

national consensus statement:
essential elements for
safe and high-quality
end-of-life care

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introduction

The health care that people receive in the last years, months and weeks of their lives can help to minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers. The purpose of this *National Consensus Statement: essential elements for safe and high-quality end-of-life care* (the Consensus Statement) is to describe the elements that are essential for delivering safe and high-quality end-of-life care in Australia. The Consensus Statement sets out suggested practice for the provision of end-of-life care in settings where acute care is provided. Clinicians, health service executives and managers, policy-makers, educators and training providers can use the principles and elements of the Consensus Statement as a guide to improving the safety and quality of end-of-life care.

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

application

The Consensus Statement aligns with the National Safety and Quality Health Service (NSQHS) Standards, but provides recommended, rather than mandatory, practice. It also aligns with the *National Consensus Statement: essential elements for recognising and responding to clinical deterioration*, and it is intended that these documents be applied together.

Health services will need to develop their own systems to address the guiding principles and elements in the Consensus Statement, so that they deliver safe, timely and high-quality end-of-life care. These systems will need to be tailored to the setting, the needs of the population, and available resources and personnel, while being in line with relevant state and territory or other programs. Systems, processes and structures for delivering safe and high-quality end-of-life care should

also work in synergy with local processes for recognising and responding to clinical deterioration.

Effective communication and coordination of care with community care providers are critical considerations when planning and implementing systems to address the elements of the Consensus Statement. Acute health services should consider how to work collaboratively with partners – such as residential aged care facilities, specialist palliative care services, general practitioners and social care agencies – to maximise the opportunity for patients to be cared for and die in their preferred place, and to optimise the coordination and delivery of end-of-life care.

Some actions within the Consensus Statement are currently aspirational. It is likely to take time for health services to develop and implement systems that enable care to be consistently delivered in accordance with all the principles and elements outlined in this document.


The actions in the Consensus Statement may need to be applied repeatedly for some patients. The process of dying is not always straightforward, and it is likely that aspects of care will need to be revisited as a patient's condition changes. For example, the patient's preferred place of care, and their psychosocial, cultural and spiritual care needs may change over time, and must therefore be repeatedly assessed.

scope

The Consensus Statement relates to situations where end-of-life care is indicated for adults who are clearly approaching the end of their lives.

It may be particularly appropriate to apply the elements of the Consensus Statement at two particular times near the end of life:

- when a patient is likely to die in the medium term (i.e. within the next 12 months), but episodes of acute clinical deterioration or exacerbation of the underlying illness may be reversible
- when a patient is likely to die in the short term (i.e. within days to weeks, or during the current admission) and any clinical deterioration is likely to be irreversible.



Some elements of the Consensus Statement may only be relevant at particular points in time, whereas others are applicable across the whole patient journey. For example, some aspects of advance care planning may no longer be as relevant when a patient is imminently dying, whereas good symptom control remains relevant during terminal care as well as for quality of life over the longer term.

The Consensus Statement is generally targeted at acute health services, including intensive care and the emergency department. It applies in all types of public and private acute hospitals, from large tertiary hospitals to small district and community hospitals. The principles and elements of the Consensus Statement also apply to situations where patients who are deteriorating are being cared for in other settings – for example, in remote clinics, specialist outpatient clinics, hospital-in-the-home services or aged care facilities. Such services may need to be networked to larger health services to facilitate the delivery of end-of-life care that aligns with the principles and elements of the Consensus Statement.

When death occurs quickly as a result of sudden and unexpected events, such as acute illness or trauma, care can and should be aligned with the Consensus Statement. However, some actions in the Consensus Statement may not be appropriate or possible in these circumstances.

Although the scope of the Consensus Statement is limited to the care of adults, many of the principles and actions may also be relevant for children at the end of their lives.

The Consensus Statement may not apply to situations where a patient's treatment is being led by a specialist palliative care doctor or team. Palliative Care Australia developed the *Standards for providing quality palliative care for all Australians* to support the delivery of high-quality, patient-centred end-of-life care in specialist palliative care services. Both the Consensus Statement and these standards are relevant when considering how to develop systems that foster a collaborative approach between acute and specialist palliative care services.

intended audience

The Consensus Statement has been developed for:

- clinicians who are involved in the provision of acute health care
- health service executives and managers who are responsible for developing, implementing and reviewing systems for delivering patient care, including end-of-life care, in individual health services or groups of health services
- providers of clinical education and training, 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, or other strategic programs dealing with the delivery of end-of-life care.

Disclaimer

The Consensus Statement describes suggested practice for the provision of end-of-life care in settings where acute care is provided. It is a guiding document designed to inform clinicians and others of *recommended* practice. It is not a legal document, and clinicians must continue to be aware of, and abide by, the laws of the jurisdiction in which they practise. Any inconsistency between the Consensus Statement and a law of a state, a territory or the Commonwealth will be resolved in favour of the relevant law.

Appendix A lists common terms and their meaning in the context of the Consensus Statement.

Appendix B lists documents that contributed to the development of the Consensus Statement.

In 2014, the Commission undertook a consultation process about the Consensus Statement. A summary of this process is in **Appendix C**.

guiding principles

1. Dying is a normal part of life and a human experience, not just a biological or medical event.
2. Patients must be empowered to direct their own care, whenever possible. A patient's needs, goals and wishes at the end of life may change over time.
3. Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs.
4. Recognising when a patient is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care.
5. The prognosis and the way that people respond to medical treatment will vary between individuals. This means that there is potential for ambiguity and uncertainty at the end of life. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers.
6. Safe and high-quality end-of-life care is patient and family-centred. Whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers. Such care should consider the patient's expressed wishes regarding the circumstances, environment and place in which they wish to die.
7. Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.
8. Safe and high-quality end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care.
9. Care of the dying is urgent care. Timely recognition of a patient's transition to the terminal phase of life must be documented and communicated to patients, families, carers and other health professionals by the interdisciplinary team. The care plan must be specifically revised to meet the unique needs of the patient, family and carers during this phase.
10. End-of-life decision-making should be shared between the interdisciplinary team and the patient. Substitute decision-makers, families and carers should be involved, in accordance with the patient's expressed wishes and/or jurisdictional legislation.

11. The interdisciplinary team has a responsibility to:

- provide timely and accurate information regarding the patient's clinical condition and its severity or stage, the expected disease trajectory, the available treatments, and the likelihood of response to such treatments
- clearly communicate information to support patients (or substitute decision-makers, families and carers) to make decisions about care, and to check that they understand the implications, consequences and risks associated with such decisions
- invite patients to participate in the process of advance care planning, and create opportunities for patients to make decisions and to communicate their values, goals and wishes regarding their end-of-life care
- offer support, expert opinion and advice so that patients (or substitute decision-makers, families and carers) can participate in fully informed, shared (or supported) decision-making
- identify existing advance care plans and provide care in accordance with the patient's expressed wishes
- document, communicate and hand over the agreed plan of care and any limitations of medical treatment to other clinicians involved in the patient's care.

