assisted dying should continue to receive the safe and high-quality end-of-life care described in this document.

## Audience

The Consensus Statement has been developed for:

- Healthcare workers who provide health care to people approaching the end of their life
- Healthcare service executives and managers responsible for developing, implementing and reviewing systems for delivering end-of-life care
- Clinical education and training providers, including universities and professional colleges
- Health professional registration, regulation and accreditation agencies
- Planners, program managers and policy makers who are responsible for developing state or territory policies, or other strategic programs delivering end-of-life care.

## Definitions

The Consensus Statement does not always specifically refer to families, carers and other support people. However, these people should be included if this is what the person at the end of their life wishes and it aligns with their cultural practices.

Terms related to healthcare workers, clinicians and multidisciplinary teams are intended to be inclusive. It is not possible to mention all professional and craft groups in this document. However, we acknowledge that there are many different professional and craft groups that support safe and high-quality end-of-life care.

The definition of key terms is provided in the glossary at the end of the Consensus Statement.

## Application

The Consensus Statement aligns with the [National Safety and Quality in Health Service \(NSQHS\) Standards](#) and the [National Safety and Quality Primary and Community Healthcare Standards](#), and provides recommended, rather than mandatory, practice. It also aligns with the third edition of the [National Consensus Statement: Essential elements for recognising and responding to acute physiological deterioration](#).<sup>13</sup> It is intended that these documents be applied together when appropriate. For services that are not required to be assessed to standards, the [Australian Charter of Health Care Rights](#) provides a useful reference framework.

Healthcare services need to tailor the guiding principles and the essential elements in the Consensus Statement to deliver timely, safe and high-quality end-of-life care suited to their setting, the needs of their population and available resources. They also need to align their work with relevant national, state and territory legislation or other programs. These should work in synergy with local processes for recognising and responding to acute physiological deterioration.

# Guiding principles

Safe and high-quality end-of-life care should:

## 1 Be person-centred and include family and carers

People have the right to direct their own care, whenever possible. Families and carers should be involved, in accordance with the person's expressed wishes and/or legislation.

## 2 Align with values, needs and wishes

End-of-life care should consider a person's expressed wishes regarding the circumstances, environment and place in which they wish to die. Their needs, goals and wishes for end-of-life care may change over time.

## 3 Provide people with information they can understand

People should be provided with health information that they can understand and be supported to make decisions at the end of their life. If a person lacks capacity to participate in decision-making about their care, a substitute decision-maker should make decisions according to their best interpretation of the preferences of the person, but only after options for supported decision-making have been exhausted.

## 4 Consider cultural, spiritual and psychosocial needs

Meeting the cultural, spiritual and psychosocial needs of people and their families and carers is as important as meeting their physical needs. This may include considerations such as beliefs and practices around the end of a person's life and dying, and the time it may take to shape practices and processes accordingly.

## 5 Include qualified, skilled and experienced multidisciplinary care

Effective communication, collaboration and teamwork that ensures continuity and coordination between teams, within and between settings, during transitions, and across multiple episodes of care is required.

## 6 Ensure the right to refuse medical treatment

Decisions regarding treatment may be made in advance and remain valid unless the person or substitute decision-maker, family or carers state otherwise.

## 7 Not be burdensome or harmful

It is unethical to provide burdensome investigations, treatments and transfers that can be of no benefit and harmful to people.

## 8 Not offer unreasonable hope

Unless required by law, clinicians are not obliged to initiate or continue treatments that will not offer a reasonable hope of benefit or improve a person's quality of life.

## 9 Continue after a person has died

Care of a deceased person, and bereavement care for families and carers, extends beyond the death of the person.

# Essential elements

Figure 1: Overview of the 10 essential elements for safe and high-quality end-of-life care







## Section A: Care processes

The essential elements 1-5 describe how end-of-life care should be approached.

The first step in providing safe and high-quality end-of-life care is to recognise people who would benefit from such care.<sup>14</sup> End-of-life care is comprehensive care delivered in a coordinated way. Everyone involved needs to work together to achieve a person's end-of-life goals. All people have a right to dignity, comfort and privacy, and to be cared for respectfully and with compassion. The prevention and relief of suffering is the highest priority.

**Shared decision making** is a critical part of making sure that each person approaching the end of their life is a partner in their own care.<sup>15</sup>



## Essential element 1: Recognising end of life

The first step in providing safe and high-quality end-of-life care is to recognise people who would benefit from such care.<sup>14</sup>

Routine use of simple trigger tools and questions can prompt healthcare workers to use their clinical judgment to make a holistic assessment of whether a person might benefit from end-of-life care.<sup>14,16</sup> Recognising that a person is at the end of their life offers opportunities to identify their needs. This includes reviewing the person's **comprehensive care plan** to align care with their expressed values, goals and wishes.

Predicting when a person will die can be difficult.<sup>17</sup> For some people, it may be hard to distinguish reversible deterioration from irreversible deterioration that is part of the normal dying process. In such cases, it may be appropriate to consider a trial of treatment for a defined period to assess the reversibility of a person's deterioration. Healthcare workers should be aware of the referral criteria, processes and timelines for accessing specialist palliative care services and other support services. Healthcare services delivering end-of-life care should:

- Aim to identify whether a person is likely to die within 12 months (the medium term), where it is possible episodes of acute deterioration may be reversible. This period can be a key opportunity to talk to the patient and their family, friends and carers about advance care planning
- Aim to identify whether a person is likely to die within days or weeks (the short term), where acute deterioration is likely to be irreversible.

