Delivering and Supporting Comprehensive End-of-Life Care: a user guide

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Introduction

Receiving safe and high-quality health care in the last years, months and weeks of someone's life can minimise the distress and grief associated with death and dying for the individual, and their family, friends and carers.

The Australian Commission on Safety and Quality in Health Care (the Commission) has a role in supporting health service organisations and clinicians to improve the safety and quality of end-of-life care, and in ensuring that this care meets the needs and preferences of the person who is dying.

Purpose and application of this guide

This guide provides practical strategies that health service organisations and clinicians can use to meet the essential elements of safe and high-quality end-of-life care and the National Safety and Quality Health Service (NSQHS) Standards (second edition) requirements. The information will also help health service organisations to understand the link between the NSQHS Standards and the **Consensus Statements** to support consistent delivery of comprehensive care.

It complements the Commission's existing guidance that helps health service organisations meet the requirements of the NSQHS Standards, and to deliver safe and high-quality **comprehensive care** and **end-of-life care**.

Health service organisations will need to consider the strategies and approaches described in this guide and determine what is most appropriate for their organisation. Organisations will need to tailor systems to their setting, needs of their local population, and available resources and personnel, and remain in line with relevant state or territory policies, processes and legislative requirements.

Resources to support high-quality end-of-life care

To help support high-quality end-of-life care, the Commission has developed the following resources:

- The **NSQHS Standards (2nd ed.)**[1], which includes comprehensive care guides[2,3]
- The Consensus Statements
  - the *National Consensus Statement: Essential elements for safe and high quality end-of-life care*[4]
  - the *National Consensus Statement: Essential elements for safe and high quality paediatric end-of-life care*[5]
- An **End-of-Life Care Audit Toolkit.**

The NSQHS Standards

Many Australians spend their last year of life going in and out of hospital, and more than half of those who die each year do so in acute care settings.[6] Therefore, it is important that the NSQHS Standards support health service organisations to improve the safety and quality of end-of-life care.

The NSQHS Standards were developed by the Commission in collaboration with the Australian Government, state and territories, the private sector, clinical experts, patients and carers. The NSQHS Standards aim to protect the public from harm and to improve the quality of health care provision. They provide a quality assurance mechanism that tests whether relevant systems are in place to ensure expected standards of safety and quality are met.[1] The NSQHS Standards also provide a foundation for health service organisations to focus on improving the safety and quality of end-of-life care within their organisation and delivering care aligned with the Consensus Statements.

The NSQHS Standards (2nd ed.) comprises eight standards:

- Clinical Governance Standard
- Partnering with Consumers Standard
- Preventing and Controlling Healthcare-Associated Infection Standard
- Medication Safety Standard
- Comprehensive Care Standard
- Communicating for Safety Standard
- Blood Management Standard
- Recognising and Responding to Acute Deterioration Standard.

The Comprehensive Care Standard and end-of-life care

The Comprehensive Care Standard relates to the delivery of comprehensive care for patients within a health service organisation. Comprehensive care is the coordinated delivery of the total health care that a patient needs or wants. Safety and quality gaps are often reported as failures to provide suitable care for specific conditions, or in specific situations or settings, or to achieve expected outcomes in particular populations.

Supporting the delivery of excellent end-of-life care is a part of delivering comprehensive care that aligns with the patient's expressed goals of care and healthcare needs, considers the impact of the patient's health issues on their life and wellbeing, and is clinically appropriate. It is important that care is provided continuously and collaboratively in line with their diagnoses and agreed goals of care. Their comprehensive care plan should reflect their individual preferences.

The Comprehensive Care Standard includes six actions that focus on end-of-life care (Table 1). These actions require health services to have systems and processes for caring for patients at the end of their lives, and for clinicians to use those systems and processes. By implementing these actions, health service organisations are laying the foundations to support the delivery of safe and high-quality end-of-life care that is person-centred and comprehensively meets the needs of the patient. These six actions can be linked to the 10 essential elements of the Consensus Statements.

Table 1: Mapping the Comprehensive Care Standard actions that focus on end-of-life care to the Consensus Statement essential elements

Comprehensive Care Standard action	Consensus Statement essential elements
5.15 The health service organisation has processes to identify patients who are at the end of life that are consistent with the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*[4]	■ **1.1** Patient-centred communication and shared decision making ■ **4.1–4.3** Use of triggers to recognise patients approaching the end of life ■ **6.5** Leadership and governance
5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care advice	■ **3.15** Components of care ■ **4.2** Use of triggers to recognise patients approaching the end of life ■ **5.5** Response to concerns ■ **6.3** Leadership and governance ■ **10.3** Systems to support high-quality care
5.17 The health service organisation has processes to ensure that current advance care plans: a) Can be received from patients b) Are documented in the patient's healthcare record	■ **3.2**, **3.3**, **3.8** Components of care ■ **6.3**, **6.6** Leadership and governance ■ **10.1**, **10.4**, **10.5** Systems to support high-quality care
5.18 The health service organisation provides access to supervision and support for the workforce providing end-of-life care	■ **2.5** Teamwork and coordination of care ■ **3.4** Components of care ■ **5.7**, **5.10** Response to concerns ■ **6.2**, **6.3**, **6.8** Leadership and governance ■ **7.1**, **7.4–7.10** Education and training ■ **8.1–8.4** Supervision and support for interdisciplinary team members
5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care	■ **5.4**, **5.8** Response to concerns ■ **6.3**, **6.7** Leadership and governance ■ **9.1–9.6** Evaluation, audit and feedback
5.20 Clinicians support patients, carers and families to make shared decisions about end-of-life care in accordance with the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*[4]	■ **1.1–1.13** Patient-centred communication and shared decision making ■ **2.1**, **2.3** Teamwork and coordination of care ■ **3.7** Components of care

Note: The Comprehensive Care Standard is a part of the National Safety and Quality Health Service Standards (second edition)[1]

Information about ways to meet the requirements of the six Comprehensive Care Standard actions described in Table 1 can be found at the following Commission web pages:

- NSQHS Standards (2nd ed.)
- Comprehensive care
- End-of-life care.

In addition, the Commission has the following resources on comprehensive care that help organisations and clinicians deliver end-of-life care:

- *Implementing the Comprehensive Care Standard: A conceptual model for supporting comprehensive care delivery*[2]
- *Implementing the Comprehensive Care Standard: Essential elements for delivering comprehensive care*.[3]

For effective and sustainable improvement, a health service organisation's response to these six comprehensive care actions on end-of-life care needs to be integrated into organisational systems and processes for safety and quality. As a result, when taking steps to meet these actions, health service organisations are encouraged to consider related requirements in the:

- Clinical Governance Standard
- Partnering with Consumers Standard
- Comprehensive Care Standard
- Communicating for Safety Standard
- Recognising and Responding to Acute Deterioration Standard.

The Consensus Statements

The Consensus Statements set out suggested practice for end-of-life care in settings where acute care is provided. They provide guiding principles for the delivery of care for people who are dying, as well as 10 essential elements required for safe and high-quality end-of-life care (See Figure 1: Overview of the 10 essential elements for safe and high-quality end-of-life care):

- Patient-centred care communication and shared decision making
- Teamwork and coordination of care
- Components of care
- Use of triggers to recognise patients approaching the end of life
- Response to concerns
- Leadership and governance
- Education and training
- Supervision and support for multidisciplinary team members
- Evaluation, audit and feedback
- Systems to support high-quality care.

End-of-life Care Audit Toolkit

The **End-of-life Care Audit Toolkit** is a set of tools that health service organisations can use to explore the safety and quality of end-of-life care delivered within their service, and to help identify where improvements can be made.

The toolkit includes:

- Templates and guidance for a retrospective healthcare record audit to identify the type of care and interventions experienced by patients who are dying
- A set of surveys that can be used to gauge clinician views and perspectives of the safety and quality of end-of-life care delivered in their organisation.

Structure of this guide

The remainder of this guide is divided into three sections:

- **Section A: Processes of care – delivering comprehensive end-of-life care** (essential elements 1–5) relate to the way in which end-of-life care should be approached and delivered, and details practical suggestions for clinicians
- **Section B: Organisational prerequisites – supporting comprehensive end-of-life care** (essential elements 5–10) relate to structural and organisational requirements for the effective delivery of safe and high-quality end-of-life care, with a focus on what health service executives and managers can do to support this
- **Section C: Extra material** includes the appendices, a glossary and the reference list.

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

PROCESSES OF CARE
Delivering comprehensive end-of-life care

1. Patient-centred care 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

ORGANISATIONAL PREREQUISITES
Supporting comprehensive end-of-life care

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

Section A: Processes of care – delivering comprehensive end-of-life care

This section describes some of the actions health service organisations and clinicians can take to deliver high-quality end-of-life care, based on the first five elements of the Consensus Statements:

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.

Clinicians can use these five elements to focus on ways to engage with consumers when discussing, planning and delivering care for someone who is dying. Such care should be focused on the patient's individual needs, preferences and circumstances.

Essential element 1:
Patient-centred communication and shared decision making

Intent

Patients at the end of life – and their family, carers and other chosen support people – are involved in planning and decision-making about current and future care.

Related Comprehensive Care Standard actions

5.17 The health service organisation has processes to ensure that current advance care plans:

a) Can be received from patients

b) Are documented in the patient's healthcare record.

5.20 Clinicians support patients, carers and families to make shared decisions about end-of-life care that is provided against the planned goals of care.

Other relevant NSQHS Standards

Partnering with Consumers Standard

Communicating for Safety Standard

What this means

Working with patients, families, carers and other support people can ensure that essential baseline information about a patient's condition is established so deterioration can be recognised and strategies for ongoing care can be identified.

As well as being experts in a person's care needs and sources of valuable health information, carers and other family members may also choose to be actively involved in a person's care.

Working in partnership with patients, families, carers and other support people relies heavily on effective communication and strategies to share decision-making.