12. For ethical reasons, it is important not to harm patients approaching the end of life by providing burdensome investigations and treatments that can be of no benefit.

13. Patients have the right to refuse medical treatments. Decisions regarding treatment may be made in advance and remain valid unless the patient (or substitute decision-maker, family and carers) state otherwise.

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

15. Care of the deceased person, and care for families and carers extends to the period after the patient has died.

essential elements

The essential elements of this Consensus Statement are the features that are required in systems to ensure safe and high-quality care for patients who are approaching the end of life. These elements do not prescribe how care should be delivered. Application of the elements will vary according to the local circumstances of the health service, the available resources, and the individual needs and preferences of the patient receiving care. Health services need to have systems in place to address all the elements.

This Consensus Statement contains 10 essential elements. Elements 1–5 relate to the way in which end-of-life care should be approached and delivered. Elements 6–10 relate to structural and organisational prerequisites for the effective delivery of safe and high-quality end-of-life care.

The following sections provide information about each element. Each section begins with a brief introductory statement, which is followed by a list of actions that describe the necessary processes and systems to effectively address the element.

Figure 1 provides an overview of the essential elements and how they fit together within the Consensus Statement. Figure 2 illustrates the type of end-of-life care interventions that might be needed as a patient approaches the end of life. These interventions are built into the actions in the Consensus Statement.

essential elements

a. processes of care

1. Patient-centred communication and shared decision-making
 2. Teamwork and coordination of care
 3. Components of care
 4. Use of triggers to recognise patients approaching the end of life
 5. Response to concerns
-

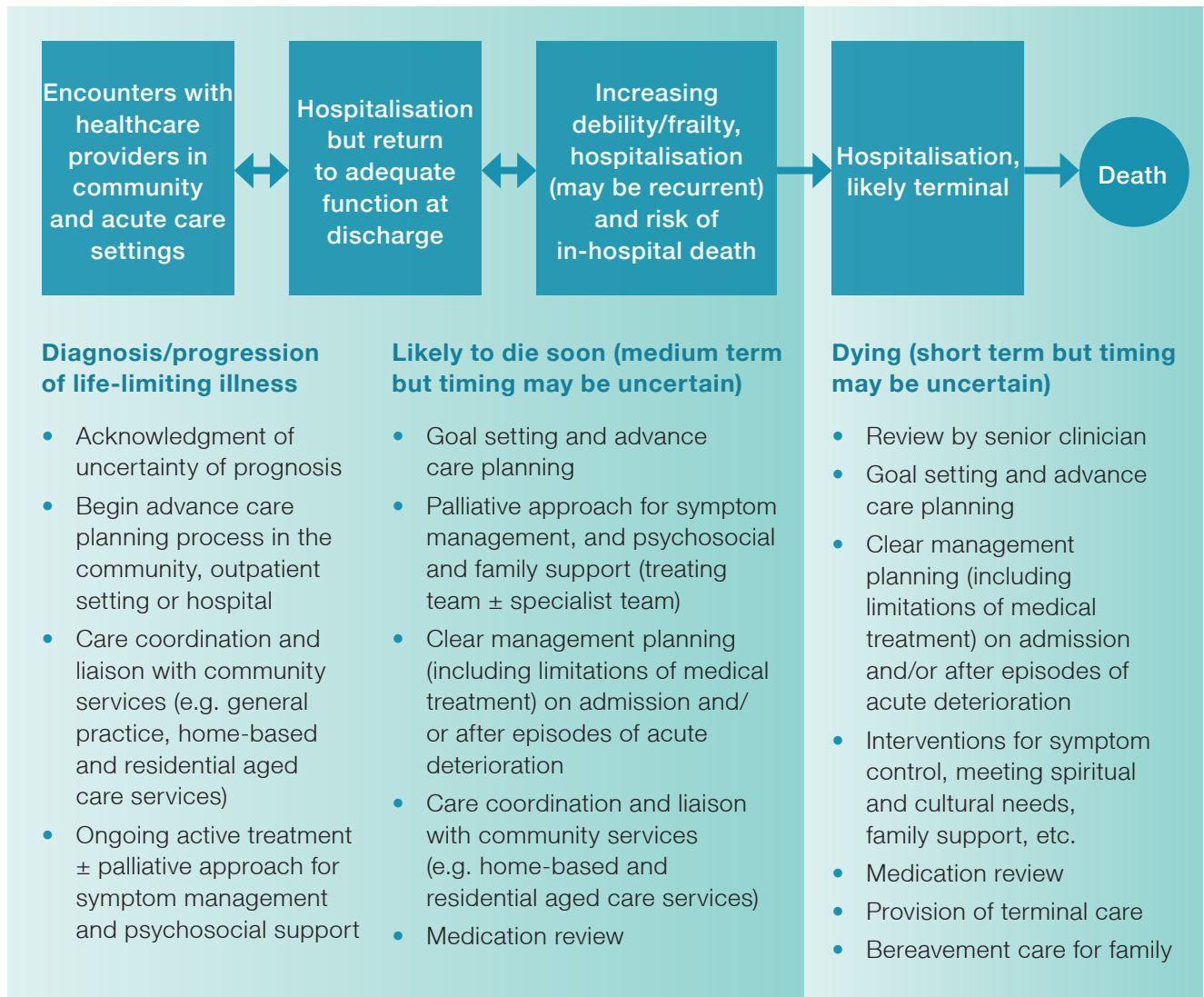
b. organisational prerequisites

6. Leadership and governance
7. Education and training
8. Supervision and support for interdisciplinary team members
9. Evaluation, audit and feedback
10. Systems to support high-quality care

Figure 1: Overview of the 10 essential elements in the Consensus Statement



Figure 2: End-of-life care interventions



part a

processes of care

1. patient-centred communication and shared decision-making

It's when [clinicians] see that they're very much in partnership with the patient and they're prepared to risk themselves to get alongside the patient. Giving the patient lots of time; being empathetic; being prepared to recognise that the patient has got a whole lot of other things going on as well as their disease.

Consumer

key points

- The patient and the interdisciplinary team are both essential participants in discussions and decision-making at the end of life. Substitute decision-makers, families and carers should be included, according to the patient's expressed wishes, and state or territory legislative frameworks.
- All communication processes should recognise and be responsive to the individual preferences and needs of patients, families, carers and substitute decision-makers.
- Having conversations about death, dying and the end of life requires compassion, knowledge, experience, sensitivity and skill on the part of the clinician(s) involved.
- A series of conversations may be needed to elicit the goals, values and wishes of a patient, and reach shared decisions about the appropriate plan for their care.

This essential element primarily relates to the process of clinicians communicating with patients, substitute decision-makers, families and carers to make decisions about care at the end of life. Depending on the needs and wishes of the patient, other members of the interdisciplinary team may also need to be involved in these discussions.