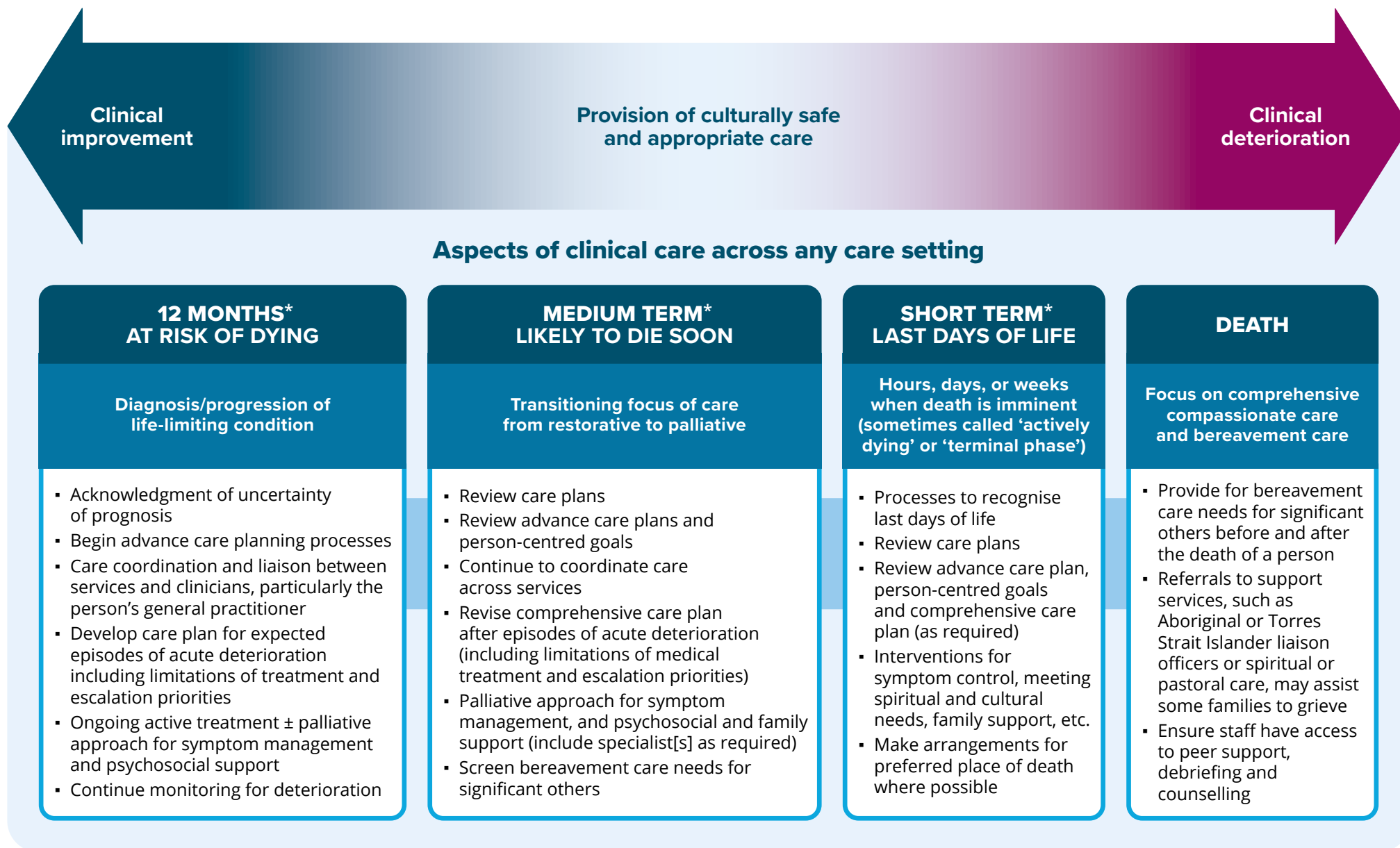
## Actions

- 1.1 Use simple screening mechanisms to recognise people who could benefit from end-of-life care interventions. Ask yourself:<sup>17,18</sup>
  - Would you be surprised if this person died in the next 12 months?
  - Would you be surprised if this person died in the next days or weeks?
- 1.2 Use condition-specific mortality risk prediction tools and monitor critical events to consider and react appropriately to end-of-life circumstances such as:<sup>19</sup>
  - Life-threatening trauma or disease
  - Life-limiting conditions
  - Poor or incomplete responses to medical treatment
  - Continued deterioration despite intervention. This may include a decline in the person's condition, or a clinical determination that they will not benefit from interventions such as surgery, dialysis or treatment in intensive care
  - Repeated escalation to the rapid response team in acute services, particularly if the person has been admitted for more than one week
  - Advanced age with increased frailty, reduced mobility and increased dependence on others to perform activities of daily life
  - Moderate to severe dementia
  - Multisystem comorbidities (such as involving the cardiovascular, pulmonary or endocrine system)
  - Reaching the limits of medical therapy
  - Multiple recent admissions to hospital for exacerbation of a chronic condition
  - Multiple or extended stays in hospital.

### Considerations for Aboriginal and Torres Strait Islander peoples

Aboriginal or Torres Strait Islander people likely to die within days or weeks will often prefer to return home to die on Country. This will often require involvement from, or collaboration with, specific Aboriginal or Torres Strait Islander community members. Healthcare services should liaise with Aboriginal or Torres Strait Islander communities to support appropriate communication and involvement.

Figure 2: End-of-life care interventions in last 12 months of life



\* Timing may be uncertain.



## Essential element 2: Person-centred communication and shared decision making

Healthcare workers should adopt a person-centred approach to communication and decision-making, to assist a person who is dying to make choices about their care. Recognising the values, needs and wishes of people in their care is an obligation of all healthcare workers.

Conversations about death, dying and the end of a person's life require compassion, knowledge, experience, sensitivity and skill on the part of healthcare workers. All communication processes should recognise and be responsive to the individual preferences and needs of the person. Plain language should be used, avoiding euphemisms such as 'not doing well'.

The purpose of an end-of-life care conversation will depend on the circumstances of the person involved. In some cases, the purpose will be to impart information. In other cases, decisions may need to be made about specific aspects of care. Early referral to support services should be promoted to improve care experiences and actively engage the person at the end of their life, as well as their family.<sup>8</sup>

The capacity of people to participate in decision-making may fluctuate, and supported decision-making may be necessary. Supported decision-making means that healthcare workers maximise opportunities for participation. This might mean deferring decisions until a person is able to participate. Where this is not possible, healthcare workers should work with the person's family or carers to support the person to be as involved in decision-making as their capacity at the time will allow. Substitute decision-makers, family members and carers should be included in decision-making in accordance with the person's expressed wishes, and state or territory legislative frameworks.