As our population ages, the number of people living with life-limiting conditions will increase. Having the knowledge of impending death is an opportunity for patients to make joint decisions with the multidisciplinary team to support the patient to have a 'good death' based on their individual values, needs and preferences.[7] When care is person-centred, the needs of the patient and their family are incorporated into clinical management. Shared decision making helps to ensure that the patient does not receive treatments contrary to their wishes.[7]

Talking about end-of-life issues can be emotionally challenging for clinicians, and patients, their families and support people. However, these discussions are needed to determine the patient's preference for the type and kind of information they want, and their level of involvement in decision-making. It is important to recognise a patient's need for information and the degree to which they wish to be included in decision-making may change. This should be accommodated.

Supporting patient participation in shared decision making facilitates excellent end-of-life care. Clinicians can help by:

- Improving their communication techniques
- Providing effective risk communication to help patients make informed decisions
- Avoiding false optimism while maintaining a sense of hope
- Providing appropriate information to patients, families, carers and support people.

Taking action

Maintaining open communication with the patient, substitute decision-makers, family and support people – together with community care providers such as general practices, pharmacies, home care services and residential aged care facilities supports excellent end-of-life care.[8]

Clinicians may use a range of practical strategies to better partner with patients, families, carers and other support people including:

- Starting the conversation
- Sharing decisions about care
- Involving support people in end-of-life care
- Helping the patient's family, carers and other support people after a patient's death.

The Commission has identified six essential elements for comprehensive care delivery, which represent different stages or processes that a patient may experience when clinical care is delivered and applies to patients regardless of their clinical condition.[3] More information on planning and delivering comprehensive care is available at the Commission's web page on **Essential elements for comprehensive care.**

Starting the conversation

For patients nearing the end of life, it is important to start conversations about their preferences and care options early.

Clinicians are often reluctant to initiate difficult conversations and discuss the likelihood of dying with patients.[9] This may be due to prognostic uncertainty and the difficulty predicting when a patient may die. Regardless of the unknowns, there is value in early end-of-life discussions to promote patient autonomy and ensure that their choices are communicated to the care team. Understanding that time is likely to be short can change patients' priorities and influence their treatment decisions.

A clinician's choice of language during end-of-life conversations can affect how well the patient and their family can understand the information. Clinicians should approach difficult conversations with sensitivity and compassion, and avoid jargon, technical terminology and euphemisms.[10] Clinicians should consider the patient's level of health literacy, and tailor communication styles accordingly. Using direct terms such as death and dying prevents ambiguity and confusion.[10] For clarity, use terms such as 'not beneficial' and 'not in the person's best interests' instead of 'futile' when discussing treatment options.

Sometimes, the relatives of dying patients will ask the clinician to withhold the prognosis from the patient – often because relatives want to prevent distressing the patient. But, most people feel the changes in their bodies and want to be aware of their prognosis. They are empowered by participating in decision-making and experience anxiety when they feel uninformed.[7] A person experiencing the loss of energy and strength that accompanies a life-limiting illness may feel confused and frustrated at the discordance between how they feel physically and their perception of the extent of their disease. There are ethical implications related to withholding information and clinicians should not withhold the truth from patients.[9,11,12]

Tips for having a conversation about end of life

- Communicate openly and honestly about their prognosis. Clearly communicating about a patient's diagnosis and prognosis is important to ensure that the patient and their support people understand the situation and can be meaningfully involved in sharing decisions and planning care. It is important to avoid euphemisms where possible, because these can cause confusion and misunderstanding about what is really happening.
- Check patients' understanding of the discussion. This might require using strategies such as **Teach-back™** or **Ask Share Know** to confirm that the patient understands the information.
- Give the patient time to digest information. Receiving bad news about health and the likelihood of death is distressing to most people, and they will need time to process the information and think about questions they want to ask. Ask if the patient wants time, and offer a follow-up conversation to go over any questions they might have. Clinicians may need to recognise that patients or carers may need key information repeated, as they may not retain or process all information shared during each discussion.
- Provide alternative sources of information about their health and care. Some patients will need to think about their diagnosis and prognosis, and may want time to look at information in more detail so they can think about the questions or options they might have.
- Ask patients how much they'd like to be involved in decision-making, and who they'd like to be involved. Some patients will want to be closely involved in decision-making, whereas others would prefer not to be involved. It is important to talk about this early with patients to ensure they have the opportunity to be involved in decision-making to the extent that they wish to. Decisions may be revisited at any time.
- Ask patients what matters to them. Patients have different needs and preferences that reflect who they are as a person and what is important to them. Patients will have different expectations, cultural and spiritual needs, and other personal preferences that may be important to their experience of death and dying.

Appendix A includes resources to guide end-of-life conversations.

Sharing decisions about care

Shared decision making is a critical strategy for clinicians to effectively partner with patients, families, carers and other support people. Shared decision making is a process of incorporating the best available clinical evidence into a discussion about a patient's values and preferences to make decisions about care together.[7]

When discussing end-of-life goals and preferences, patients need to understand that their time may be limited and clinicians need to honestly present the realistic risks and potential benefits of treatments that are appropriate to the patient's condition. Describing best-case and worse-case scenarios – and the most likely case – can often help patients understand their disease progression.

End of life is a time when people may decide that their personal needs are more important than their clinical needs.

Involving support people in end-of-life care

Carers and other family members are experts in a person's care needs and sources of valuable health information. They may also choose to be actively involved in a person's care. Health service organisations can support carers in this role through policies and programs that enable practical strategies such as providing:

- Beds or chairs for overnight stays
- Refreshments and other amenities
- Discounted parking
- Unrestricted visiting hours
- Training carers and families on how to safely care for someone (for example, giving medicines, lifting techniques, feeding people).

Helping the patient's family, carers and other support people after a death[13]

Excellent end-of-life care considers the bereavement period and supports the patient's family after the patient has died. Additional care includes providing information on grief and bereavement, and access to pastoral care and psychosocial support. When a family is having difficulties with bereavement, services should help refer them to specialist counselling.

Essential element 2:
Teamwork and coordination of care

Intent

Clinicians partner with patients, families and support people, to plan and deliver comprehensive end-of-life care.

Related Comprehensive Care Standard actions

5.5 The health service organisation has processes to:

a) Support multidisciplinary collaboration and teamwork

b) Define the roles and responsibilities of each clinician working in a team.

5.6 Clinicians work collaboratively to plan and deliver comprehensive care.

Other relevant NSQHS Standards

Clinical Governance Standard

Partnering with Consumers Standard

Communicating for Safety Standard

What this means

Many patients at the end of life receive care from different clinical and nonclinical staff, and are cared for in a variety of clinical and nonclinical care settings. To improve the experience for the patient, information about the patient and their care needs to be communicated and coordinated effectively.

For a health service organisation, this means accurate, understandable and relevant information is exchanged in a timely manner with other members of the care team, and with the patient and their support people. It is also important that information and care is transferred when a patient transitions between different wards, services or healthcare teams.

Taking action

Clinicians can use different strategies to better partner with patients, families, carers and other support people such as:

- Identifying the care coordinator or person with overall responsibility for the patient's care
- Using communication tools
- Using referral processes.

Identifying the person with overall responsibility for the patient's care

Identifying a care coordinator who takes overall responsibility for managing a patient's care is essential to ensure continuity, effective communication and optimal care coordination. The care coordinator may be:

- A designated position
- A clinician in the multidisciplinary team
- A support person
- The patient's general practitioner.

From a patient perspective, a care coordinator is often the 'go-to' person, acting as an information conduit between the patient, their family and support people, and other multidisciplinary team members. The care coordinator can help patient's process bad news and changes in prognosis, and explain what a treatment can mean for that patient. Having someone take the lead and coordinate care can also reduce the burden on the patient and their family.

Using communication tools

Teamwork is essential to provide excellent end-of-life care, and good communication is imperative to effective teamwork. Using structured communication techniques – such as ISBAR, Check back, I PASS the BATON or a Huddle – can improve the transfer of clinical information and responsibility among clinicians, and strengthen teamwork behaviours and attitudes.

Similarly, some technologies and tools such as the My Health Record system can be used to improve communication by reducing duplication of effort and encouraging improved collaboration between clinical partners.

More information on communication techniques and tools is available at the Commission's web page on **Communicating for safety**.

Using referral processes

Referring clinicians, specialist clinicians and services need to work collaboratively to ensure that patients receive coordinated and consistent end-of-life care.[14] Referral criteria and processes for patients at the end of life should be formalised, documented, and accessible to, and used by, clinicians. When specialist services are not on site, systems must support easy collaboration.

Essential element 3:
Components of care

Intent

All patients at the end of life receive care that is aligned with their goals of care.

Related Comprehensive Care Standard actions

5.9 Patients are supported to document clear advance care plans.

5.13 Clinicians use processes for shared decision making to develop and document a comprehensive and individualised plan that:

a) Addresses the significance and complexity of the patient's health issues and risks of harm

b) Identifies agreed goals and actions for the patient's treatment and care

c) Identifies the support people a patient wants involved in communications and decision-making about their care

d) Commences discharge planning at the beginning of the episode of care

e) Includes a plan for referral to follow-up services, if appropriate and available

f) Is consistent with best practice and evidence.

5.17 The health service organisation has processes to ensure that current advance care plans:

a) Can be received from patients

b) Are documented in the patient's healthcare record.

Related Comprehensive Care Standard actions
continued

5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care.

5.20 Clinicians support patients, carers and families to make shared decisions about end-of-life care in accordance with the National Consensus Statement: Essential elements for safe and high-quality end-of-life care.

Other relevant NSQHS Standards

Partnering with Consumers Standard

Communicating for Safety Standard

What this means

Goals of care describe what a patient wants to achieve during their care. Such goals can be clinical or personal, and can be worked out during shared decision making.[15] Identifying goals of care helps to organise and prioritise care activities and contributes to improved satisfaction, quality of life and self-efficacy for patients.[13,15] Refer also to the Commission's website page **Implementing the Comprehensive Care Standard: Deliver comprehensive care**.

Taking action

There are different strategies clinicians can use to identify a patient's goals of care at the end of life.

More information on goals of care is available at the Commission's web page on **Essential element 2: Identifying goals of care**.