A number of significant events might indicate that conversations about end-of-life care should occur. In an acute health service, these include events when:

- a patient (or substitute decision-maker, carer or family member, if the patient lacks capacity) expresses interest in discussing end-of-life care
- a life-limiting condition is diagnosed
- a patient who is likely to die in the short or medium term is admitted, or deteriorates during their admission
- a patient living with a life-limiting illness has had recurrent, unplanned, recent admissions
- a previously well person who has suffered an acute life-threatening event or illness is admitted
- unexpected, significant physical deterioration occurs
- a patient is dying.

The purpose of conversations about end-of-life care will depend on the circumstances of the patient. In some cases, the primary purpose of communicating with patients, and their families and carers will be to impart information. In other cases, decisions about specific aspects of care, including care of the dying, may need to be made. Regardless of the purpose of the conversation, there is opportunity to begin or continue the process of shared decision-making.

Shared decision-making is a critical part of making sure that patients approaching the end of their lives are partners in their own care. Shared decision-making is more than just providing information to patients and their families, or asking them questions to inform a clinically driven decision. It is a process that allows patients, substitute decision-makers, families and interdisciplinary teams to work together to make decisions in the patient's best interests, based on the best scientific evidence available, the realities of the patient's clinical condition and treatment options, and the patient's choices, values and preferences. Doctors, nurses and other involved clinicians should use their clinical skills and experience, and their knowledge of the patient's values and preferences to make recommendations that inform the decision-making process.

Maximising the input and voice of patients is an obligation for all clinicians. However, some patients – such as those with cognitive or intellectual impairment, or severe mental illness – may not be able to participate fully in decision-making, and the capacity of patients to participate in decision-making may fluctuate. Supported decision-making may be necessary for such patients. Supported decision-making means that clinicians assess the patient's decision-making capacity and maximise opportunities for participation by patients with impaired capacity. This might mean deferring decisions until the patient is more able to participate – for example, until treatable causes of impaired decision-making, such as depression or delirium, are ameliorated. Where this is not possible, clinicians should work with carers and families to support patients to be as involved in decision-making as their capacity at the time will allow.

When opportunities for shared or supported decision-making are limited or impossible – for example, because the patient is dying suddenly and unexpectedly – clinicians should check that the patient, substitute decision-maker, family and carers have a shared understanding of what has been discussed and the subsequent plan of care.

actions

- 1.1 Clinicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions, to increase the likelihood of delivering high-quality end-of-life care aligned with the patient's values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations.
- 1.2 The clinical team should work with the patient, family and carers to identify the substitute decision-maker, family spokesperson or other key contacts that the patient wishes to be involved in discussions about their care.
- 1.3 In some cultures, mainstream assumptions about death and dying, and about patients and families as decision-makers may not be correct. Culturally appropriate decision-maker(s) should be identified as early as possible so that strategies can be put in place for obtaining their input into discussions about end-of-life care.
- 1.4 Clinicians should seek to understand, and be respectful, sensitive and responsive to, the individual preferences and needs of all patients, substitute decision-makers, families and carers, regardless of aspects of identity such as culture, religious belief, gender or sexual preference.

- 1.5 Whenever possible, clinicians should prepare for having conversations about end-of-life care. Necessary preparation may include:
- reaching consensus among all of the clinical teams involved in the patient's care about the patient's prognosis and what treatment options are appropriate to recommend
 - ensuring familiarity with the patient's history and current condition (this may include discussion with key community care providers), their family structure, and cultural needs and preferences
 - arranging adequate time for uninterrupted discussion
 - ensuring that patients have access to their regular communication aids
 - arranging for the appropriate people to be in attendance – ideally, this will include the patient; their substitute decision-maker, carers and family members; the most senior doctor available; the nurse responsible for the patient's care; and other members of the interdisciplinary team, such as interpreters, Aboriginal support workers, chaplains or social workers
 - ensuring that discussions can be held in an appropriately quiet and private environment.
- 1.6 The patient, substitute decision-maker, family and carers should be provided with written information about which clinician is responsible for leading and coordinating their care. Whenever possible, this clinician should be directly involved in discussions about the patient's end-of-life care.
- 1.7 Whenever possible, clinicians should work with patients, families and carers to ensure that key family members, substitute decision-makers and carers are present during end-of-life discussions. This will ensure that consistent messages are given about treatment options, their likelihood of success, risks and prognosis. This is particularly important when patients are in the process of transition to the terminal phase, as conflict and uncertainty among family and carers can result in avoidable suffering.
- 1.8 Clinicians should provide an honest and straightforward summary of their clinical assessment of the situation, what they consider to be appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the patient's condition improving in response to such treatment. Clinicians should be compassionate and sensitive, use plain language, and avoid the use of medical jargon.
- 1.9 Clinicians should express empathy for the patient's situation. They should allow adequate time for those involved to absorb, process and react to the information they are being given. Multiple discussions may be required.
- 1.10 End-of-life discussions should routinely include the provision of information about organ and tissue donation for transplantation, in circumstances where donation is possible. These discussions should be conducted with advice from the state or territory DonateLife agency and should preferably be led by clinicians who have attended the core Family Donation Conversation workshop.
- 1.11 Clinicians should check that patients, families and carers have been provided with sufficient support to make decisions. This includes support for patients, substitute decision-makers, families and carers who have communication difficulties associated with cultural and linguistic diversity, or decision-making difficulties associated with disability, mental illness or cognitive impairment.
- 1.12 Clinicians should clearly document the content of the discussion and any agreed plan of care in the patient clinical record. Any unresolved issues that require further follow-up should also be documented, along with a plan for follow-up.
- 1.13 The content of the discussion and plan of care, including any limitations of medical treatment, should be communicated to all teams involved in the patient's care, including relevant community care providers.

2. teamwork and coordination of care

To be able to plan appropriate death as you would plan appropriate discharge at a multidisciplinary level, that would be good.

Nurse – public hospital focus group

key points

- For a patient's end-of-life preferences and needs to be fulfilled, members of the healthcare team(s) who are involved in their care need to work together effectively.
- The healthcare team includes the interdisciplinary team in the health service; the patient and their substitute decision-maker, family and carers; and community care providers, such as those working in community and residential aged care facilities, and general practices.
- Processes should be in place to support care coordination and continuity, particularly at the interface between different services and teams (e.g. between the hospital and community-based services, or between the treating team and after-hours care providers).

Patients often receive care from a range of organisations with different systems, roles and approaches to managing end-of-life care. Interdisciplinary teams include individuals with varied experience, values and perspectives on planning and providing end-of-life care. Unless an identified person takes overall responsibility for coordinating a patient's care, and ensuring effective communication and collaboration, patients can receive discordant information and poorly coordinated care.

The interdisciplinary team should respect and use each other's expertise, and that of the patient, substitute decision-maker, family and carers. For effective teamwork, roles and responsibilities need to be clear, and processes need to be in place for the organisation and exchange of information.