### Actions

- 2.1 Identify opportunities for proactive and pre-emptive advance care planning and end-of-life care discussions with a person, to align care with their values and wishes, and reduce the need for urgent, after-hours discussions in emergency situations.
- 2.2 Work with the person to identify their substitute decision-maker, family spokesperson or other key contacts who they wish to be involved in discussions about their care. Extra support may be required for those with additional communication or decision-making needs.
- 2.3 Identify culturally appropriate decision-maker(s) as early as possible so that strategies can be put in place for obtaining their input in discussions about end-of-life care. Common assumptions about death and dying, and about persons and families as decision-makers may not be correct.
- 2.4 Be respectful, sensitive and responsive to the preferences and needs of the person at the end of their life, including with regard to their identity, culture, religious beliefs, gender, orientation and loved ones (including family of choice).
- 2.5 Prepare to have conversations about end-of-life care that can include:
  - Discussions involving the person's general practitioner or care coordinator about prognosis and options to develop a coordinated approach to planning and delivering end-of-life care
  - Familiarisation with the person's history and current condition, their family structure, and cultural and spiritual needs and preferences

## ■ Essential element 2: Person-centred communication and shared decision making

- Organising enough time for uninterrupted discussion in a quiet and private environment
  - Ensuring that the person has access to their tailored communication aids and interpreters as required
  - Arranging for the appropriate people to be in attendance – ideally, this will include the person’s family, carer or substitute decision-maker, and other relevant healthcare workers or teams.
- 2.6 Provide the person with information identifying the healthcare workers responsible for leading and/or coordinating their end-of-life care. Whenever possible, involve these healthcare workers in discussions.
- 2.7 Ensure end-of-life conversations are person-centred and tailored to meet the health literacy needs of the person and any other participants – and that they occur regularly.
- 2.8 Provide the person with an honest and straightforward summary in plain language, including a clinical assessment of the situation, appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the person’s condition improving in response to such treatment.
- 2.9 Be compassionate and sensitive to the person’s situation. Allow enough time for those involved to absorb, process and react to information provided. Multiple discussions may be required.
- 2.10 Include information in end-of-life discussions about organ and tissue donation for transplantation in circumstances where donation is possible and there is no identified cultural objection. Ensure these discussions are conducted with advice from the state or territory DonateLife agency and are led by healthcare workers who have attended the core Family Donation Conversation workshop.
- 2.11 Clearly document the content of discussions and any agreed plan of care in the person’s healthcare record and My Health Record if available. Document any unresolved issues along with a plan for follow-up.
- 2.12 Communicate the content of the discussion and plan of care, including any limitations of medical treatment and resuscitation plans, to all healthcare workers involved in the person’s care and ensure to prioritise the person’s wishes.

### **Considerations for Aboriginal and Torres Strait Islander peoples**

It is important to ensure there is a culturally safe environment for Aboriginal and Torres Strait Islander people at the end of their life. Healthcare services should provide access to advice and support from Aboriginal and Torres Strait Islander liaison officers, where possible, or ensure appropriate community contact information is available.

Communication styles should be tailored, and cultural differences related to decision-making should be accommodated to the extent that the person wishes. Healthcare workers should introduce themselves in person to Aboriginal and Torres Strait Islander people who are involved, wherever possible. At minimum, a videoconference should be offered.

Clinicians may be required to explain the end-of-life plan (which may be better understood as an end-of-life story) to multiple people to ensure informed decision-making can occur.

There are many differences in the way nonverbal communication may be interpreted, and silence is not unusual in conversations. There are also many Aboriginal and Torres Strait Islander languages<sup>20</sup>, and English may be a second or third language. Clinicians should engage interpreters to ensure the information conveyed is appropriate and understood. Aboriginal or Torres Strait Islander support staff can assist clinicians to clarify the requirements of the person at the end of their life, and the people who should be involved in communication and decision-making.

### **Considerations for people with communication difficulties**

Communication difficulties at the end of a person's life are common and may impact a person's ability to safely and readily express their thoughts and the decisions they make about care. People may require tailored communication aids and supports to participate in care planning and decision-making due to difficulties with verbal communication or other factors, including changes in cognition or fluctuating alertness.

The inability to verbalise thoughts does not equate to limited decision-making capacity. Supported decision-making that identifies what the person can understand and what communication aids or methods will best support them is essential. A person with decision-making capacity should be afforded opportunities to express decisions and be supported to communicate.

A communication aid that has been designed for the person and includes frequently used words or concepts, images and diagrams may aid end-of-life care discussions. Communication needs should be frequently reassessed, with provision to make use of appropriate expertise.

### **Consideration for people with dementia**

Consideration should be given to providing extra communication support to those with dementia. This could involve having discussions in a comfortable and familiar environment and at a time of day that increases the person's ability to participate, accounting for medications, clinical issues, fatigue, anxiety and other physiological factors. Support people including substitute decision-makers should be involved.



## Essential element 3: Multidisciplinary collaboration and coordination of care

Overall responsibility for coordinating a person's end-of-life care and ensuring effective communication and collaboration should be allocated.<sup>23</sup>

This responsibility could be allocated to a general practitioner, nurse, allied health professional, family member or someone else depending on the circumstances. The appointed person should understand the requirements, have capacity to perform the role, and understand that they are part of a multidisciplinary team caring for the person at the end of their life.

People often receive care from a range of organisations that have different approaches to managing end-of-life care. Multidisciplinary collaboration is a process where healthcare workers from different disciplines and/or healthcare services share clinical information to optimise the delivery of comprehensive care for a person. This includes ensuring effective communication and liaison between all healthcare services involved in care, particularly at the interface between different services and teams, such as between hospital and community-based services, or between the treating team and after-hours care providers. Plans should specify how information at these transition points will be communicated to a person and their family, carers and other support people.

Coordinating approaches reduces the risk of a person at the end of their life receiving contradictory information and poorly organised care.<sup>24</sup> It also improves the experiences of care for people and their families.<sup>25</sup> Coordinated care requires clear roles and responsibilities for different people involved, and defined processes for care planning. The goals and wishes of a person at the end of their life should be included in a comprehensive care plan. The plan needs to be accessible and clear to all healthcare workers so that care can be effectively coordinated.