Asking what matters to the patient

For patients nearing the end of life, personal goals may become more important than clinical goals.[13] Therefore, it is important to have a conversation about the patient's preferences for how they are cared for as their health deteriorates. Clinicians should talk with their patients about their goals in a timely manner, and address a wide range of physical and psychosocial concerns. Do not focus on resuscitation alone.

Ask the patient about what is important to them regarding their health care, and what they would like to achieve through treatment. Offer the patient, and their families, carers and other support people the opportunity to discuss their goals of care when there will be minimal interruptions, and in an appropriate place.

Considering spiritual and cultural needs

Patients may choose to discuss goals with people that provide different types of support. There are a wide variety of ways in which people from different cultural backgrounds deal with death and dying. Appreciating and allowing for cultural differences and diversity will improve the end-of-life experience for patients, families, carers and other support people.[16]

Special rituals associated with death and dying can be elaborate and long depending on someone's cultural background. They may be of great importance to the person and reflect their values and beliefs.[17] Spiritual care practitioners can help other members of the healthcare team understand the patient's spiritual needs for consideration during care planning.

Sharing decision-making

Provide patients with relevant information about available care options relevant to their condition, talk about the risks and benefits of those options, and check that the patient understands the information being discussed.

Shared decision making allows goals to be identified and encourages patients to set their own goals.[18] The process of sharing decisions during goal setting may decrease anxiety and increase the wellbeing of patients.

Identifying who is involved in helping achieve the goals

The patient, family, carer or other support people, as well as the lead clinician and multidisciplinary team, all have a role to play in identifying and supporting the patient to achieve their goals of care. Ensure the patient and everyone in the team clearly understands their role in this process.

A multidisciplinary approach increases the range of goals that can be attained. Assigning steps and tasks to members of the multidisciplinary team, the patient, family, carers or other support people make it clear who is responsible for parts of the care plan. The approach also allows for the inclusion of functional, psychosocial and spiritual goals that help to improve a patient's wellbeing.[15]

Clearly communicating and documenting the goals

Everyone in the care team needs to understand the patient's goals. Clear verbal communication and documentation of goals of care ensures everyone has the same information and is focused on the same end points.

Verbally communicate and document intended care and goals to everyone the patient wants involved, in a way that is easy to understand. This ensures everyone has the same information and is focused on the same goals.

Track progress and check in to see if the patient's goals have changed, and revisit the goals for the patient as their care progresses, if their condition changes, or if their needs and preferences alter. Goal setting is an ongoing and iterative process.

Discussing and planning for future care

Advance care planning is a way to prepare for likely future health scenarios. Advance care planning is especially important for people who[19]:

■ Are older and frail

■ Have a chronic illness, multiple diseases or an early cognitive impairment

■ Are approaching their end of life.

Advance care planning should be based in shared decision making principles. These plans should reflect what a patient would like to happen should they no longer be able to make their own decisions. Early advance care planning can reduce the distress of substitute decision-makers by ensuring that the patient's wishes are known. Other members of the multidisciplinary team, such as social workers and senior nurses, can play a valuable role in assisting patients with advance care planning.

Appendix B is a list of resources to assist with advance care planning.

Essential element 4:
Use of triggers to recognise patients approaching the end of life

Intent

Patients who are likely to benefit from end-of-life care interventions are identified without delay.

Related Comprehensive Care Standard actions

5.15 The health service organisation has processes to identify patients who are at the end of life that are consistent with the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*.[4]

5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care advice.

Other relevant NSQHS Standards

Recognising and Responding to Acute Deterioration Standard

What this means

A 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.[4] This can be challenging for clinicians, as there is often a degree of uncertainty in determining prognosis and predicting death. There are some structured tools available.

The Consensus Statement specifies that it is important to recognise patients at two critical points[4]:

- 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 (the last days of life).

Identifying patients at these two points provides an opportunity to start a conversation with the patient about their options and preferences, and discuss the type of care they would like to receive in the future.

Taking action

There are different strategies clinicians can use to identify patients that may be approaching the end of their life, and instigate discussions about their care options.

Using tools and techniques to identify patients nearing the end of life

There are a range of tools and techniques that clinicians can use to help identify patients nearing the end of life. A review undertaken for the Commission identified 58 tools that are potentially suitable for the Australian context (see Appendix C). However, the evidence base supporting their use is limited. Clinicians need to assess the applicability of tools to the patient's clinical condition and setting in which the patient is being cared. When selecting tools, consider practical implementation factors that would influence a clinician's uptake of use.

Implementation strategies to encourage understanding and uptake in use should be incorporated in education. The Commission has undertaken exploratory surveys for the Australian Government Department of Health to determine clinician use of palliative care and prognostic assessment tools. The survey may be repeated regularly as part of the program of work to improve end-of-life care.

Two often used tools and techniques are:

- **The Surprise Question**[20]: The surprise question is a simple screening tool that relies on clinical reflection and judgement to identify people nearing the end of life. It involves the clinician considering a reflective question – 'Would you be surprised if this patient died within the next [X] months?'
- **Supportive & Palliative Care Indicators Tool (SPICT™)**[21]: SPICT™ is a conversation guide, including a set of questions, that helps clinicians identify people with general indicators of poor or deteriorating health, and clinical signs of life-limiting conditions for assessment and care planning. NHS Lothian and the University of Edinburgh Primary Palliative Care Research Group developed the tool.

Using clinical judgement to recognise factors

Although there is no agreed set of clinical indicators that definitively signify the end of life, there are a number of factors that – alone or in combination – could signal to clinicians that a patient may benefit from starting a conversation about their preferences should their condition deteriorate. These factors include:

- Multiple hospital admissions, especially unplanned admissions
- Complex multimorbidity
- Frailty
- Known trajectories of death for certain conditions
- At the point of diagnosis for some conditions, such as dementia and motor neurone disease
- Poor performance status on clinical scales (e.g. Australian-modified Karnofsky scale, Eastern Cooperative Oncology Group performance status)
- Continual problems with symptoms such as
  - unrelieved pain
  - dyspnoea and respiratory difficulties
  - nausea/vomiting and gastrointestinal issues
  - appetite changes, anorexia and oral health problems
  - fatigue/insomnia
  - psychological issues, such as depression and anxiety
- Considerable changes in condition requiring the introduction of new interventions (e.g. percutaneous endoscopic gastrostomy feeding or ventilator support).

Educating and training clinicians to identify patients at the end of life

Health service organisations providing excellent end-of-life care have processes to improve clinicians' comfort around discussing death and dying. This includes education to improve awareness of the symptoms that indicate a person could be deteriorating and the significance of the deterioration.

One example of an educational modules developed for clinicians is Flinders University's **End-of-Life Essentials Project**. This includes a suite of free peer-reviewed online education modules on health care at the end of life in acute hospitals for nurses, doctors and allied health professionals. A range of implementation tools are also available to assist managers and clinicians to implement a unified approach to strategies and processes to inform end-of-life care.

Another example is the **AMBER care bundle**, a tool that integrates identification of patients nearing end of life with actions and education for clinicians. Guy's and St Thomas' NHS Foundation originally developed the AMBER care bundle, and NSW Health adapted it for use in the Australian setting.

5

Essential element 5:
Response to concerns

Intent

Clinicians respond to patient suffering quickly and appropriately.

Related Comprehensive Care Standard actions

5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care advice.

5.18 The health service organisation provides access to supervision and support for the workforce providing end-of-life care.

5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care.

Other relevant NSQHS Standards

Communicating for Safety Standard

Recognising and Responding to Acute Deterioration Standard

What this means

It is important that a suitable skilled clinician or team provides timely and appropriate assistance when concerns are raised about a patient approaching the end of life and[22]:

- Is in distress
- Has a complex condition or difficult to manage symptoms
- For whom end-of-life decision-making is complex.

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, the NSQHS Standards now requires health service organisations to have communication processes for patients, families and carers to directly communicate critical information and escalate care concerns.

The patient, their support people or the clinicians and team caring for the patient may raise concerns. Concerns can relate to the patient's physical, mental, psychological or spiritual state as the patient nears the end of their life. Different responses may be needed depending on the type of concerns raised.

Taking action

There are strategies clinicians can use to respond to concerns about a patient at the end of life. These include:

- Supporting escalation of patient and family concerns
- Responding to physical health concerns
- Responding to mental, psychological, spiritual and cultural concerns.

Supporting escalation of patient and family concerns

There should be policies and processes that describe how patients, families and support people can communicate critical information or their concerns about changes in the patient's condition to the clinicians who are responsible for the patient's care. Processes could include informing patients, families and support people about:

- What could be considered critical information, changes they should look out for or their concerns about the patient's condition
- How they can communicate this information to the clinicians responsible for the patients care
- How they can access resources or communication tools that support them to communicate critical information to clinicians.

Clinicians should let patients and their support people know about processes to raise and escalate their concerns. Information on how to escalate concerns could be provided:

- On admission
- On posters, notices in ward areas or patient rooms
- As messages on waiting-room TVs
- On the organisation's website.

Responding to physical health concerns

A member of the clinical team, or a member of another team (such as an after-hours medical registrar or specialist palliative care clinician) may initially respond to concerns about end-of-life care.

If the patient does not improve with the original treatment plan, clinicians may need to escalate care to specialist palliative care or specialised services relevant to the specific concern. For instance, if the patient is experiencing unresolved pain, referral to a specialist pain management clinic or specialty team would be appropriate.

In some health service organisations, 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.

Responding to mental, psychological, spiritual and cultural concerns

It is important to ensure that the most appropriate person is involved in responding to mental, psychological, spiritual or cultural concerns for a patient. Having access to a multidisciplinary team that effectively communicates about the patients care, concerns and needs is key to safe and high-quality end-of-life care.

Allied health professionals such as mental health professionals, psychologists, social workers, Aboriginal and Torres Strait Islander health workers, spiritual care practitioners, speech pathologists and occupational therapists are often critical in addressing concerns about mental, psychological, spiritual and cultural health.

Timely referrals, and communication and coordination across the multidisciplinary team are essential for sensitive and compassionate end-of-life care.