The patient's goals of care and the treatment plan need to be clear to all members of the interdisciplinary team, so that care can be effectively coordinated. This includes ensuring effective communication and liaison with care providers in the community, such as general practitioners, nurse practitioners, community nursing services, Aboriginal health services, home care workers, and managers of community and residential aged care facilities.

actions

- 2.1 The clinician with overall responsibility for leading and coordinating a patient's care must be clearly identified. If the patient is unable to speak for themselves, their substitute decision-maker must also be clearly identified.
- 2.2 The roles and responsibilities of different team members should be clearly defined and understood by all those involved in a patient's care, including the patient themselves, and their substitute decision-maker, family and carers.
- 2.3 If there is disagreement or ambiguity about the appropriate options for future treatment among members of the healthcare team(s), the range of views and the reasons for them should be discussed with the patient, substitute decision-maker, family and carers.
- 2.4 Appropriate processes should be in place to enable all team members, including junior clinicians, to engage with the broader team, voice concerns, and act on the expressed preferences and consent of the patient.
- 2.5 Experienced team members are responsible for providing supervision, leadership, support, mentorship and teaching to develop the skills and capacity of junior team members in relation to end-of-life care.

3. components of care

You have to have a system in place for recognising that people are dying. You have to have a system in place for negotiating goals of care. You need to have in place advance care planning processes, and you need to ensure that you've got clinical processes in place for pain and symptom management, and care of the family. They're the very basic things that everybody should be entitled to.

National manager of palliative care – private hospital network

key points

- All patients have a right to maintain their dignity, comfort and privacy, and to be cared for respectfully and with compassion.
- End-of-life care is every clinician's responsibility.
- Processes should be in place to support proactive, anticipatory and individualised planning for end-of-life care.
- Active medical treatments and end-of-life care are not mutually exclusive. Many patients may benefit from an approach in which medical treatments for their disease are provided in conjunction with palliative interventions to improve or maintain the best possible quality of life, and provide symptom relief.

The goal of the interdisciplinary team providing end-of-life care should be to deliver care that is appropriate to the needs and condition of the patient, and aligned with their expressed wishes. Opportunities should be sought to identify the patient's goals and wishes for their future care; offer psychosocial, spiritual, cultural and emotional support; provide treatments that maintain or improve quality of life; and avoid unnecessarily burdensome or unwanted investigations and treatments.

Patients have the right to refuse medical treatment. These decisions may or may not be recorded in an advance care plan or directive.

Doctors are under no obligation to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the patient's quality of life. Specific medical decisions about what treatments would be provided in the event of critical deterioration may be recorded in resuscitation plans.

For many patients approaching the end of life, there will be a long period of transition when treatment will continue for reversible complications or reversible episodes of clinical deterioration. Patients at this stage may benefit from a palliative approach, in conjunction with active medical treatment of their illness. This kind of dual care can provide support and improve symptom management, and therefore help patients to maintain their quality of life.

When a patient enters the terminal phase of their illness, some treatments will cease to provide benefit, and will become uncomfortable and burdensome. For patients in the terminal phase of illness, the plan of care should generally focus on providing comfort to both the dying patient and their family and carers. The plan for a patient's terminal care should be clearly documented, including plans for managing physical, psychosocial, emotional, cultural or spiritual distress.

actions

- 3.1 The psychosocial, cultural and spiritual needs of patients, families and carers should be assessed, and care should be provided in accordance with their wishes, values and needs. Support should be offered for patients, carers and families who wish to include cultural or religious practices in their care, such as particular foods, singing, ceremonies or healing.
- 3.2 Patients who are likely to die within the short or medium term should be informed about the process and purpose of advance care planning, and asked if they would like to instigate or revisit their advance care plan.
- 3.3 As part of the advance care planning process, clinicians should ask about, and document, a patient's wishes in regard to donation of their organs and tissues for clinical use or research purposes after death, where this is clinically appropriate.
- 3.4 Unnecessary burdens associated with medical treatment should be avoided for dying patients. For example, nonbeneficial and/or unwanted observations, surgical interventions, investigations, medications and treatments should not be prescribed or administered. Where a clinician feels pressured – by the patient, family, carer or another health professional – to provide such interventions, they should seek advice and support from an experienced colleague who is able to assist with a second opinion and sensitive discussion.
- 3.5 The goals of care, the treatment plan and any limitations of medical treatment for the current admission should be appropriately discussed with the patient, and their substitute decision-maker, family and carers, and clearly documented in the patient clinical record by the treating medical officer or team. This should occur as early as possible in the patient's admission to the health service, and the information should be routinely reviewed and updated throughout the admission.
- 3.6 The rationale for medical decisions to discontinue or withhold nonbeneficial observations, investigations or treatments should be clearly communicated with the patient, family and carers.
- 3.7 The goals of care, treatment plan and any limitations of medical treatment should be revisited with the patient, substitute decision-maker, family and carers when significant changes in the patient's condition or circumstances occur – for example, when the patient is in transition to the terminal phase. The patient, substitute decision-maker, family and carers should be empowered to request further discussion and a review of the plan at any time.
- 3.8 Information about the advance care plan, clinical treatment plan, goals of care, any limitations of medical treatment and the patient's treatment preferences should be readily available to all clinicians involved in the patient's care, including those involved in caring for the patient in emergencies, after hours and, where relevant, in the community.

- 3.9 The patient, family and carers should not feel abandoned by the healthcare team, or fear that care will be stopped or reduced, when the goals of care shift from cure to comfort because the patient is dying. Care, compassion, open and honest communication about what to expect, and the comfort of the dying patient remain priorities.
- 3.10 All patients, including people with chronic or severe mental illness, intellectual disability or cognitive impairment, have the right to adequate pain relief and symptom control, and to the prevention and relief of suffering. Physical symptoms should be managed in alignment with the patient's wishes, and treatment reviewed regularly. If communication problems make it difficult to ascertain the patient's wishes or needs, it is important to seek advice from, and consult with, families and carers.
- 3.11 Dying patients should be supported to receive oral food and fluids for as long as they wish.
- 3.12 Family and carers should be supported to spend time with a dying patient in accordance with their wishes, including in the period immediately after death.
- 3.13 Bereaved family and carers should be provided with written information about how to access bereavement support when they have left the health service.
- 3.14 Clinicians should explore and discuss alternatives to hospital-based care, when possible and appropriate, and as preferred by the patient. If feasible, this could include the patient's usual residence, a local hospital, a community or residential aged care facility, or a hospice or other palliative care facility.
- 3.15 Clinicians should liaise with other relevant services and provide referral, as necessary – for example, to specialist inpatient or community palliative care services.

4. use of triggers to recognise patients approaching the end of life

It takes a lot of skill sometimes to recognise when somebody is dying.