### Actions

- 3.1 Assign a healthcare worker to lead and coordinate a person's end-of-life care. If the person at the end of their life is unable to communicate, a substitute decision-maker is also identified.
- 3.2 Explain the roles and responsibilities of all healthcare workers to the person and all those involved in their care.
- 3.3 Ensure all members of the multidisciplinary team are aware that they are responsible for:
  - Communicating in a person-centred way, and sharing and supporting decision-making
  - Identifying existing advance care plans and providing care in accordance with the person's expressed values, needs and wishes
  - Referring people with specific needs to appropriate services
  - Documenting and communicating the agreed care plan and any limitations of medical treatment when handing over care responsibilities to other healthcare workers involved in the person's care.
- 3.4 Discuss the range of views around future treatment with the person to minimise confusion and ensure that they understand their options.
- 3.5 Establish processes for healthcare workers and the person and their family, carers and other support people to voice concerns and respond accordingly.





## Essential element 4: Comprehensive care

The goal of healthcare workers providing end-of-life care should be to deliver comprehensive care that is culturally safe and appropriate to the needs and condition of the person at the end of their life. It should also be aligned with their expressed wishes and goals. These should be sought early, with appropriate psychosocial, spiritual, cultural, religious and emotional support offered in response.<sup>22</sup>

For many people approaching the end of their life, there will be a long period of transition when treatment will continue for reversible complications or reversible episodes of deterioration. People may benefit from a palliative approach in conjunction with active medical treatment of their illness. People have the right to refuse medical treatment, and clinicians are under no obligation to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the person's quality of life.<sup>26</sup> Specific medical decisions about treatments that could be provided in the event of deterioration may be recorded in the comprehensive care plan. These would include therapies that may be tried for a short time to test their ability to reverse deterioration and any other potential effects.

Processes should be in place to support proactive, anticipatory and individualised planning for end-of-life care. When treatments cease to provide benefit or become uncomfortable and burdensome, planning should focus on providing comfort to both a person and their family and carers. Bereavement care should continue for family and carers beyond the person's death as required.

### Actions

- 4.1 Discuss goals of care, the comprehensive care plan and any limitations of medical treatment early. Ensure these things are clearly documented in a person's healthcare record by healthcare workers. Ensure documentation is routinely reviewed and updated.
- 4.2 Offer or revisit **advance care planning** if the person is likely to die within 12 months. This may take multiple meetings with the person and others involved in care.
- 4.3 Avoid unnecessary tests and treatments, to reduce the burden associated with medical treatment. This includes deprescribing medicines and avoiding non-beneficial investigations or interventions, and unnecessary observations.
- 4.4 Clearly communicate medical decisions, including the rationale, to discontinue or not instigate non-beneficial observations, investigations or treatments with the person, and document those decisions.
- 4.5 Reconsider the goals of care, the comprehensive care plan, and any limitations of medical treatment including resuscitation plans as the person's condition or circumstances change. Provide the person and any others involved with the opportunity to discuss their treatment further and to review their comprehensive care plan at any time.
- 4.6 Ensure the comprehensive care plan is readily available to all healthcare workers involved in the person's care.
- 4.7 When care priorities change, reassure the person that comprehensive compassionate care continues for people at the end of their life.

## Essential element 4: Comprehensive care

- 4.8 Prioritise adequate pain relief and symptom control to prevent and relieve suffering. Manage physical symptoms and provide for psychosocial, emotional, social and spiritual needs within scope of practice and in alignment with the person's wishes and comprehensive care plan. Review treatment with the team regularly.
- 4.9 Provide a plan for eating and drinking that supports dignity, quality of life and enjoyment of food and drink for as long as the person wishes.
- 4.10 Consider a process to determine the risks and benefits of transferring the person between services or to their home, in alignment with their wishes.
- 4.11 Develop processes to assess the risk of prolonged or complicated grief for family and other loved ones.
- 4.12 Identify local support resources for bereavement referrals and provide information to bereaved family and carers about how to access support in a format they can use.
- 4.13 Establish partnerships with organisations that can provide ongoing bereavement care for families and healthcare workers.
- 4.14 Co-develop bereavement models of care according to clinical settings – for example, community health or intensive care models.

### Considerations for Aboriginal and Torres Strait Islander peoples

Priorities identified by Aboriginal and Torres Strait Islander people and families should be determined, and care should be culturally appropriate, respectful and align with identified needs. Consideration should also be given to supporting people at the end of their lives to return to Country and providing end-of-life care on Country whenever possible and in alignment with the person's wishes.

It may be important to include additional family members and decision-makers from a person's community, regardless of the person's ability to communicate.

Referral to rural services or remote clinics to ensure a smooth transition between services should include plans and the person's preferences and bereavement support requirements. This may require a facilitated introduction or handover. Broader referral pathways should be considered for Aboriginal and Torres Strait Islander families to support culturally appropriate burials and bereavement practices.

### Considerations for people with dementia

Activities that enhance engagement with external stimuli can reduce symptoms associated with dementia in people at the end of their life. The symptomatic benefits of Namaste Care<sup>7</sup> and other approaches that provide comforting and meaningful sensory-based experiences at the end of life should be considered. These approaches provide ongoing opportunities to interact and engage, and to develop interpersonal trust. They also equip carers to cope more effectively with changes in behaviour and the psychological symptoms of dementia. Communication aids may be necessary to assess the need for pain relief or other symptom management.

## Considerations for people with disability

- Plan for reasonable adjustments
- Understand the person and the disability
- Communicate directly with the person and their family and carers
- Act to provide required care

A National Disability Insurance Scheme (NDIS) support coordinator may be part of the multidisciplinary team that cares for a person at the end of their life. The *National Disability Insurance Scheme Act 2013* established the NDIS and recognises the rights of people with a disability to:

- Participate equally in society
- Receive reasonable and necessary supports for this participation
- Have choice and control over decisions in their life.