Section B: Organisational prerequisites – supporting comprehensive end-of-life care

To achieve safe and high-quality end-of-life care, systems and processes that support clinicians to provide care consistently and effectively need to be in place.

This section describes some of the actions health service organisations can take to ensure organisational capability and capacity to deliver high-quality end-of-life care based on the five elements from the Consensus Statements:

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

Comprehensive care guides

Supporting the delivery of excellent end-of-life care is about delivering comprehensive care – that is, coordinated delivery of the total health care required or requested by a patient. This care is aligned with the patient's expressed goals of care and healthcare needs, considers the impact of the patient's health issues on their life and wellbeing, and is clinically appropriate. The Commission has developed a range of resources on comprehensive care that may be useful when considering organisational improvements for end-of-life care, including:

- *Implementing the Comprehensive Care Standard: A conceptual model for supporting comprehensive care delivery*[2]
- *Implementing the Comprehensive Care Standard: Essential elements for delivering comprehensive care.*[3]

6

Essential element 6:
Leadership and governance

Intent

End-of-life care should be included in the governance system of health service organisations.

Related Comprehensive Care Standard actions

5.1 Clinicians use the safety and quality systems from the Clinical Governance Standard when:

a) Implementing policies and procedures for comprehensive care

b) Managing risks associated with comprehensive care

c) Identifying training requirements to deliver comprehensive care.

5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care advice.

5.18 The health service organisation provides access to supervision and support for the workforce providing end-of-life care.

5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care.

Other relevant NSQHS Standards

Clinical Governance Standard

What this means

A systematic approach and committed leadership are necessary to support implementation of change within healthcare systems. Executive and clinical leaders at all levels of the organisation's clinical and corporate governance structures should provide proactive and practical support to the multidisciplinary teams and managers who are responsible for delivering end-of-life care.[23]

Health service organisations should ensure that the governance of systems for the delivery of end-of-life care aligns with the NSQHS Clinical Governance Standard and the Partnering with Consumers Standard. The **National Model Clinical Governance Framework** can assist health service organisations to implement clinical governance processes to support safer and better care for patients.

Taking action

There are several strategies that health service organisations can use to embed policies, procedures, processes and protocols to support high-quality end-of-life care into leadership and governance systems. These include:

- Regularly report to governing bodies about the safety and quality of end-of-life care
- Practicing compassionate leadership
- Fostering leaders who model delivery of safe and high-quality end-of-life care.

Regularly report to governing bodies about the safety and quality of end-of-life care

Health service organisations should establish systems and processes to regularly collect information, and monitor and regularly report to governing bodies about the safety and quality of end-of-life care delivery. This may include:

- Findings from regular audit and review processes
- Family, carer and support people's experiences of end-of-life care
- Staff experience, and feedback on caring for people at the end of their life
- Innovation and improved approaches to delivering end-of-life care.

Developing, monitoring and reviewing an organisation-wide plan or policy could help clarify expectations, roles and responsibilities, and improve consistency of processes within the service. This would also provide a level of accountability, visibility and governance.

Practising compassionate leadership

Compassionate leadership creates conditions where the needs and wellbeing of patients, carers and families, and the healthcare workforce are prioritised. For the workforce, compassionate leadership also creates avenues for professional development. Compassionate leadership is increasingly reported as having positive influence on end-of-life care and demonstrates qualities suited to managing end-of-life care services.[24]

Compassionate leadership contributes to improved innovation in health service organisations, and has been linked to reduced compassion fatigue. Evidence has shown that compassionate leadership shares qualities with servant leadership, resonant leadership, authentic leadership and relational leadership – all of which have been identified as leadership styles that may be suited for people who lead end-of-life care services.[24] For the workforce to succeed, compassion understanding and empathy are key characteristics of leadership and should be embedded in the organisation's values.

Fostering leaders who model delivery of safe and high-quality end-of-life care

Health service organisations can help provide safe and high-quality end-of-life care by fostering leaders who encourage a culture of ownership and responsibility for providing excellent end-of-life care. Board members, executives and leaders set the vision of great person-centred care and model desired behaviour.

Leaders that inspire role-modelling from those around them have qualities such as trustworthiness, integrity, a positive attitude, accountability and responsibility.[25] These leaders take time to know their employees, offer support and encouragement, promote a safe and healthy workplace, and lead by example.

To develop compassionate leadership approaches across the organisation, champions should be recognised at all levels of the organisation, and be appointed to guide implementation of end-of-life care improvement initiatives across administrative, research and clinical areas. Identify workforce members or clinical areas who provide exemplary end-of-life care and acknowledge their successes.

7

Essential element 7:
Education and training

Intent

Clinicians have the skills and knowledge to provide appropriate end-of-life care.

Related Comprehensive Care Standard actions

5.1 Clinicians use the safety and quality systems from the Clinical Governance Standard when:

a) Implementing policies and procedures for comprehensive care

b) Managing risks associated with comprehensive care

c) Identifying training requirements to deliver comprehensive care.

5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care advice.

5.18 The health service organisation provides access to supervision and support for the workforce providing end-of-life care.

Other relevant NSQHS Standards

Clinical Governance Standard

What this means

Education and training for clinicians and other workforce members should be provided on orientation so they understand their individual roles, responsibilities and accountabilities in delivering safe and high-quality end-of-life care. Refresher training should be provided whenever it is required.

The workforce will have different requirements for training according to their role and experience. Training should be tailored to the audience, such as clinical and nonclinical workforce. Topics to cover in workforce education could include:

- Talking about dying and end-of-life care goals with patients
- Cultural sensitivity and the role of culture in influencing a patient's experience of dying
- Supporting families, carers and other support people through end-of-life care
- Understanding grief
- Using locally agreed tools (e.g. comprehensive care plan for the dying patient, trigger tools)
- Appropriate observations and interventions
- Appropriate prescribing and use of terminal care as-required medicines
- Using opioids safely
- Documentation requirements
- Policies and procedures around death
- Recognising and responding to symptoms of deterioration
- Caring for a patient after death.

An example of freely available education and training is the **End-of-Life Essentials program** developed by Flinders University. This program is based on the Consensus Statements, and has been developed for and with doctors, nurses and allied health professionals around Australia.

Taking action

There are several strategies health service organisations can use to support workforce education and training to deliver high-quality end-of-life care. This includes:

- Using evidence-based teaching and learning strategies
- Providing communication training
- Using simulation training for breaking bad news
- Providing training and support for family, carers and other support people.

Using evidence-based teaching and learning strategies

Developing skills in end-of-life care can be obtained through a number of learning strategies including experiential learning, reflection, self-directed learning, mentoring, scenario analysis and role-playing. The following recommendations can be applied to a diverse range of settings and by all providers of end-of-life care education[26]:

- Use adult-learning teaching methods and concepts, including blended learning
- Use a multidisciplinary team of educators who have expertise in end-of-life and palliative care to facilitate learning
- Provide discipline-specific learning, where required, in addition to teaching common topics to the whole workforce
- Ensure the curriculum is culturally relevant, safe and respectful
- Use approaches that explore values, attitudes, assumptions and beliefs to promote the development of positive feelings about the care for people who are dying and their families and other support people
- Consider the range of clinical practice settings in the organisation to provide appropriate clinical learning opportunities that integrate the principles of end-of-life care.

Providing communication training

Communicating bad, sad or difficult news can be one of the hardest tasks for clinicians. Effectively communicating bad news with respect, empathy and compassion is a skill that is rarely taught but often necessary in health care. The way that health professionals deliver bad news can have a profound effect on a patient's psychological adjustment and functioning.[27,28]

Clinicians need to develop expert communication skills to deliver bad news to patients and families. Patients and families will have different information needs and capacity for understanding, processes and responding to bad news.

Many clinicians receive communication training as part of their professional development. Health service organisations could facilitate or provide extra training, such as about:

- Effective patient–clinician communication
- Including patients and their families and carers at transitions of care
- Using structured communication tools
- Shared decision making
- Risk communication
- Communicating within a team.

Resources to support communication are available on the Commission's **Communicating for Safety portal**.

Using simulation training for breaking bad news

Clinicians need to prepare themselves to feel upset or uncomfortable about delivering bad news. Role-playing can be useful in allowing clinicians to prepare for[29]:

- Dealing with unfamiliar situations
- Refining their communication and listening skills
- Learning from mistakes
- Becoming accustomed with the emotions that may arise when breaking bad news.

Health service organisations could integrate simulation training into their education and professional development programs. Advanced life support training and in-service education workshops are an opportune time for communication skills training and for clinicians to practice breaking bad news. Training topics could include:

- How to have difficult conversations
- How to do open disclosure.

Providing training and support for family, carers and other support people

Carers, families and support people may require education and training so they can help the dying person with their care needs. The clinical workforce usually delivers this training informally at the bedside. Health service organisations could consider developing more resources such as videos and pamphlets to support learning.

Strategies to support access to bereavement services and information about what happens after a patient dies include:

- Making funeral arrangements
- Explaining the requirements of coroner's cases and other obligatory notifications.

Essential element 8:
Supervision and support for multidisciplinary team members

Intent

Clinicians and other members of the healthcare team who provide end-of-life care have access to support, mentoring and supervision.

Related Comprehensive Care Standard actions

5.5 The health service organisation has processes to:

a) Support multidisciplinary collaboration and teamwork

b) Define the roles and responsibilities of each clinician working in a team.

5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care advice.

5.18 The health service organisation provides access to supervision and support for the workforce providing end-of-life care.

Other relevant NSQHS Standards

Clinical Governance Standard

What this means

Dealing with death and dying can be challenging for clinicians and other workforce members, and can add considerably to workplace stress. Chronic, unmanaged stress can erode empathy and potentially contribute to poorer experiences for patients, families and carers.[24] Health service organisations need to put processes in place to help workforce members access 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 help the clinicians and other workforce members, and to prevent or resolve distress.

Taking action

There are several strategies that health service organisations can use to ensure clinicians receive appropriate supervision and support to care for patients at the end of life.