Intensive care liaison nurse – public hospital focus group

key points

- Recognition systems in acute health services should aim to identify patients at two critical points:
 - when a patient is likely to die in the medium term (i.e. within the next 12 months), but episodes of acute clinical deterioration may be reversible
 - when a patient is likely to die in the short term (i.e. within days to weeks, or during the current admission) and clinical deterioration is likely to be irreversible.

A fundamental first step in providing safe and high-quality end-of-life care is to recognise those patients who would be likely to benefit from such care. Considering the likelihood of a patient dying offers opportunities to identify their needs, review the goals and plan of care, and consider how best to align care with the individual's expressed values, goals and wishes. Routine use of simple trigger tools and questions can prompt clinicians to use their clinical judgment to make a holistic assessment of whether a patient might benefit from end-of-life care.

Predicting prognosis and the timing of dying can be difficult. For some patients, it may be difficult to distinguish clinical deterioration that is reversible from deterioration that is irreversible and 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 reversibility of a patient's deterioration.

Clinicians should be aware of the referral criteria, processes and timelines for accessing specialist palliative care services.

actions

- 4.1 The 'surprise' question should be used by clinicians as a simple screening mechanism to recognise patients who could benefit from end-of-life care interventions. Clinicians should ask themselves:
- Would you be surprised if this patient died in the next 12 months?
 - Would you be surprised if this patient died during this admission, or in the next days or weeks?
- 4.2 A critically important trigger for assessment, discussion and consideration of referral to specialist palliative care is when the patient, family members, carers or other members of the interdisciplinary team request palliative care, or express concern or worry that the patient is dying or has unmet end-of-life care needs.
- 4.3 Clinicians should consider other useful triggers for recognition and review of patients who may benefit from end-of-life care interventions. Such triggers might be derived from condition-specific mortality risk prediction tools or from critical events, such as:
- diagnosis of life-limiting conditions
 - poor or incomplete response to medical treatment, continued deterioration despite medical treatment, and/or development of new clinical problems during inpatient admission
 - repeated calls to the rapid response team, particularly if the patient has been admitted for more than one week
 - advanced age with increased frailty, reduced mobility and increased dependence on others to assist in performing activities of daily living
 - moderate to severe dementia
 - multisystem comorbidities (cardiovascular, pulmonary, endocrine, etc.)
 - maximal medical therapies already in place
 - decline in the patient's condition, or a clinical determination that they will not benefit from interventions such as surgery, dialysis or treatment in intensive care
 - multiple recent admissions to hospital for exacerbation of a chronic condition
 - unexpected or inappropriately prolonged stays in hospital.

5. response to concerns

As physicians, we are about investigating and treating ... It's a bit of a mind switch, that what you are doing is actually harmful and hurting rather than helping.

Doctor – public hospital focus group

Where do you go for help when [dying] is not being recognised? When there is a group of carers saying 'No, we shouldn't be escalating care here'. Where do you go in the hospital when there is conflict among healthcare workers about the level of care appropriate for an individual?

Intensive care liaison nurse – public hospital

key points

- It should be as easy to access support for the provision of appropriate end-of-life care as it is to escalate care for reversible deterioration.
- A patient in physical, psychosocial or spiritual distress requires rapid assistance from a suitably skilled care provider. The prevention and relief of suffering is of paramount importance.
- When responding to concerns that end-of-life care needs are not being adequately recognised or addressed, responders may require access to a second opinion from an independent senior clinician (possibly from a separate health service).
- When managing conflict, complex family dynamics or ethical dilemmas, responders may require access to a person who is skilled in mediation, the rights of the person, bioethics and/or the law.

When concerns are raised about a patient approaching the end of life who is in distress, has a complex condition or difficult-to-manage symptoms, or when end-of-life decision-making is particularly complex, it is important that timely and appropriate assistance can be obtained from a suitably skilled clinician or team. The nature and timing of the response may depend on the nature of the issue causing concern and the person who has raised the concern. For example, a different response may be needed for concerns raised by a family member about a patient's physical pain or distress from the response required to resolve conflict or an ethical dilemma.

The initial response to concerns about end-of-life care issues may be provided by a member of the clinical team, such as the senior registrar or consultant, or by a member of another team, such as an after-hours medical registrar or specialist palliative care clinician. In some health services, such as small rural hospitals, responding to concerns may require access to external clinicians (e.g. general practitioners) or the use of technology (e.g. videoconferencing) to access off-site help, such as intensive care or specialist palliative care. Public advocates may also be a useful source of assistance in cases involving conflict about what is in the best interest of the patient.

actions

- 5.1 The criteria and processes for accessing help for end-of-life issues that are causing concern should be clearly defined in relevant policies and procedures.
- 5.2 The patient, substitute decision-maker, family and carers should understand the triggers and process for requesting an urgent review, and the process for responding to their request.
- 5.3 Processes should be in place to enable patients, substitute decision-makers, families, carers and members of the interdisciplinary team to escalate concern until a satisfactory resolution is achieved. This should include access to a second opinion if there are concerns that end-of-life care needs are not being adequately recognised or addressed by the clinical team.
- 5.4 Concern or worry that a patient is dying or approaching the end of their life and has unmet end-of-life care needs should prompt interdisciplinary review of the goals of care and the treatment plan, leading to appropriate recommendations for follow-up and ongoing communication. This applies regardless of whether the concern is raised by the patient; their substitute decision-maker, family or carers; or a clinician.
- 5.5 Clinicians should have rapid access to specialist palliative care advice 24 hours a day and 7 days a week. This may include access by telephone or videoconference.
- 5.6 To avoid after-hours decisions to limit medical treatment or stop nonbeneficial treatments, pre-emptive planning should be undertaken by the team with overall responsibility for the patient's care. When after-hours decision-making is required as a result of sudden or unexpected deterioration in the patient's condition, the patient should be followed up by the responsible team as soon as possible.
- 5.7 The responder(s) providing assistance in emergency situations should have access to support from a clinician of sufficient authority to make decisions about stopping nonbeneficial treatments and providing palliative care.
- 5.8 Responders should document in the health care record appropriate, detailed and structured information about the outcomes of the call for assistance, discussions with the patient and/or substitute decision-maker, and the plan for follow-up or further review of the patient.
- 5.9 If the responder is not part of the clinical team, they should communicate with the responsible medical officer in an appropriate, detailed and structured way about the outcomes of the call for assistance, and the plan for follow-up or further review of the patient.
- 5.10 Although resolving the concerns of the patient, carers or family should be the first priority, whenever possible, responders providing assistance should also use calls for assistance as a teaching and mentoring opportunity for other clinicians and students.

part b

organisational prerequisites

6. leadership and governance

I think there has to be a consensus view driven through clinical governance as to the approach. The only way you're going to drive change is to have an agreed approach. In our organisation, that can only be through clinical governance.

Surgeon – public hospital focus group

I think [there] needs to be responsibility from that higher level to say 'this hospital supports care of the dying'.