## Bereavement support

Bereavement support includes the emotional, psychosocial and spiritual support provided to families and loved ones before and after the death of a person. It is designed to help people cope with grief, loss and adjustment.<sup>6</sup> In Australia, bereavement support may look different in different communities, depending on the lived experiences and cultural backgrounds of those involved. For example, some culturally and linguistically diverse communities may prefer to be directly involved in end-of-life care.<sup>7</sup> At the same time, it is important to recognise that there will always be different individual responses and preferences within any community. When providing end-of-life care, healthcare workers need to address family members' unique needs rather than act as a proxy for a person at end of life.<sup>8</sup>

Bereavement support is fundamental for families and friends to have a good end-of-life care experience. Care extends beyond the death of a person, and abrupt cessation may be detrimental. Some families are also at risk of prolonged or complicated grief. Early assessment and supportive measures to address the bereavement needs of families minimises adverse physical and emotional responses. Routine referrals to support services, such as Aboriginal or Torres Strait Islander liaison officers or spiritual or pastoral care, may assist some families to grieve. Referral to partner organisations may also be required.



## Essential element 5: Responding to concerns

When concerns are raised about a person approaching the end of their life or decision-making is particularly complex, timely and appropriate assistance should be obtained from a suitably skilled healthcare worker or team.

Physical, psychosocial, cultural or spiritual distress requires rapid assistance from a suitably skilled healthcare worker. A second opinion should be provided by an independent healthcare worker when responding to concerns that end-of-life care needs are not being adequately addressed.

Responding to concerns may require the support of additional healthcare workers, or the use of videoconferencing or teleconferencing to access off-site help, such as specialist palliative care or consultants. A person skilled in mediation and/or the law should be available for managing conflict, complex family dynamics or ethical issues.

### Actions

- 5.1 Ensure that there is a system in place for people to independently raise concerns about end-of-life care, or to seek a second opinion when needed.
- 5.2 Establish policies and procedures that clearly define criteria and processes for raising concerns about end-of-life care.
- 5.3 Support a person at the end of their life, and their family and carers, to understand the triggers and process for requesting an urgent review of care and how this will be provided.
- 5.4 Undertake a rapid healthcare review if a concern regarding unmet end-of-life care needs is raised.
- 5.5 Provide healthcare workers and the person and their family and carers with rapid access to specialist palliative care advice by agreed means.
- 5.6 Ensure a medical officer or nurse practitioner of sufficient authority to make decisions about stopping non-beneficial treatments is contactable when a rapid response to acute deterioration is required.
- 5.7 Avoid after-hours decisions to limit medical treatment or stop non-beneficial treatments, if possible. When after-hours decision-making is required because of a sudden or unexpected deterioration in the person's condition, a review by the healthcare worker responsible for coordinating care should occur as soon as possible.
- 5.8 Communicate critical information to the person responsible for care coordination in a detailed and structured way. This should include the outcomes of any call for assistance, and the plan for follow-up or further review of care options for the person at the end of their life.
- 5.9 Calls for assistance should be used as a teaching and mentoring opportunity for other healthcare workers and students when appropriate.



## Section B: Organisational processes

The essential elements 6–10 describe the organisational processes required for the effective delivery of safe and high-quality end-of-life care.

Healthcare services delivering care to people at the end of their life should recognise and prioritise this care.<sup>8</sup> This includes working with organisations or sectors to optimise care continuity and communication between different service providers particularly during transitions of care. Policies and systems need

to guide the actions of boards, executives, managers, healthcare workers and other employees, volunteers, and students, to ensure a consistent and responsive approach.



## Essential element 6: Leadership and governance

Healthcare services should use established systems and processes, as required by applicable standards, to deliver end-of-life care. A systematic approach and committed leadership are necessary to improve the experiences of someone at the end of their life. Cultural change may be required to prioritise end-of-life care in some healthcare settings. Approaches to managing eligible patients' access to voluntary assisted dying also need to be considered.

Qualified and skilled healthcare workers are required to provide safe and high-quality end-of-life care. Permanent positions can be more successful than time-limited roles. Ongoing learning and support should be provided. Healthcare services should also provide practical support to prevent moral injury and burnout of healthcare workers.

### Actions

- 6.1 Provide opportunities to people at the end of their life to partner with the healthcare service to support governance of end-of-life care.
- 6.2 Incorporate the development, implementation and ongoing review of systems for end-of-life care into governance frameworks and include processes for:
  - Appropriate delegation of responsibilities and accountability for decisions and actions
  - Representation of people at the end of their lives, families and carers, healthcare workers, managers and executives
  - Regular review of performance data, including interventions, education, and training, and advice on potential for improvements
  - Regular review of resource allocation, and advice on potential for improvements.
- 6.3 Implement a policy regarding end-of-life care that addresses:
  - Governance arrangements, including reporting requirements
  - The roles, responsibilities and accountabilities of healthcare workers providing end-of-life care
  - Provision of specialist services, when required
  - Processes for advance care planning and appropriate medical treatment
  - Processes or tools for identifying people at the end of their life
  - Alignment with systems for recognising and responding to deterioration
  - Access to specialist palliative care advice and services
  - Communication processes and tools

- Processes to ensure healthcare workers are not pressured to provide non-beneficial interventions
  - Processes to ensure clear transitions of care and communication between healthcare services
  - Cultural safety
  - Dispute resolution processes, including mediation, bioethics expertise and legal support, in situations of complex end-of-life decision-making or conflict
  - Training and education requirements for healthcare workers
  - Access to professional clinical supervision to suit the varied needs of healthcare workers
  - Access to formal and informal debriefing or counselling that includes strategies to mitigate moral injury and burnout of healthcare workers
  - Evaluation, audit and feedback processes.
- 6.4 Identify potential variations in the application of the end-of-life care policy that might exist in different circumstances (such as after hours).
- 6.5 Implement policies and processes that address advance care directives, organ and tissue donation, limitations of medical treatment, and end-of-life decision-making to ensure that the care delivered in response to deterioration is consistent with appropriate clinical practice and the person's expressed wishes.

### Considerations for Aboriginal and Torres Strait Islander peoples

Cultural safety creates an environment that is safe for Aboriginal and Torres Strait Islander people and aims to address institutional racism and discrimination. Cultural safety plans and policies for end-of-life care should be developed and reviewed in partnership with Aboriginal and Torres Strait Islander people, families and carers, other support people and other services.