Reducing workforce distress

Caring for people who are dying and their families can be stressful for clinicians and other workforce members. Health service organisations should develop processes to ensure that all members of the workforce know how to access supervision and support. Resources and training materials to help clinicians develop skills in self-care, reflective practice and providing peer support to colleagues are also useful.[30]

It is important to have a safe space where staff can reveal that they have been affected by a patient's death. Acknowledging that it is not a weakness or unprofessional to be touched by a patient's death is essential for allowing clinicians to express their feelings.[30]

Debriefing and discussing experiences as a team

Clinicians need to be given opportunities to talk openly about issues related to end-of-life care. This is especially important when there is conflict, controversy or disagreement around clinical management strategies.[29] Morbidity and mortality meetings are an opportunity to reflect on the end-of-life care provided, not just review whether the death was preventable. Morbidity and mortality meetings can also, along with debriefing sessions, provide a forum for clinicians to discuss their feelings and work through emotions. Some health service organisations have adopted Schwartz Rounds, where clinical caregivers discuss difficult emotional and social issues that arise from their work. Regardless of the format, clinicians need to recognise when a patient or family has affected them and take opportunities to talk freely about the human dimension of health care. Appendix D has an example discussion.

Promoting employee assistance programs

Many health service organisations have employee assistance programs that provide free and independent counselling to enhance psychological wellbeing for their workforce. These programs often employ external companies to provide confidential emotional and mental health support of employees in their work and personal lives. Health service organisations should regularly promote their employee assistance program to ensure the workforce has access to professional support.

Supporting nonclinical workforce members

Nonclinical members of the workforce who encounter dying patients and their families can also be affected by a patient's death.[30] Cleaners, porters, ward clerks, food services staff and other members of the workforce should be invited to debriefing sessions, when appropriate, and be given information about employee assistance programs. Non-clinicians should be included in any events that encourage good teamwork and support, such as team-bonding exercises, education and training sessions, and workforce celebrations.

Referring to bereavement services where needed

Some health service organisations routinely make follow-up contact with the bereaved family a few weeks after death. This allows clinicians to identify family members who are struggling and who may need referral to bereavement services or other support.

It may be appropriate to refer a workforce member to specialist bereavement services if they have severe or prolonged distress.

Essential element 9:
Evaluation, audit and feedback

Intent

The quality of end-of-life care is continuously measured, assessed and improved.

Related Comprehensive Care Standard actions

5.2 The health service organisation applies the quality improvement system from the Clinical Governance Standard when:

a) Monitoring the delivery of comprehensive care

b) Implementing strategies to improve the outcomes from comprehensive care and associated processes

c) Reporting on delivery of comprehensive care.

5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care.

Other relevant NSQHS Standards

Clinical Governance Standard

What this means

The processes and systems for delivering end-of-life care should be continuously monitored and evaluated to establish their effectiveness, track performance over time and determine priorities for improvement.

Health service organisations should audit the whole organisation for improvement and quality assurance purposes. The Commission developed the **End-of-Life Care Audit Toolkit** so hospitals can compile data in a manageable and uniform way. Having the capacity to collect and analyse these data allows organisations to:

- Review how care is being delivered
- Identify opportunities for better alignment with the Consensus Statement
- Identify ways to improve end-of-life care in general.

Taking action

There are several strategies that health service organisations can use to monitor, evaluate and improve the delivery of end-of-life care within their organisation.

Auditing end-of-life care delivery

Auditing the records of patients who have died in the health service organisation can help identify how end-of-life care is being delivered, including where inappropriate care may be delivered and if there are opportunities for improvement.[31]

The Commission has developed an **audit tool** that supports data collection, to provide a picture of current end-of-life processes in a health service organisation. The tool is freely available for organisations to use at their discretion to guide local improvement. Data are extracted from the records of patients who have died within the organisation, and includes:

■ Demographic data

■ Details on admission

■ Location of care and death

■ Previous admission patterns

■ Documented preferences for end-of-life care

■ Identified decision-makers

■ Evidence of resuscitation or escalation of care

■ Evidence of palliative care.

The Commission does not currently benchmark or collect the audit tool data.

Seeking clinicians' views on end-of-life care delivery

One of the challenges in implementing safe and high-quality end-of-life care is supporting and equipping clinicians to confidently deliver care that meets the needs and preferences of the patient at the end of life.

Clinicians are at the forefront of decision-making, so understanding their views and perspectives is critical to informing the education, support and strategies required to improve end-of-life care.

Use a **clinician survey** to capture the views of clinicians about the quality of end-of-life care in their hospital.

Seeking families, carers and support people's views on end-of-life care delivery

Health service organisations should actively engage consumers to evaluate service provision. The satisfaction of family, carers and other support people is based on their experience of the communication and support from the healthcare team. This information can be used to improve care.

Examples of strategies that can be used to seek these views include:

■ AHPEQS (Australian Hospital Patient Experience Question Set)

■ Patient and family satisfaction surveys

■ Computer-assisted personal interviewing

■ Analysis of complaints

■ Follow-up phone calls

■ Patient or family stories

■ Case conferences when patient and family members are included

■ Debriefing sessions when family members are included.

When collecting retrospective data, correspondence sent to family members after the patient's death should never be addressed to the patient.

Understanding team experience of end-of-life care delivery

Morbidity and mortality team meetings and grand rounds are valuable for reflection, education and improvement.[29] They allow an opportunity to critically analyse the care delivered and reported outcomes. Holding meetings regularly and including the whole multidisciplinary team embeds a richer learning environment and supports a culture of safety and improvement.

All clinical disciplines should attend team meetings or morbidity and mortality meetings. Team members should be allowed to identify enablers and barriers in the processes and systems where change may improve the experience of end-of-life care for the patient, family and the workforce. Reviewing the care provided against the expected, and actual, outcomes can be useful.

Meetings should be in a format designed to discuss the systems and processes of care, the workforce's emotional responses, and opportunities for improvement and plans for action. These meetings are not to discuss individual performance issues.

Reviewing comprehensive care plans

Organisations should have processes to monitor the effectiveness of implementing comprehensive care plans, as required in the NSQHS Standards. For patients at the end of life, the plan should detail the patient's preferences and goals for end-of-life care. Reviewing how care was delivered against the plan and preferences provides an opportunity to identify where improvements can be made.

The Commission has a range of resources that organisations can use to review how comprehensive care was delivered, including to patients at the end of life. Some of these are discussed in **Essential element 6: Review and improve comprehensive care delivery**.

Essential element 10:
Systems to support high-quality care

Intent

Systems align with NSQHS Standards to improve patient outcomes.

Related Comprehensive Care Standard actions

5.1 Clinicians use the safety and quality systems from the Clinical Governance Standard when:

a) Implementing policies and procedures for comprehensive care

b) Managing risks associated with comprehensive care

c) Identifying training requirements to deliver comprehensive care.

5.2 The health service organisation applies the quality improvement system from the Clinical Governance Standard when:

a) Monitoring the delivery of comprehensive care

b) Implementing strategies to improve the outcomes from comprehensive care and associated processes

c) Reporting on delivery of comprehensive care.

5.4 The health service organisation has systems for comprehensive care that:

a) Support clinicians to develop, document and communication comprehensive care plan for patients' care and treatment

b) Provide care to patients in the setting that best meets their clinical needs

c) Ensure timely referral of patients with specialist health care needs to relevant services

d) Identify, at all times, the clinician with overall accountability for a patient's care.

Related Comprehensive Care Standard actions *continued*

5.15 The health service organisation has processes to identify patients who are at the end of life that are consistent with the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*.[4]

5.16 The health service organisation providing end-of-life care has processes to provide clinicians with access to specialist palliative care.

Other relevant NSQHS Standards

Clinical Governance Standard

Partnering with Consumers Standard

Medication Safety Standard

Communicating for Safety Standard

Recognising and Responding to Acute Deterioration Standard

What this means

Health service organisations should embed best-practice end-of-life care in systems and processes. This may include policies and procedures to:

- Allow access to specialist palliative care advice
- Check the availability of specialist palliative care medicines
- Streamline end-of-life care pathways.

Health service organisations should also ensure that systems and processes are integrated and align with the requirements of the NSQHS Standards, especially the Clinical Governance Standard, the Partnering with Consumers Standard, the Communicating for Safety Standard, and the Recognising and Responding to Acute Deterioration Standard.

Taking action

There are several strategies that health service organisations can use to embed end-of-life care within their organisational systems and processes including:

- Developing an organisation-wide approach to delivering safe and high-quality end-of-life care
- Engaging with consumers when developing policies and process for end-of-life care
- Ensuring access to palliative care specialist advice
- Ensuring systems for access to palliative medications and equipment
- Refining processes for communication.

Developing an organisation-wide approach to delivering safe and high-quality end-of-life care

A health service organisation can improve their end-of-life care by developing an organisation-wide approach that may include:

- Using local data to understand common issues in the delivery of end-of-life care within the service
- Developing or adopting models of care that support improvement in end-of-life care for patients
- Implementing processes for monitoring delivery and outcomes of delivery of end-of-life care
- Providing access to training and education for the workforce on delivering safe and high-quality end-of-life care.

Developing an organisation-wide policy could help clarify expectations, roles and responsibilities, and improve consistency of processes within the service. A policy could also provide a level of accountability, visibility and governance.

Engaging with consumers when developing policies and process for end-of-life care

The health service organisation's governing body should develop effective partnerships with patients and consumers, and promote the organisation's engagement with patients and consumers.[23] When developing processes, policies and procedures, include consumer and clinician input to ensure their views and experiences are incorporated into governance. The governing body should define the expected quality of the patient experience, and set safety and quality priorities and targets.

Consumers should also be involved in the development of information about health service organisations to ensure that it is clear, easy to understand and relevant to the needs of patients and the local community.

Ensuring access to palliative care specialist advice

Health service organisations with a specialist palliative care service need to develop formal referral guidelines and processes for accessing informal advice from a specialist palliative care clinician.