Nurse – public hospital focus group

key points

- End-of-life care should be included in the governance system for the organisation.
- Safety and quality of end-of-life care, including care provided in the terminal phase, should be monitored by the executive level of governance in the organisation.
- Leadership at all levels in the organisation is required for safe and high-quality end-of-life care.

For many organisations, significant cultural change will be necessary to develop successful and sustainable systems for delivering safe and high-quality end-of-life care, and to effect improvements in the experiences of patients, families and carers. To achieve this, a systematic approach and committed leadership are necessary. Executive and clinical leaders at all levels of the organisation's clinical and corporate governance structures should provide proactive and practical support to the interdisciplinary teams and managers who are responsible for delivering end-of-life care.

Health services should ensure that the governance of systems for the delivery of end-of-life care aligns with NSQHS Standard 1 (Governance for safety and quality in health service organisations) and Standard 2 (Partnering with consumers).

actions

- 6.1 Patients, and their families and carers should be partners in the development and governance of organisational systems for delivering end-of-life care.
- 6.2 The health service executive should consider how best to allocate resources within the context of the organisation's strategic plan to support the delivery and effective functioning of systems for providing end-of-life care.
- 6.3 A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include:
 - governance arrangements
 - roles and responsibilities
 - communication and documentation processes
 - processes for advance care planning and limiting medical treatment
 - alignment with systems for recognising and responding to clinical deterioration
 - access to specialist palliative care advice and services
 - the interface with external services, such as community and social care providers, residential aged care facilities and external hospice providers

- clear dispute resolution processes, including access to mediation, bioethics and legal support in situations of complex end-of-life decision-making or conflict
 - training and education requirements
 - access to professional clinical supervision, and formal and informal debriefing, to suit the varied needs of clinicians
 - access to support and debriefing for nonclinical staff
 - evaluation, audit and feedback processes, and reporting requirements.
- 6.4 The policy framework for end-of-life care should apply across the acute health service. It should identify potential variations in its application that might exist in different circumstances (such as at different times of day or in satellite locations).
- 6.5 The policy framework for end-of-life care should operate in synergy with recognition and response systems for patients who are clinically deteriorating.
- 6.6 Policies and processes should be in place regarding 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 patient's expressed wishes.
- 6.7 A formal governance process should be in place to oversee the development, implementation and ongoing review of systems for end-of-life care. If a committee has this role, it should:
- have appropriate responsibilities delegated to it, and be accountable for its decisions and actions to the executive
 - monitor the effectiveness of interventions and education
 - have a role in reviewing performance data
 - provide advice about the allocation of resources
 - include consumers, interdisciplinary team members, managers and executives.
- 6.8 Organisations should have systems in place to ensure that essential resources required for the provision of safe and high-quality end-of-life care (e.g. private space for family meetings, equipment and medications) are always operational and available.
- 6.9 Organisations should work with local community-based service providers to build capacity for people to be cared for in their preferred place of death (e.g. at home).

7. education and training

I think when it comes to ongoing professional development they should be seeking ways to get the patient experience into that. At the moment there is only the complaints process for patients to get their experience across.

Consumer

I found that staff just didn't know ... There was avoidance, yes, but they didn't know what to do, they didn't know what they were supposed to do. They haven't got that exposure or experience to know how to treat a dying patient, or that patients are allowed to die.

Tissue and organ donation nurse educator – public hospital

key points

- It is important that all care providers have a shared understanding of the local terminology, policies, processes and practices associated with end-of-life care.
- The skills and knowledge required to manage end-of-life care are complex and need a specific educational focus.
- Education and training should enable clinicians to manage all phases of end-of-life care, from advance care planning to recognition of dying and management of terminal care.

Having an educated and suitably skilled and qualified workforce is essential to providing appropriate end-of-life care. Education should commence early in training programs and continue as part of clinicians' professional development. It should cover elements 1–5 in the Consensus Statement, local referral and communication processes, and relevant legislation and other regulatory frameworks. It should also include training about how to have discussions and conversations about end-of-life care.

A range of methods can be used to teach appropriate knowledge and skills about end-of-life care. They include face-to-face and online techniques, simulation, reflective learning, case studies, death reviews, mentoring and supervised clinical practice. Organisations should also consider accessing existing external training programs.

actions

- 7.1 All members of the interdisciplinary team should receive education about their roles and responsibilities in relation to local systems and processes for recognising and managing end-of-life care.
- 7.2 All clinicians should be familiar with the *Guiding principles* of this Consensus Statement and able to apply the *Processes of care* elements (elements 1–5).
- 7.3 Patients, families and carers should be invited to participate in providing education about end-of-life care, since patient stories can be powerful tools for teaching. It is important that patients, families and carers are adequately supported to share their experiences.
- 7.4 Junior and student clinicians should be encouraged and enabled to take up the learning opportunities offered by participating in family meetings, multidisciplinary case review meetings, mortality and morbidity conferences, and adverse event reviews.
- 7.5 Clinicians should receive ongoing education about disease-specific symptom assessment and evidence-based symptom management relevant to their area of practice.
- 7.6 Education should cover ethical and medico-legal issues, including the relevant professional ethical frameworks, and the relevant legislation in the state or territory of clinical practice.
- 7.7 Education should include specific competencies for providing culturally responsive end-of-life care to Aboriginal and Torres Strait Islander people, and to people from other culturally and linguistically diverse communities.
- 7.8 Education should include specific training for providing end-of-life care to people with limited capacity to participate in decision-making – for example, those with mental illness, disability or cognitive impairment. This should include education about the role and legal status of families, carers and substitute decision-makers.
- 7.9 Ongoing formal training in communication skills should be offered to clinicians at all levels, as these skills are critical to the delivery of end-of-life care.
- 7.10 All members of the interdisciplinary team should receive education about how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues. They should also receive information about how to seek help, if required.

8. supervision and support for interdisciplinary team members

I get asked to teach junior doctors about self-care and I tell them that unfortunately they are in a profession where bravado is seen as the way to operate ... We are very, very bad at this. I found as a junior doctor doing my physician training, learning to cope with the deaths of 17 or 18-year-olds on the oncology ward, I couldn't look to anyone in medicine, if tears came to your eyes you were not supposed to show anyone.

General medicine physician – public hospital

Often the patient is palliated and [the death] is okay but for us the process to get there was quite painful and distressing.

Nurse unit manager – public hospital

key points

- Dealing with death and dying can be challenging for interdisciplinary team members. The potential impact of providing end-of-life care should not be minimised by clinicians, the team or the health service.
- Health services should facilitate access to peer support, mentoring and appropriate clinical supervision.

Dealing with death and dying can be challenging for members of the interdisciplinary team, and for other staff members such as ward clerks, porters and cleaners. It can add considerably to workplace stress. Chronic unmanaged stress can erode empathy and potentially contribute to poorer experiences for patients. It is important that systems are in place to facilitate access to peer support, mentoring and appropriate clinical supervision.