### Cultural competence

Consideration of a family's needs should be individualised and culturally responsive. This requires an organisation-wide approach to planning, implementing and evaluating services for people from culturally and linguistically diverse backgrounds, including migrant and refugee communities.

To support cultural competence, a service or provider should:

- Value diversity
- Have the capacity for cultural self-assessment
- Be conscious of the dynamics that occur when cultures interact
- Improve cross-cultural knowledge
- Adapt service delivery so that it reflects an understanding of the diversity between and within cultures
- Support clinicians to provide culturally responsive care through provision of tools and resources (including time to become culturally competent).



## Essential element 7: Support, education and training

An educated and suitably skilled and qualified workforce is essential to providing appropriate end-of-life care.<sup>27</sup> All healthcare workers should have a shared understanding of the healthcare services terminology, policies, processes and practices. Education should include:

- Decision-making, capacity and consent
- **Shared decision making**
- Advance care planning
- Local referral and communication processes, and relevant legislation and other regulatory frameworks
- **Person-centred care**
- Disease-specific training as required – for example, in supporting people with dementia
- How to have conversations about end-of-life
- Inclusion and diversity
- Cultural safety.

Dealing with death and dying can be challenging for healthcare workers and can also affect other staff members such as administrative staff, food servers and cleaners. It can add considerably to workplace stress. Chronic unmanaged stress can erode empathy and potentially contribute to poorer experiences for people being provided end-of-life care.<sup>28</sup> It is important that systems are in place to facilitate access to peer support, mentoring and appropriate clinical supervision for healthcare workers and support staff.

The primary purpose of supervision systems should be to support members of multidisciplinary teams and other healthcare workers, and to prevent or resolve distress. These systems may also contribute to learning and the development of skills in the delivery of end-of-life care.

### Actions

- 7.1 Develop and maintain a policy that describes how supervision and support will be provided to healthcare workers who care for people at the end of their life.
- 7.2 Provide relevant education to all members of the workforce about recognising people at the end of their life and managing their care. Make sure education is provided at the commencement of employment and as part of regular professional development.



- 7.3** Ensure healthcare workers caring for people at the end of their life are provided with education and support to:
- Identify people approaching the end of their life
  - Initiate interventions to support safe and high-quality end-of-life care that is relevant to their scope of clinical practice
  - Support the cultural, spiritual and psychosocial needs of the person at the end of their life
  - Recognise disease-specific illness trajectories and changing care priorities, including limitations of medical treatment that are relevant to their scope of clinical practice
  - Understand the role of advance care planning
  - Understand substitute decision-making when providing care to people who are unable to make decisions for themselves
  - Understand shared and supported decision-making strategies
  - Understand end-of-life ethical and medico-legal issues, including the relevant professional ethical frameworks and the relevant legislation in the state or territory of practice, including:
    - refusal of treatment
    - withholding and withdrawing treatment
    - futile or non-beneficial treatment
    - voluntary assisted dying
  - Support provision of end-of-life care in an appropriate environment
  - Document and communicate effectively
  - Escalate concerns in a timely manner.
- 7.4** Encourage healthcare workers providing end-of-life care to participate and learn from discussions with people at the end of their life and their families, multidisciplinary case reviews, reviews of health records, mortality and morbidity meetings, and adverse event reviews.
- 7.5** Ensure healthcare workers are taught culturally safe approaches to providing end-of-life care to Aboriginal and Torres Strait Islander peoples and those from culturally and linguistically diverse groups, as well as appropriate approaches for people with disability, including dementia.
- 7.6** Offer ongoing formal training in communication skills to healthcare workers at all levels, as these skills are critical to the delivery of end-of-life care. Training may include specific skills, such as those offered by DonateLife on core and practical Family Donation Conversations.
- 7.7** Ensure healthcare workers providing end-of-life care are educated about how to recognise and develop strategies to cope with and resolve feelings of moral distress and burnout in themselves and their colleagues. Provide information and access to support services.
- 7.8** Encourage and support people at the end of their life to participate in providing personal stories about their experiences. These can be powerful tools for learning, and quality and system improvement.
- 7.9** Ensure healthcare workers know how to access peer support, mentoring and clinical supervision. Provide this information at the commencement of employment and as part of regular professional development. This may include accessing external services for clinical supervision, counselling or debriefing.
- 7.10** Support healthcare workers to develop skills in self-care, reflective learning and providing peer support to colleagues. Experienced healthcare workers may help develop the skills and capacity of other healthcare workers.



## Essential element 8: Care setting

The care setting is an important consideration for both a person at the end of their life and their family. When visiting care settings outside the home, family members may experience a lack of space and privacy, reporting feelings of 'being watched' and not being able to talk openly with their loved ones.<sup>7</sup> Access to private physical spaces for gatherings contributes to the quality of care offered at the end of a person's life. The provision of spaces for cultural practices such as family gatherings, chanting or other important rituals associated with end of life should be considered.

Where possible, make after-hours access available and support access to digital technology such as video calls.

### Actions

- 8.1 Build capacity for people to be cared for in their preferred place of death where possible – for example, at home or on Country. This could best be accomplished by healthcare services working together.
- 8.2 Establish systems to ensure that essential resources required for the provision of safe and high-quality end-of-life care are operational and available. Examples include private space for family meetings as well as appropriate equipment and medicines.
- 8.3 Establish systems and processes to support families to access care settings after hours and when other circumstances impact healthcare services, such as during a pandemic.
- 8.4 Ensure healthcare services can provide private physical spaces that meet the individual needs of the person at the end of their life, including spaces for families, and others that the person chooses, to gather.
- 8.5 Support families, loved ones and carers to access the person at any time during the last days of life – to the extent that the person wishes.



## Essential element 9: Evaluation, audit and feedback

All deaths where end-of-life care has been provided by a healthcare service should be routinely reviewed to determine the safety and quality of the person's end-of-life care and how care could be improved. Evaluation should not just assess the potential preventability of death.