If the organisation does not have a specialist palliative care service, develop agreements to seek advice from, and make referrals to, specialist palliative care providers in nearby organisations or in the community. In some cases, specialist palliative care advice may be limited to telephone support and videoconferencing. Such advice can be a source of primary information or a valuable sounding board to help make decisions about a patient's management. Develop clear guidelines to indicate when and how to seek such advice.

Ensuring systems for access to palliative medicines and equipment

Specific processes can be put into place to ensure clinicians can easily access palliative medicines. The facility type, size and location and access to pharmacy and other resources will be factors that need to be considered.

Systems also need to be in place for clinicians to access equipment such as pressure relieving devices, hoists, oxygen concentrators and syringe drivers. This is especially vital if a patient wants to die at home.

The **End-of-life care web page** has more information on medication management at the end of life.

Refining processes for communication

Delivering excellent end-of-life care depends on health service organisations having effective processes for:

- Communicating goals of care
- Discussing prognoses and advance care planning.

Developing clear communication processes helps the workforce to convey the required information, particularly during high-risk times such as transitions of care within and between health service organisations.

The **End-of-life care web page** has more information on developing end-of-life care processes.

Section C:
Extra material

Section C includes the appendices, a glossary and the reference list.

Appendix A: Resources to guide end-of-life conversations

PREPARED MODEL – A GUIDE FOR CLINICIANS
FOR CONVERSATIONS ABOUT THE LAST DAYS OF LIFE

P — Prepare for the discussion	• Confirm the clinical situation and appropriate treatment options • Try to ensure privacy and uninterrupted time. Mentally prepare yourself • Gauge patient and family readiness to discuss/develop a plan • Negotiate who should be present.
R — Relate to the person	• Introduce yourself and explain your role • Develop rapport and show empathy, care and compassion • Consider cultural and contextual factors which may influence preferences • Use appropriate body language and actively listen.
E — Explore priorities and concerns	• Clarify patient/caregiver's understanding of their situation and how much detail they want to know, before giving information • Explore the patient's priorities for care given their situation • Explore the family's priorities and concerns as well as their need for support • Summarize the patient's and family's most important priorities and concerns, and check if you have it right.
P — Provide information	• Ask permission to discuss what to expect • Pace and tailor delivery of information about the clinical situation and prognosis to the patient's/families' current understanding and wish for information • Explain uncertainty, limitations and unreliability of prognostic information • Offer recommendations for the patient's medical care for the last days of life that are clinically appropriate and, wherever feasible, align with the patient's priorities.
A — Acknowledge emotions and concerns	• Explore and acknowledge the patient's and caregiver's fears and concerns about dying • Respond to the patient's and caregiver's emotion and distress throughout the conversation • Acknowledge your own emotions – caring for the dying is an emotional time for all including the staff caring for the person. Remember to take time to reflect on the experience and care for yourself and your team.
R — Foster Realistic hope	• Be honest without being blunt and do not give misleading or false information • Reassure that all support and care will be given to control pain and other symptoms, and ensure the person is as comfortable as possible • Explore and facilitate any last realistic goals or wishes and ways of coping.
E — Encourage questions	• Be prepared to repeat explanations • Check understanding and if information provided meets needs • Leave the door open for topics to be discussed again in the future • Consider providing the CEC "Asking questions can help" leaflet • If you don't know the answers to questions, acknowledge the importance of the question and facilitate further information from appropriate sources or acknowledge uncertainty (e.g. how long).
D — Document	• Write a summary of what has been discussed in the medical record • Speak or write to other key health care providers involved in the patient's care e.g. Notify the GP when the patient dies. *The arrows indicate that these steps (E/P/A) are not linear. You will need to respond appropriately to emotions and concerns throughout the conversation.

PREPARED MODEL
FOR CONVERSATIONS ABOUT DYING – USEFUL PHRASES, QUESTIONS AND IDEAS FOR CLINICIANS

Prepare for the discussion
- "Is there anyone else you would like to be here with you while we talk?"

Relate to the person
- Remember we need to honour the dying person. This is a sacred time for them and their family. Small acts of kindness and respect for the person and their family can have a profound impact
- Spend much more time listening than talking
- *"If I've heard you right, you seem to be saying…"*

Exploring understanding, information needs, concerns and priorities
- Use open ended questions to explore (where feasible) the patient's concerns and priorities about how they are cared for and then explore the family's concerns and priorities for the patient's care, and their needs for support
- *"What have you been told about what is happening and what to expect?"*
- *"How much detail would you like from me about what is happening and what to expect?"*
- *"What is most important to you now about how we look after you?"*
- *"If [person's name] were able to talk to us, what do you think [he/she] would want us to know?"*
- *"Do you (or person's name) have any spiritual beliefs or cultural practices that we need to know about when thinking about the best care for you (or him/her)?"*
- *"Is there anything you really don't want to happen in terms of your care?"*
- *"Is there anything else we should know about your (or your relative/friend's) values and priorities in order to take the best care of you (or your relative/friend)?"*
- *"How can we best support the family?"*
- *"Are there any special rituals that you would like to arrange after (person's name) dies?"*

Providing information
- Give a warning when breaking the initial bad news. e.g. I'm afraid I have something serious to discuss
- As a guide give no more than 3 facts at a time, then stop talking and allow the person space to respond; avoid jargon
- *"Is it OK if we discuss a plan for how best to care for you now and in the future?"*
- *"We can see from your Dad's condition (not responding, swallowing, not eating and drinking etc.) that he is starting to die"*
- *"I'm concerned that (x) may not have very long to live and, while we don't know exactly how long he/she may have to live, we do know that time is likely to be short"*
- *"We recommend continuing good care and stopping (or not attempting) treatments that would be ineffective and distressing"*
- *"When the time comes I recommend allowing you to die naturally and doing everything we can to ensure you're as comfortable as possible. I recommend not attempting treatments, like CPR, that could cause distress and would not work in your situation"*

Acknowledging emotions and concerns
- Sometimes silence can be helpful, consider touch when culturally appropriate
- *"What are your biggest concerns at this point?"*
- *"Can you bear to tell me what's going through your mind after what we've just discussed?"*
- *"You mentioned you were concerned about …. Can you tell me more about that?"*
- *"It sounds like this information is different from what you expected. I think this would be very upsetting for anyone"*
- *"It can be very hard to think about dying. What worries you the most about what we've discussed?"*

Fostering realistic hope
- If there is uncertainty about whether or not the patient will die soon: *"We can prepare in case he/she gets much sicker while still hoping for the best"*
- *"What are the things you would like to do while you are still well enough?"*
- *"We will do everything we can to ensure that you are as comfortable as possible"*
- *"No matter what happens our team will be here to support you"*

Encouraging questions
- *"Do you have any questions or other concerns? Have I given you the information you need so far?"*
- *"Don't hesitate to ask me or the doctors/nurses again about any of the things we have discussed today"*
- *"If you think of anything else you want to ask me please write it down"*

Information sourced from: Clayton JM, Hancock KM, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Med J Aust 2007; 186(12):S77-108. Copyright 2007. The Medical Journal of Australia – adapted with permission. The Medical Journal of Australia does not accept responsibility for any errors in adaptation.

Last Days of Life

CLINICAL EXCELLENCE COMMISSION

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Further resources

- **Start the Conversation** – Australian Government
- **SHAPE End-of-life conversations** – e-learning for NSW Health employees
- **Dying to Talk** – Palliative Care Australia
- **Vital Talk** – a US website with freely available educational videos, communication tools, courses and resources.

Appendix B: Advance care planning

This section lists organisations and web pages that provide information about advance care planning.

National

- Advance Care Planning Australia:
- Aboriginal and Torres Strait Islander populations
- Advance care planning and mental health
- Cognitive Decline Partnership Centre (University of Sydney)
- Australian Government Department of Health.

State and territory

- ACT Government
- Clinical Excellence Queensland
- Government of Western Australia
- NSW Health
- NT Government
- SA Health
- Tasmanian Government
- Victoria Health.

Appendix C: Tools to recognise end of life

Table 2 identifies tools that were identified as possibly appropriate in the Australian healthcare setting to support clinicians to recognise end of life. The health service organisation should evaluate any tool for its validity, reliability, applicability and appropriateness before using it in the organisation.

Table 2: Tools that support end-of-life care

Tool name	Setting	Topic
ADEPT (Advanced Dementia Prognostic Tool)	Aged care	Dementia
AMBER care bundle	Hospital	General
APACHE II (Acute Physiology and Chronic Health Evaluation)	Intensive care unit (ICU)	General
Bruera poor prognostic indicator	Palliative care unit/ hospice	General
CARING	Hospital	General
CARSI (confusion, age [< 65, ≥ 65 to < 85 or ≥ 85], respiratory rate and shock index) CARASI (confusion, age [< 65, ≥ 65 to < 85 or ≥ 85], respiratory rate and temperature-adjusted shock index)	Hospital	Pneumonia
CHA2DS2 (Congestive heart failure, Hypertension, Age, Diabetes, previous Stroke/transient ischemic attack) CHA2DS2VASc (Congestive heart failure, Hypertension, Age, Diabetes, previous Stroke/transient ischemic attack, Vascular disease, Sex category)	Hospital	Syncope
Chuang Prognostic Scale	Palliative care unit/ hospice	General
CURB65 (Confusion, Urea, Respiratory, Blood pressure, Age 65) CRB65 (Confusion, Respiratory, Blood pressure, Age 65)	Primary care/general practice and hospital	Pneumonia
DECAF (Dyspnoea, Eosinopenia, Consolidation, Acidaemia, Atrial Fibrillation) score	Hospital	Chronic obstructive pulmonary disease
D-PaP (Dementia Palliative Prognostic) Score	Palliative care unit/ hospice	General
FACIT-Pal (Functional Assessment of Chronic Illness Therapy–Palliative Care)	Outpatient/ambulatory and hospital	General
Gagne Index	Community dwelling	General