Supervision and support systems may contribute to learning and the development of skills in the delivery of end-of-life care, but their primary purpose should be to support members of the interdisciplinary team and other staff members, and to prevent or resolve distress.

actions

- 8.1 A policy framework should exist outlining how supervision and support are provided to clinicians and other staff members who are in contact with patients and their families.
- 8.2 Clinicians and other staff members who are in contact with patients and their families should know when and how to access peer support, mentoring and clinical supervision. This information should be provided at the start of employment and as part of regular refresher training.
- 8.3 Clinicians should know how to access support after particularly distressing or problematic episodes of care. This may involve accessing external services for formal clinical supervision, counselling or debriefing.
- 8.4 Clinicians should be supported to develop skills in self-care, reflective learning and providing peer support to colleagues.

9. evaluation, audit and feedback

The quality of death is what I think we should be measuring, not the fact of death. There's all this literature about the fact of death, do MET [medical emergency team] calls save lives ... but quality of death, well it's silent. The literature is just silent. We don't measure it.

Intensivist – private hospital

key points

- Ongoing monitoring of the effectiveness of end-of-life care systems and processes is essential for quality improvement.
- Evaluation should address the quality and safety of the end-of-life care provided, not just the potential preventability of death.

Ongoing monitoring and evaluation of processes and systems for delivering end-of-life care are essential, to establish their efficacy, track performance over time and determine priorities for improvement.

actions

- 9.1 Data about the effectiveness of processes and systems for delivering end-of-life care should be collected, reviewed and reported locally (including over time).
- 9.2 Clinicians must lead evaluation and audit, and feed back aggregate, de-identified data to their peers and colleagues.
- 9.3 Monitoring and evaluation strategies should be developed to capture feedback about the quality of end-of-life care from multiple disciplines (e.g. medicine, nursing, social work), as well as from patients, substitute decision-makers, families and carers.
- 9.4 Evaluation and monitoring should be simple, inexpensive and feasible. The processes should use routinely collected data and data linkage, where possible.

9.5 Measures of the safety and quality of end-of-life care could include:

- whether triggers to identify patients approaching the end of life were correctly used and applied
- effectiveness of treatment of symptoms
- documentation of the patient's wishes, and alignment of the patient's expressed wishes with actual care
- real-time feedback on patient experiences of care
- feedback on their experiences from families and carers of patients who received end-of life care
- whether any existing advance care directive or plan was enacted
- the category of death (expected/unexpected/diagnosis)
- the time lapse between deciding to palliate or referring to specialist palliative care, and death
- transfers of care in the last week of life (e.g. transfers to or from intensive care).

9.6 Methods for collecting data could include:

- retrospective audit of case notes (e.g. documentation of discussions, patient preferences, anticipatory plan of care and plan of care in the terminal phase; appropriateness and frequency of clinical observations)
- medication chart safety review (e.g. to determine whether inappropriate medications were stopped, and palliative medications were prescribed and administered appropriately)
- follow-up with families, carers, clinicians and other staff involved in the patient's end-of-life care
- use of tools developed for specific settings (e.g. the Family Satisfaction in the Intensive Care Unit survey)
- multidisciplinary mortality and morbidity review.

9.7 All deaths should be routinely reviewed to determine whether the safety and quality of the patient's end-of-life care were acceptable, and how they could have been improved.

10. systems to support high-quality care

In the same way that we are concerned about falls management, or medication management, we should be concerned about safety and quality in terms of how we manage people at the end of their life.

National manager of palliative care – private hospital group

I see this as a multistep process ... we want to change the culture but that's not going to happen, [we] need to find concrete ways to change practice.

Palliative care consultant – public hospital

key points

- Taking a systems approach to providing end-of-life care is necessary to embed and sustain improvements.
- Systems for end-of-life care should be integrated into existing organisational, and safety and quality systems to support their sustainability and opportunities for organisational learning.
- Systems for end-of-life care should align with the requirements of the NSQHS Standards.

Organisations should consider opportunities to systematise the approach to end-of-life care where this will support best practice. For example, developing consistent processes for accessing palliative medications might improve the timeliness of treatment for distressing symptoms. Technological systems such as the personally controlled electronic health record may also provide benefits to patients – for example, by improving communication with external care providers, and improving continuity and coordination of care as patients are transferred in and out of acute health services. These systems should align with the requirements of the NSQHS Standards.

actions

- 10.1 Systems should be in place to support clinicians to work with patients, families and carers to receive, prepare, review and/or update advance care plans and directives, according to the wishes of the patient. These systems should align with NSQHS Standard 1 (Governance for safety and quality in health service organisations) and Standard 9 (Recognising and responding to clinical deterioration in acute health care).
- 10.2 Systems should be in place to provide clinicians with access to essential palliative medications 24 hours a day and 7 days a week. These systems should align with NSQHS Standard 4 (Medication safety).
- 10.3 Systems should be in place to provide timely access to input from specialist palliative care clinicians, when required for patients with complex palliative care needs or as a supportive resource for other clinicians. This may include off-site access via videoconferencing or teleconferencing.
- 10.4 Organisations should implement processes to improve communication between health services at transitions of care. This should include processes for communicating the content of discussions about prognosis and advance care planning. These processes should align with NSQHS Standard 6 (Clinical handover).

- 10.5 Health services should work with community care providers to ensure that systems are in place for communicating and accessing advance care directives or plans developed in community care settings.
- 10.6 Systems should be in place to facilitate appropriate documentation about end-of-life care, and to reduce the burden of documentation and data collection when possible.
- 10.7 Technological systems and solutions should be implemented where they will support safe and high-quality end-of-life care, in accordance with the essential elements in this Consensus Statement.

appendices

appendix a: terminology

Clarity and agreement are lacking about the meaning of many terms that are commonly used in relation to end-of-life care. It is important for all those involved in providing end-of-life care to have a common understanding of what such terms mean in practice. Below is a list of some common terms and their meanings in the context of this document.

Term	Description
Acute healthcare facility ¹	A hospital or other healthcare facility providing healthcare services to patients for short periods of acute illness, injury or recovery.
Advance care directive ²	A type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care, and appoint a substitute decision-maker to make decisions about health care and personal life management. In some states, these are known as advance health directives.
Advance care plan ²	An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care, and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.
Advance care planning ²	A process of planning for future health and personal care, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.
Carer ³	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 or chronic illness) or mental illness, or they are frail and aged. 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.
Clinician ¹	A healthcare provider, trained as a health professional. Clinicians include registered and nonregistered practitioners, or members of a team of health professionals providing health care who spend the majority of their time providing direct clinical care.
Dying	The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks. This is sometimes referred to as 'actively dying'.

1. Australian Commission on Safety and Quality in Health Care. *National Safety and Quality Health Service Standards*. Sydney: ACSQHC, 2011.

2. Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. *A national framework for advance care directives*. Adelaide: Australian Health Ministers' Advisory Council, 2011.