### Actions

- 9.1 Collect, review and report data about the effectiveness of processes and systems for delivering end-of-life care.
- 9.2 Ensure processes exist for reporting data to inform governance and planning.
- 9.3 Develop monitoring and evaluation strategies that capture multidisciplinary feedback – and feedback from people receiving care – about the quality of end-of-life care.
- 9.4 Routinely use collected data for evaluation and monitoring processes, and support data linkage where possible. Ensure systems are simple, inexpensive, feasible and fit for purpose.
- 9.5 Ensure measures of the safety and quality of end-of-life care are ethically collected, accessed, used and stored with the following minimum data set:
  - De-identified demographics of people at end of life, including disaggregated Aboriginal and Torres Strait Islander data (where possible) to support directed improvement activity
  - Triggers used to identify that a person is approaching the end of their life
  - Assessment of documentation of shared decision making and the person's goals of care
  - Alignment of the person's goals of care with actual care
  - Effectiveness of the treatment of symptoms, including the use pain relief, and the management of secretions and agitation
  - Assessment of investigations and interventions in the final 48 hours of life
  - Evidence related to advance care directives or plans being documented or received, and enacted
  - Access of specialist palliative care services
  - Concordance with limitations of medical treatment and resuscitation plans
  - The category of death: expected, unexpected, diagnosis
  - The time lapse between recognition of end of life or referral to specialist palliative care and death
  - Transfers of care in the last week of life – for example, transfers to hospital from home, or from ward to intensive care
  - Bereavement support provided
  - Barriers and enablers identified by healthcare workers to provide safe and high-quality end-of-life care.

9.6 Methods for collecting data could include:

- Retrospective audit of case notes
- Review of medicines prescribed and administered
- Review of interventions and investigations
- Review of documentation of response to treatment (including medicines) for symptom management
- Follow-up with healthcare workers and other staff involved in the person's end-of-life care
- Feedback on experiences from substitute decision-makers, families and carers of people who received end-of-life care
- Data from mortality and morbidity review meetings.

9.7 Include audit and feedback in the quality improvement process for clinical improvement, education and service provision.

### Using data for improvement

Data from evaluation, audit and feedback can be used to improve performance of recognition and response systems<sup>1,2</sup> and ensure that systems are operating as planned.<sup>3-5</sup>

The [End-of-life audit toolkit](#) is available to assist services in auditing.

Involvement in relevant national palliative care and end-of-life care data collections can also aid in service planning.



## Essential element 10: Systems to support high-quality care

Organisations should consider opportunities to systematise the approach to end-of-life care where this will support best practice. End-of-life care should be integrated into existing organisational systems, and safety and quality systems to support sustainability and provide opportunities for organisational learning.

These systems should align with the requirements of the National Safety and Quality Health Service (NSQHS) Standards and the Primary and Community Healthcare Standards when applicable. Aligning systems for comprehensive care with those for end-of-life care, including those related to recognition and response to acute deterioration, will help to ensure that people at the end of their life receive coordinated, appropriate and effective care from their multidisciplinary team.

Digital platforms such as My Health Record may provide benefits by improving communication between care providers and improving continuity and coordination of care.

### Action

- 10.1 Provide systems that support healthcare workers to receive, prepare, review and update advance care plans and directives, according to the wishes of the person at the end of their life. Ensure these systems align with the [Clinical Governance Standard](#) and [Recognising and Responding to Acute Deterioration Standard](#), where these Standards apply.
- 10.2 Ensure systems appropriately identify essential palliative medicines and provide access to them for people at the end of their life for example provision for anticipatory prescribing. These systems should align with the [Medication Safety Standard](#), where applicable.
- 10.3 Enable systems to provide timely access to specialist palliative care clinicians, where required for people with complex palliative care needs or as a supportive resource for other healthcare workers. This may include off-site access via virtual health care.
- 10.4 Ensure technological systems are designed to improve the experience of the person at the end of their life and healthcare workers.
- 10.5 Implement processes to improve communication between healthcare services at transitions of care in relation to prognosis, advance care planning, treatment and medicines. Check these processes align with the [Communicating for Safety Standard](#), where applicable.
- 10.6 Ensure systems between healthcare services support safe, secure access and sharing of comprehensive care plans, advance care directives or plans developed in other settings.
- 10.7 Facilitate systems for accurate, efficient and appropriate documentation and data collection about end-of-life care.

# Glossary

Term	Description
<b>Actively dying</b>	The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks.
<b>Advance care directive<sup>29</sup></b>	<p>A voluntary, person-led document completed and signed by a competent person that focuses on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance care directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity.</p> <p>In some states, these are known as advance health directives.</p>
<b>Advance care plan<sup>29</sup></b>	A document that captures an individual's beliefs, values and preferences in relation to future care decisions, but which does not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).
<b>Advance care planning<sup>29</sup></b>	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require skills to facilitate these conversations effectively. The national quality standards for aged care, general practice and healthcare services all promote advance care planning. Individuals can also choose to engage in advance care planning with people who are not health practitioners, such as friends or family.
<b>Anticipatory prescribing</b>	When medicines are prescribed and dispensed in preparation for a time when a person needs them. They can be used to manage symptoms in the home, with the goals of rapid relief and avoidance of unplanned or unwarranted admission to a healthcare facility.
<b>Carer<sup>30</sup></b>	<p>A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal, chronic or mental illness), or because they are frail and aged.</p> <p>An individual is not a carer merely because they are the spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care.</p>
<b>Clinician<sup>30</sup></b>	A healthcare worker, trained as a health professional, including registered and non-registered practitioners. Clinicians may provide care within a healthcare service organisation as an employee, a contractor or a credentialed healthcare provider, or under other working arrangements. They include nurses, midwives, medical practitioners, allied health practitioners, pharmacists, technicians and others who provide health care, as well as students who provide health care under supervision.
<b>Cultural competence<sup>31</sup></b>	A set of congruent behaviours, attitudes and policies that come together in a system, agency or among healthcare workers to enable that system, agency or those professionals to work effectively in cross-cultural situations.