Tool name	Setting	Topic
GMFCS (Gross Motor Function Classification Scale) and other specific measures of functioning	Outpatient/ambulatory and hospital	Often used for children with cerebral palsy or other physical disabilities
GPS (Glasgow Prognostic Score) mGPS (modified Glasgow Prognostic Score)	Not reported	Colorectal cancer in this study but developed for lung cancer and has been used for other types of cancer
GRACE ACS (Global Registry of Acute Coronary Events Acute Coronary Syndrome) risk calculator	Primary care/general practice and outpatient/ ambulatory	Acute coronary syndrome
GSF PIG (Gold Standards Framework – Prognostic Indicator Guide)	Primary care/general practice and hospital	Targets adults coming to the end of their lives that may need support via extra services (advance care, end of life, palliative care)
GWTG PMT (Get With the Guidelines – Stroke Patient Management Tool)	Hospital	Stroke
HOMR (Hospital-patient One-year Mortality Risk) score	Hospital	Syncope
iScore (Ischemic Stroke Predictive Risk Score)	Hospital	Stroke
Jellinge (hypoalbuminemia screen)	Hospital	General
Levine Index	Hospital	General
MDS MMRI-R (Minimum Data Set – Mortality Risk Index Revised)	Aged care	General
MEDS (Mortality in the Emergency Department Sepsis) score	Emergency department (ED)	Infection
MELD (Model for End-Stage Liver Disease) score	Hospital	Liver disease
MEWS (Modified Early Warning Score)	Hospital and ED	Surgery, but can be used for all patients as intended to identify patients at risk of deterioration
MHPM (Maintenance Hemodialysis Prognostic Model)	Outpatient/ambulatory	Kidney disease
MPI-SVaMA (Multidimensional Prognostic Index for mortality based on information collected by the Multidimensional Assessment Schedule)	Hospital and primary care/general practice	General
MPM0-III (Mortality Probability Model, version III)	Intensive care unit	General

Tool name	Setting	Topic
NECPAL CCOMS-ICO© Tool	Primary care/general practice	General
NRS (Nutrition Risk Screen)	Hospital	Congestive heart failure
NRI (Nutritional Risk Index)	Hospital	Congestive heart failure
OBSERVANT (Observational Study of Appropriateness, Efficacy and Effectiveness of AVR-TAVR Procedures for the Treatment of Severe Symptomatic Aortic Stenosis)	Outpatient/ambulatory and hospital	Transcatheter aortic valve replacement
OPS (Objective Prognostic Score)	Palliative care	General
PaP (Palliative Prognostic Score)	Palliative care/hospice	General
PARIS (Systolic Blood Pressure, Age, Respiratory Rate, Loss of Independence, and Peripheral Oxygen Saturation)	Hospital	General
P-CaRES (Palliative Care and Rapid Emergency Screening)	ED	General
PC-NAT (Palliative Care Needs Assessment Tool)	Palliative care/hospice	General
PPI (Palliative Prognostic Index)	Palliative care/hospice	General
P-PREP (Pediatric Extracorporeal Membrane Oxygenation Prediction)	ICU/hospital	Children primarily with respiratory failure receiving extracorporeal membrane oxygenation
PPS (Palliative Performance Scale)	Palliative care unit/ hospice	General
PREDICT (modified CARING tool)	ED	General
PSI (Pneumonia Severity Index)	Hospital	Pneumonia
RADPAC (Rapport, Analysis, Debate, Propose, Agreement, Close)	Primary care/general practice	General
SAPS-11 (Simplified Acute Physiology Score II)	Hospital	General
SHFM (Seattle Heart Failure Model)	Outpatient/ambulatory and hospital	Heart failure
SNAPPE-II (Score for Neonatal Acute Physiology Perinatal Extension)	ICU	Neonates undergoing surgery
SOAR (Stroke subtype, Oxford Community Stroke Project classification, Age, prestroke modified Rankin) score mSOAR (adds National Institutes of Health Stroke Scale data)	Hospital	Stroke

Tool name	Setting	Topic
SOFA (Sequential Organ Failure Assessment) score, and variants	ICU/hospital/ED	General
SPEED (Screen for Palliative and End-of-life care needs in the Emergency Department)	ED	Cancer
SPICT™ (Supportive and Palliative Care Indicators Tool)	Primary care/general practice and hospital	General
SQ (Surprise Question)	Various	General
STORM (acute coronary Syndrome in paTients end Of life and Risk assessment)	Hospital	Acute coronary syndrome
TM80+ (Tree Model)	ICU	General
Unnamed (Glare)	Outpatient/ambulatory	Cancer
Unnamed (Lee)	Hospital	Stroke
Unnamed (Zalenski 7-item palliative care screen)	ICU	General
VES-13 (Vulnerable Elders Survey – 13)	Community dwelling	General
VON-RA (Vermont Oxford Risk Adjustment) Tool	ICU	Neonates

Appendix D: Multidisciplinary team meetings

The following questions or discussion points are useful for structuring multidisciplinary team meetings that discuss morbidity and mortality.

Discuss every patient death:

- Have we had the right conversations?
- Did the patient know they were dying?
- Did the family know?
- Did we manage the patient's symptoms well?
- Would we do anything different in hindsight?
- Do we need any equipment or education (i.e. in service) to do better next time?

Suggested ways to select appropriate review cases includes those that:

- Are emotionally resonant
- Involve multiple disciplines/perspectives
- Shine a light on an issue or experience that's not often discussed
- Inspire participants to share their own experiences
- Highlights instances of compassionate care and/or barriers to providing compassionate comprehensive care
- Describes enabling leadership.

Strategies for identifying a range of topics include:

- Rotation of responsibility for case selection among different individuals or departments
- Areas of relevant local, state or national focus (e.g. hospital-acquired complications or healthcare variation)
- Topics related to current or annual events, holidays or seasonal trends (e.g. World Sepsis Day)
- Cases that highlight contributions from allied health and support staff
- Cases involving external providers, multiple teams or unusual circumstances
- Consider uplifting and challenging topics.

Source: Adapted from **The Schwartz Center**.

Glossary

Term	Definition
Carer	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 a spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care. A person is not considered a carer if they are paid, a volunteer for an organisation, or caring as part of a training or education program.[32]
Clinical governance	An integrated component of corporate governance of health service organisations. It ensures that everyone – from frontline clinicians to managers and members of governing bodies, such as boards – is accountable to patients and the community for assuring the delivery of safe, effective and high-quality services. Clinical governance systems provide confidence to the community and healthcare organisation that systems are in place to deliver safe and high-quality care.
Clinician	A healthcare provider, trained as a health professional, including registered and non-registered practitioners. Clinicians may provide care within a health 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, technicians, scientists and other clinicians who provide health care, and students who provide health care under supervision.
Comprehensive care	Health care that is based on identified goals for the episode of care. These goals are aligned with the patient's expressed preferences and healthcare needs, consider the impact of the patient's health issues on their life and wellbeing, and are clinically appropriate.
Comprehensive care plan	A document or electronic view describing agreed goals of care, and outlining planned medical, nursing and allied health activities for a patient. Comprehensive care plans reflect shared decisions made with patients, families, carers and other support people about the tests, interventions, treatments and other activities needed to achieve the goals of care. The content of comprehensive care plans will depend on the setting and the service that is being provided. Different health service organisations may refer to this plan differently and may be called different things in different health service organisations. For example, a care or clinical pathway for a specific intervention may be considered a comprehensive care plan.
Consumer	A person who has used, or may potentially use, health services, or is a carer for a patient using health services. A healthcare consumer may also act as a consumer representative to provide a consumer perspective, contribute consumer experiences, advocate for the interests of current and potential health service users, and take part in decision-making processes.[33]
Diagnosis	The identification by a clinician of a condition, disease or injury, made by evaluating the symptoms and signs presented by a patient.[34]
Discipline	A branch of knowledge within the health system.[35]
Diversity	The varying social, economic and geographic circumstances of consumers who use, or may use, the services of a health service organisation, as well as their cultural backgrounds, disability status, religions, beliefs and practices, languages spoken, sexual orientation, gender identity and gender expression, and sex characteristics.

Term	Definition
End of life	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be months to 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. People are generally considered to be 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: ■ 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.[4]
End-of-life care	Care and treatment at the end of life that includes physical and psychosocial assessment, which are delivered by clinicians and other members of the workforce. It also includes spiritual care, support of families and carers, and care of the patient's body after their death.[4]
Goals of care	Clinical and other goals for a patient's episode of care that are determined in the context of a shared decision-making process.
Governance	The set of relationships and responsibilities established by a health service organisation between its executive, workforce and stakeholders (including patients and consumers). Governance incorporates the processes, customs, policy directives, laws and conventions affecting the way an organisation is directed, administered or controlled. Governance arrangements provide the structure for setting the corporate objectives (social, fiscal, legal, human resources) of the organisation and the means to achieve the objectives. They also specify the mechanisms for monitoring performance. Effective governance provides a clear statement of individual accountabilities within the organisation to help align the roles, interests and actions of different participants in the organisation to achieve the organisation's objectives. In the NSQHS Standards, governance includes both corporate and clinical governance.
Health care	The prevention, treatment and management of illness and injury, and the preservation of mental and physical wellbeing through the services offered by clinicians, such as medical, nursing and allied health professionals.[36]
Health literacy	The Australian Commission on Safety and Quality in Health Care separates health literacy into two components[37]: ■ 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 health system. It affects the ways in which consumers access, understand, appraise and apply health-related information and services.
Health service organisation	A separately constituted health service that is responsible for implementing clinical governance, administration and financial management of a service unit(s) providing health care at the direction of the governing body. A service unit involves a group of clinicians and others working in a systematic way to deliver health care to patients. It can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients' homes, community settings, practices and clinicians' rooms.
Last days of life	The hours, days or, occasionally, weeks when a patient's death is imminent. This is sometimes referred to as the period when a person is actively dying or the terminal phase.