3. *Carer Recognition Act 2010*. (Accessed 16 July 2014, at www.comlaw.gov.au/Details/C2010A00123.)

Term	Description
End of life ⁴	<p>The period when a patient 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 patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.</p>
End-of-life care ⁴	<p>Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. 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"> • advanced, progressive, incurable conditions • general frailty and co-existing conditions that mean that they are expected to die within 12 months • existing conditions, if they are at risk of dying from a sudden acute crisis in their condition • life-threatening acute conditions caused by sudden catastrophic events.
Family ⁵	<p>Those who are closest to the patient in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice.</p>
Goals of care	<p>The aims for a patient's medical treatment, as agreed between the patient, family, carers and healthcare team. Goals of care will change over time, particularly as the patient enters the terminal phase.</p> <p>Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient.</p> <p>The patient's goals of care may also include nonmedical goals – for example, returning home or reaching a particular milestone, such as participating in a family event.</p>
Interdisciplinary team ⁴	<p>A team of providers who work together to develop and implement a plan of care. Membership depends on the services required to identify and address the expectations and needs of the patient, carers and family. An interdisciplinary team might typically include one or more doctors, nurses, social workers, spiritual advisers, pharmacists and personal care workers. Other disciplines may be part of the team, depending on the needs of the patient and the resources available. Hospital volunteers, patients, carers and family members may also be considered as part of the interdisciplinary team.</p>

4. General Medical Council. *Treatment and care towards the end of life: good practice in decision making*. (Accessed 16 July 2014, at www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp.)

5. Palliative Care Australia. *Palliative care: glossary of terms*. Canberra: Palliative Care Australia, 2008.

Term	Description
Limitations of medical treatment	<p>Medical decisions that may be made to limit the treatments that are, or could be, provided when they will not benefit the patient. A decision to not attempt cardiopulmonary resuscitation if a patient 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 patient's death. This is quite different from the practice of euthanasia, where death is deliberately and purposefully hastened.</p>
Nonbeneficial treatment	<p>Interventions that will not be effective in treating a patient's medical condition or improving their quality of life. Nonbeneficial treatment may include interventions such as diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Nonbeneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.</p>
Palliative care ⁶ or palliative approach	<p>An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).</p>
Patient	<p>The primary recipient of care.</p>
Resuscitation orders/plans	<p>Documents completed by a doctor to outline the plan of care in relation to emergency treatment of severe clinical deterioration.</p> <p>Not for resuscitation (NFR) and do not attempt resuscitation (DNAR) orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the patient 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 (e.g. decisions to call a medical emergency team or transfer a patient to intensive care if they deteriorate).</p>

6. World Health Organization. *WHO definition of palliative care*. (Accessed 16 July 2014, at www.who.int/cancer/palliative/definition/en.)

Term	Description
Specialist palliative care	<p>Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate nonspecialist clinicians who are providing palliative care.</p>
Substitute decision-maker ⁷	<p>A person appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-makers have legal authority to make these decisions; the relevant legislation varies between jurisdictions (states and territories).</p> <p>A document that appoints a substitute decision-maker to make health, medical, residential and other personal decisions (but not financial or legal decisions) is considered to be an advance care directive. More than one substitute decision-maker may be appointed under an advance care directive.</p> <p>There are three categories of substitute decision-makers:</p> <ul style="list-style-type: none"> • substitute decision-makers chosen by the person (e.g. one or more enduring guardians appointed under a statutory advance care directive, or a nominated substitute decision-maker in a common law advance care directive) • substitute decision-makers assigned to the person by the law in the absence of an appointed substitute decision-maker (e.g. family member, carer or 'person responsible') • substitute decision-makers appointed for the person (e.g. a guardian appointed by a guardianship tribunal).
Terminal phase	<p>The hours, days or, occasionally, weeks when a patient's death is imminent. This is sometimes referred to as the period when a patient is actively dying.</p>

7. Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. *A national framework for advance care directives*. Adelaide: Australian Health Ministers' Advisory Council, 2011.

appendix b: contributing documents and web sites

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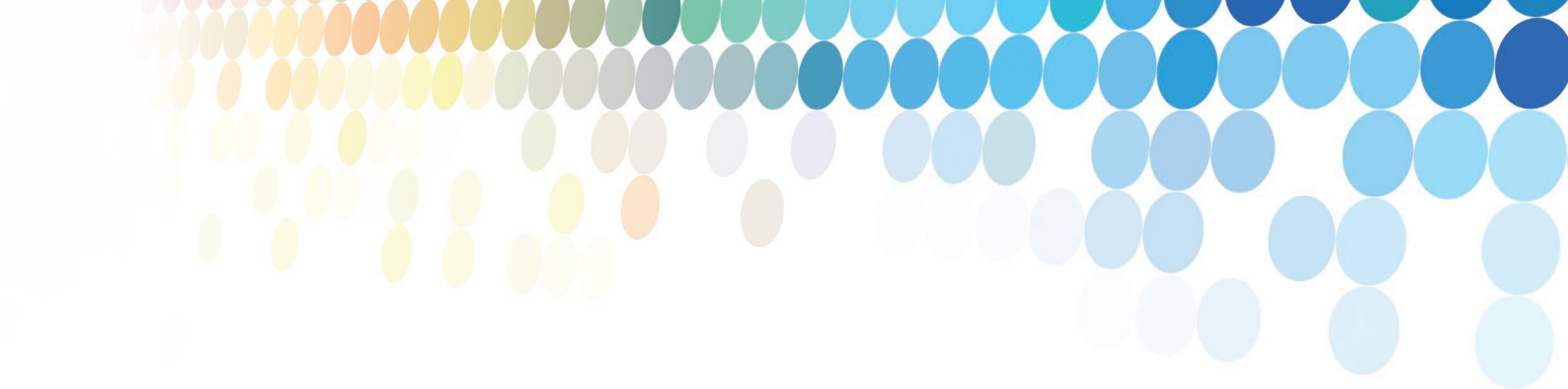
appendix c: consultation about the consensus statement

A draft version of this Consensus Statement was released for consultation in January 2014. More than 200 individuals and organisations responded to an online survey, and 74 formal submissions were received. Consultation workshops were held in each of the states and territories. These involved more than 340 health professional and consumer participants. Feedback from the consultation process has been incorporated into this final Consensus Statement. Details of the consultation feedback can be found in the consultation report on the Commission's web site.

A background paper, *Safety and quality of end-of-life care in acute hospitals*, provided the foundation for the development of this Consensus Statement. It is available on the Commission's web site:

www.safetyandquality.gov.au/publications/safety-and-quality-of-end-of-life-care-a-background-paper/

During the preparation of the background paper, a series of preliminary consultation interviews and focus groups were held with consumers and carers, interdisciplinary team members, hospital executives and policy-makers from around Australia. Quotations from these interviews are used in the Consensus Statement.





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