Term	Description
Cultural safety <sup>31</sup>	<p>Identifies that health consumers are safest when clinicians have considered power relations, cultural differences and patients' rights. Part of this process requires clinicians to examine their own realities, beliefs and attitudes. Cultural safety is defined not by the clinician but by the health consumer's experience – the individual's experience of the care they are given, and their ability to access services and to raise concerns. The essential features of cultural safety are:</p> <ul style="list-style-type: none"> <li>■ An understanding of one's culture</li> <li>■ An acknowledgement of difference, and a requirement that caregivers are actively mindful and respectful of difference(s)</li> <li>■ Informed by the theory of power relations – any attempt to depoliticise cultural safety is to miss the point</li> <li>■ An appreciation of the historical context of colonisation and how racism at individual and institutional levels has impacted, and continues to impact, First Nations people's lives and wellbeing</li> <li>■ That its presence or absence is determined by the experience of the recipient of care and not defined by the caregiver.</li> </ul>
Diversity <sup>32</sup>	<p>The varying social, economic and geographic circumstances of consumers who use, or may use, healthcare services, as well as their cultural backgrounds, disability status, religions, beliefs and practices, languages spoken, sexual orientation, gender identity and gender expression, and sex characteristics.</p>
End of life	<p>The period when a person is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown.</p> <p>This period may be years in the case of persons with chronic or malignant disease, or very brief in the case of persons who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.</p>
End-of-life care	<p>Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by healthcare workers. It also includes support of families and carers, and care of the patient's body after their death.</p> <p>People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:</p> <ul style="list-style-type: none"> <li>■ Advanced, progressive, incurable conditions</li> <li>■ General frailty and co-existing conditions that mean that they are expected to die within 12 months</li> <li>■ Existing conditions, if they are at risk of dying from a sudden acute crisis in their condition</li> <li>■ Life-threatening acute conditions caused by sudden catastrophic events.</li> </ul>
Family <sup>33</sup>	<p>The term family includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family.</p>
Frailty <sup>34</sup>	<p>A state of age-related deficits recognising the heterogeneity in health status of people as they age.</p>

Term	Description
<b>Goals of care</b> <sup>30</sup>	Clinical and other goals for a patient’s episode of care that are determined in the context of a shared decision making process.
<b>Healthcare service</b> <sup>32</sup>	A separately constituted organisation that is responsible for implementing clinical governance, administration and financial management of a service unit or service units providing health care to patients. It can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients’ homes, community and primary healthcare settings, practices and clinicians’ rooms.
<b>Healthcare worker</b>	A person working in health, community or aged care settings. This includes registered health practitioners, other health practitioners, carers. Support staff in these settings (such as those in administration or cleaning) are not considered healthcare workers in this consensus statement.
<b>Health literacy</b> <sup>30</sup>	The Australian Commission on Safety and Quality in Health Care separates health literacy into two components – individual health literacy and the health literacy environment. Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action. The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the healthcare system, which affect the ways in which consumers access, understand, appraise and apply health-related information and services.
<b>Limitations of medical treatment</b>	<p>Medical decisions that may be made to limit the treatments that are, or could be, provided when they will not benefit the person. A decision to not attempt cardiopulmonary resuscitation if a person suffers a cardiopulmonary arrest is one example of a limitation of medical treatment.</p> <p>Similar terms that are in common use include withdrawal or withholding of medical treatment.</p> <p>Decisions to limit medical treatment may avoid prolongation of dying but will not cause a person’s death.</p>
<b>Medicine</b> <sup>35</sup>	A chemical substance given with the intention of preventing, diagnosing, curing, controlling or alleviating disease, or otherwise improving the physical or mental wellbeing of people. These include prescription, non-prescription, investigational, clinical trial and complementary medicines, irrespective of how they are administered.
<b>Multidisciplinary team</b> <sup>30</sup>	Clinicians from multiple disciplines who work together to deliver comprehensive care that deals with as many of the patient’s health and other needs as possible. The team may operate under one organisational umbrella or may be from several organisations brought together as a unique team. As a patient’s condition changes, the composition of the team may change to reflect the changing clinical and psychosocial needs of the patient. Multidisciplinary care includes interdisciplinary care. (A discipline is a branch of knowledge within the health system.)
<b>Non-beneficial treatment</b>	Interventions that will not be effective in treating a person’s medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medicines, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Non-beneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.



Term	Description
<b>Palliative approach/ palliative care</b>	An approach to treatment that improves the quality of life of people and their families facing life-limiting illness by preventing and relieving suffering. It involves early identification, and assessment and treatment of pain and other problems (physical, psychosocial, and spiritual).
<b>Person-centred care<sup>30</sup></b>	An approach to the planning, delivery and evaluation of health care that is founded on mutually beneficial partnerships among clinicians and patients. Person-centred care is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Key dimensions of person-centred care include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of carers and family, and access to care. Also known as patient-centred care or consumer-centred care.
<b>Resuscitation orders/plans</b>	<p>Documents completed by a medical officer to outline the plan of care in relation to emergency treatment of severe clinical deterioration.</p> <p>Not for resuscitation and do not attempt resuscitation orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the person has a cardiac or respiratory arrest. In some organisations, decisions about other specific limitations of medical treatment may also be listed as part of a resuscitation plan (for example, decisions to call a medical emergency team or transfer a person to intensive care if they deteriorate).</p>
<b>Specialist palliative care</b>	Services provided by healthcare workers who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to persons with complex palliative care needs, and providing consultation services to support, advise and educate non specialist healthcare workers who are providing palliative care.
<b>Shared decision making<sup>30</sup></b>	A discussion and collaboration between a person and their healthcare worker that brings together the person's values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, in order to reach the most appropriate healthcare decisions for that person.
<b>Supported decision-making<sup>32</sup></b>	Enables a person with cognitive impairment to remain involved in decisions about their health care rather than having their decision-making capacity removed.
<b>Voluntary assisted dying<sup>36</sup></b>	<p>Voluntary assisted dying (VAD) is the assistance provided by a health practitioner to a person with a terminal disease, illness or medical condition to end their life. It includes:</p> <ul style="list-style-type: none"> <li>■ Self-administration, where the person takes the VAD medication themselves and</li> <li>■ Practitioner administration, where the person is given the medication by a health practitioner.</li> </ul>

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