Term	Definition
Leadership	Having a vision of what can be achieved, and then communicating this to others and evolving strategies for realising the vision. Leaders motivate people, and can negotiate for resources and other support to achieve goals.[38]
Multidisciplinary team	A team including 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.[22] Multidisciplinary care includes interdisciplinary care. Also see **Discipline**.
Palliative care	An approach to treatment that focuses on improving the quality of life of patients and families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and thorough assessment and treatment of pain and other problems that can be physical, psychosocial and/or spiritual.[4]
Patient	A person who is receiving care in a health service organisation.
Person-centred care	An approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships between clinicians and patients.[39] 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 family and carers, and access to care.[40] Also known as patient-centred care or consumer-centred care.
Policy	A set of principles that reflect the organisation's mission and direction. All procedures and protocols are linked to a policy statement.
Procedure	The set of instructions to make policies and protocols operational, which are specific to an organisation.
Process	A series of actions or steps taken to achieve a particular goal.[41]
Protocol	An established set of rules used to complete a task or a set of tasks.
Quality improvement	The combined efforts of the workforce and others – including consumers, patients and their families, researchers, planners and educators – to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development.[42] Quality improvement activities may be undertaken in sequentially, intermittently or continuously.
Risk	The chance of something happening that will have a negative impact. Risk is measured by the consequences of an event and its likelihood.
Risk management	The design and implementation of a program to identify and avoid or minimise risks to patients, employees, volunteers, visitors and the organisation.
Risk screening	A short process to identify patients who may be at risk of, or already have, a disease or injury. It is not a diagnostic exercise; rather, it is a trigger for further assessment or action.

Term	Definition
Safety culture	A commitment to safety that permeates all levels of an organisation, from the clinical workforce to executive management. Features commonly include[43]: ▪ Acknowledgement of the high-risk, error-prone nature of an organisation's activities ▪ A blame-free environment in which individuals are able to report errors or near misses without fear of reprimand or punishment ▪ An expectation of collaboration across all areas and levels of an organisation to seek solutions to vulnerabilities ▪ A willingness of the organisation to direct resources to deal with safety concerns.
Screening	A process of identifying patients who are at risk of, or already have, a disease or injury. Screening requires enough knowledge to make a clinical judgement.
Shared decision making	A consultation process in which a clinician and a patient jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the patient's values, preferences and circumstances.[44]
Specialist palliative care	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 non-specialist clinicians who are providing palliative care.[4]
Spiritual care	The provision of assessment, counselling, support and ritual in matters of a person's beliefs, traditions, values and practices, enabling the person to access their own spiritual resources.
Training	The development of knowledge and skills.
Workforce	All the people working in a health service organisation, including clinicians and any other employed or contracted, locum, agency, student, volunteer or peer workers. The workforce can be members of the health service organisation or medical company representatives providing technical support who have assigned roles and responsibilities for care of, administration of, support of, or involvement with patients in the health service organisation. Also see **Clinician**.

References

1. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Sydney: ACSQHC; 2017.

2. Australian Commission on Safety and Quality in Health Care. Implementing the Comprehensive Care Standard: a conceptual model for supporting comprehensive care delivery. Sydney: ACSQHC; 2018.

3. Australian Commission on Safety and Quality in Health Care. Implementing the Comprehensive Care Standard: essential elements for delivering comprehensive care. Sydney: ACSQHC; 2018.

4. Australian Commission on Safety and Quality in Health Care. National consensus statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC; 2015.

5. Australian Commission on Safety and Quality in Health Care. National consensus statement: essential elements for safe and high-quality paediatric end-of-life care. Sydney: ACSQHC; 2016.

6. Broad JB, Gott M, Hongsoo K, Boyd M, He C, Connolly M. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Publ Health 2012;58(2):257–67.

7. Frank RK. Shared decision making and its role in end of life care. Brit J Nurs 2009;18(10):612–8.

8. Frost DW, Cook DJ, Heyland DK, Fowler RA. Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: a systematic review. Crit Care Med 2011;39(5):1174–89.

9. Hendricks J, Cope V, Sundin D, editors. Factors influencing medical decision – making for seriously ill patients in the acute care hospital. 5th Annual Worldwide Nursing Conference; 2017 24–25 July; Singapore.

10. Rawlings D, Tieman JJ, Sanderson C, Parker D, Miller-Lewis L. Never say die: death euphemisms, misunderstandings and their implications for practice. International journal of palliative nursing 2017;23(7):324–30.

11. McCabe MS, Wood WA, Goldberg RM. When the family requests withholding the diagnosis: who owns the truth? J Oncol Pract 2010;6(2):94–6.

12. American Medical Association. Withholding information from patients: code of medical ethics opinion 2.1.3 [Internet]. Chicago: AMA; 2020 [cited 2020 November 4]. Available from: **https://www.ama-assn.org/delivering-care/ethics/withholding-information-patients#:~:text=Except%20in%20emergency%20situations%20in,or%20consent%20is%20ethically%20unacceptable**

13. Boa S, Duncan EAS, Haraldsdottir E, Wyke S. Goal setting in palliative care: a structured review. Prog Pall Care 2014 2014/12/01;22(6):326–33.

14. Tassinari D, Drudi F, Monterubbianesi MC, Stocchi L, Ferioli I, Marzaloni A, et al. Early palliative care in advanced oncologic and non-oncologic chronic diseases: a systematic review of literature. Rev Recent Clin Trials 2016;11(1):63–71.

15. Australian Commission on Safety and Quality in Health Care. Implementing the Comprehensive Care Standard: identifying goals of care. Sydney: ACSQHC; 2019.

16. Spiritual Health Association. Guidelines for quality spiritual care in health. Melbourne: SHA; 2020.

17. Pace JC, Mobley TS. Rituals at end-of-life. Nurs Clinics N Am 2016;51(3):471–87.

18. Kalsi D, Ward J, Lee R, Wee B, Fulford KW, Handa A. Recognizing the dying patient, when less could be more: a diagnostic framework for shared decision-making at the end of life. Journal of patient experience 2020;7(4):621–8.

19. Advance Care Planning Australia. What is advance care planning [Internet]. Melbourne: Austin Health; 2018 [cited 2019 July 22]. Available from: **https://www.advancecareplanning.org.au/individuals/what-is-advance-care-planning**

20. Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NKJ. The 'surprise question' for predicting death in seriously ill patients: a systematic review and meta-analysis. CMAJ 2017;189(13):E484–E93.

21. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 2014;4(3):285–90.

22. Mitchell GK, Tieman JJ, Shelby-James TM. Multidisciplinary care planning and teamwork in primary care. MJA 2008;188(S8):S61–S4.

23. Australian Commission on Safety and Quality in Health Care. National Model Clinical Governance Framework. Sydney: ACSQHC; 2017.

24. Hewison A, Sawbridge Y, Tooley L. Compassionate leadership in palliative and end-of-life care: a focus group study. Leadersh Health Serv 2019;32(2):264–79.

25. Nancarrow SA, Booth A, Ariss S, Smith T, Enderby P, Roots A. Ten principles of good interdisciplinary teamwork. Hum Resour Heal 2013;11(19):1–11.

26. CareSearch. Develop skills in teaching and learning in palliative care [Internet]. Adelaide: Australian Government; 2018 [cited 2019 January 14]. Available from: **https://www.caresearch.com.au/caresearch/tabid/3887/Default.aspx**

27. Ptacek J, Eberhardt T. Consensus recommendations for breaking bad news. JAMA 1996;276(6).

28. Monden KR, Gentry L, Cox TR. Delivering bad news to patients. Proc (Bayl Univ Med Cent) 2016;29(1):101–2.

29. Buljac-Samardzic M, Dekker-van Doorn CM, van Wijngaarden JDH, van Wijk KP. Interventions to improve team effectiveness: a systematic review. Health Pol 2010;94(3):183–95.

30. Hill RC, Dempster M, Donnelly M, McCorry NK. Improving the wellbeing of staff who work in palliative care settings: a systematic review of psychosocial interventions. Pall Med 2016;30(9):825–33.

31. Australian Commission on Safety and Quality in Health Care. Development of the end-of-life audit toolkit: a summary report. Sydney: ACSQHC; 2018.

32. Carer Recognition Act 2010, No. 123 (2010).

33. Consumer Health Forum of Australia. About consumer representation [Internet]. Canberra: CHF; 2020 [cited 2020 April 23]. Available from: **https://chf.org.au/representation**

34. The American Heritage Science Dictionary. Diagnosis [Internet]. Houghton Mifflin Company; 2018 [cited 2019 July 7]. Available from: **www.dictionary.com/browse/diagnosis**

35. Oxford University. Discipline [Internet]. Oxford: Oxford University Press; 2020 [cited 2020 April 23]. Available from: **www.lexico.com/definition/discipline**

36. Australian Commission on Safety and Quality in Health Care. Australian Open Disclosure Framework. Sydney: ACSQHC; 2013.

37. Australian Commission on Safety and Quality in Health Care. Health literacy: taking action to improve safety and quality. Sydney: ACSQHC; 2014.

38. World Health Organization. Leadership and management. In: Operations manual for delivery of HIV prevention, care and treatment at primary health centres in high-prevalence, resource constrained settings. Geneva: WHO; 2008:264–81.

39. Institute for Patient- and Family-Centred Care. Patient- and family-centred care [Internet]. Bethesda, MD: IPFCC; 2020 [cited 2020 April 23]. Available from: **www.ipfcc.org/about/pfcc.html**

40. Australian Commission on Safety and Quality in Health Care. Patient-centred care: improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC; 2011.

41. Oxford University. Process [Internet]. Oxford: Oxford University Press; 2020 [cited 2020 April 23]. Available from: **www.lexico.com/definition/process**

42. Batalden PB, Davidoff F. What is 'quality improvement' and how can it transform healthcare? Qual Safe Health Care 2007;16(1):2–3.

43. Institute for Healthcare Improvement. Quality improvement and patient safety glossary [Internet]. Boston, MA: IHI; 2015 [cited 2015 July 9]. Available from: **www.ihi.org/education/IHIOpenSchool/resources/Pages/Tools/QualityImprovementAndPatientSafetyGlossary.aspx**

44. Hoffmann TC, Legare F, Simmons MB, McNamara K, McCaffery K, Trevena LJ, et al. Shared decision making: what do clinicians need to know and why should they bother? MJA 2014;201(1):35–9.