

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

TRIM: D22-40333

September 2022

National Consensus Statement

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

Consultation Draft

Published by the Australian Commission on Safety and Quality in Health Care
Level 5, 255 Elizabeth Street, Sydney NSW 2000

Phone: (02) 9126 3600

Email: mail@safetyandquality.gov.au

Website: www.safetyandquality.gov.au

ISBN: XXX-X-XXXXXX-XX-X OR

ISSN (print): XXXX-XXXX (for yearly publications only. Delete if using ISBN)

ISSN (online): XXXX-XXXX (for yearly publications only Delete if using ISBN))

© Australian Commission on Safety and Quality in Health Care 2022

All material and work produced by the Australian Commission on Safety and Quality in Health Care (the Commission) is protected by copyright. The Commission reserves the right to set out the terms and conditions for the use of such material.

As far as practicable, material for which the copyright is owned by a third party will be clearly labelled. The Commission has made all reasonable efforts to ensure that this material has been reproduced in this publication with the full consent of the copyright owners.

With the exception of any material protected by a trademark, any content provided by third parties and where otherwise noted, all material presented in this publication is licensed under a [Creative Commons Attribution–NonCommercial–NoDerivatives 4.0 International licence](https://creativecommons.org/licenses/by-nc-nd/4.0/).



Enquiries about the licence and any use of this publication are welcome and can be sent to communications@safetyandquality.gov.au.

The Commission's preference is that you attribute this publication (and any material sourced from it) using the following citation:

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; 2022

Disclaimer

The content of this document is published in good faith by the Commission for information purposes. The document is not intended to provide guidance on particular healthcare choices. You should contact your health care provider for information or advice on particular healthcare choices.

The Commission does not accept any legal liability for any injury, loss or damage incurred by the use of, or reliance on, this document.

Contents

Introduction	4
Purpose	4
Scope	4
Application	5
Guiding principles.....	7
Essential Elements.....	8
Section A: Care processes	8
Section B: Organisational prerequisites	8
Essential element 1: Recognising end of life	9
Essential element 2: Person-centred communication and shared decision making.....	11
Essential element 3: Multidisciplinary collaboration and coordination of care	14
Essential element 4: Comprehensive care.....	16
Essential element 5: Responding to concerns	18
Essential element 6: Leadership, governance, and readiness.....	19
Essential element 7: Support, education, and training.....	21
Essential element 8: Care setting and bereavement support	23
Essential element 9: Evaluation, audit and feedback	24
Essential element 10: Systems to support high-quality care	26
Glossary.....	27
References.....	30

Introduction

The health care that people receive in the last years, months and weeks of their lives can help to minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers.³⁻⁶ The purpose of this National Consensus Statement: essential elements for safe and high-quality end-of-life care (the Consensus Statement) is to describe the elements that are essential for delivering safe and high-quality end-of-life care in Australia. The Consensus Statement sets out suggested practice for the provision of end-of-life care in settings where health care is provided.

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

Since 2015, evidence supporting safe and high-quality end-of-life care has evolved. This second edition of the Consensus Statement has been developed to incorporate the findings of two rapid literature reviews^{7, 8} and consultation with primary and community care.

Purpose

The Consensus Statement sets out agreed practice for prompt recognition of end of life and safe, high-quality care.

The Consensus Statement has been developed for:

- Healthcare workers who are involved in the provision of health care to people who are approaching the end of their life
- Aged care and health service executives and managers who are responsible for developing, implementing, and reviewing systems for delivering person-centred care, including end-of-life care, in individual health services or groups of health services
- Providers of clinical education and training, including universities and professional colleges
- Health professional registration, regulation, and accreditation agencies
- Planners, program managers and policy makers who are responsible for developing state or territory, or other strategic programs dealing with the delivery of end-of-life care.

Scope

This Consensus Statement applies to all services where healthcare is provided to people approaching end of life, including hospitals, hospices, residential aged care facilities and home settings. The Consensus Statement relates to situations where people who are approaching the end of their lives would benefit from receiving safe and high-quality end-of-life care.

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

Safety and quality standards, such as the National Safety and Quality Health Service (NSQHS) Standards and the National Safety and Quality Primary and Community Healthcare (NSQPCH) Standards require that organisations put systems in place that are consistent with this Consensus Statement.⁹ Health service organisations that are not assessed or undertake voluntary assessment can also use this Consensus Statement to guide improvements in end-of-life care.

It may be particularly appropriate to apply the elements of the Consensus Statement at two points in time near the end of life:

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

End-of-life care is person-centred, and actions should be applied when relevant to the person's condition. For example, some aspects of advance care planning may no longer be as relevant when a person is actively dying, whereas good symptom control remains relevant during terminal care as well as for quality of life over the longer term.

Voluntary assisted dying (VAD) laws have been passed in Australian states and will be in effect by November 2023. Specific requirements for VAD are not discussed in this document as each state has its own legislation that regulates access and should be referred to if a person is considering this option.

The Consensus Statement does not always specifically refer to substitute decision-makers, family, carers and other support people, however these people should be included if this is what the person at end of life prefers.

The elements and actions within the Consensus Statement are designed to apply to all clinical conditions, and all people, including adults, adolescents, children and babies. Any differences will be specified.

Application

The Consensus Statement aligns with the NSQHS Standards and NSQPCH Standards, and provides recommended, rather than mandatory, practice. It also aligns with the [*National Consensus Statement: essential elements for recognising and responding to acute physiological deterioration \(3rd ed\)*](#),¹⁰ and it is intended that these documents be applied together.

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

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

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

Guiding principles

1. Dying is a part of life and a human experience, not just a biological or medical event.
2. Safe and high-quality end-of-life care is person and family-centred. People must be allowed to direct their own care, whenever possible.
3. Care should be aligned with the values, needs, and wishes of the individual, and their family or carers. Such care should consider the person's expressed wishes regarding the circumstances, environment, and place in which they wish to die. A person's needs, goals, and wishes at the end of life may change over time.
4. People should be provided with health information that they understand and supported to make decisions. If a person lacks capacity to participate in decision-making about their care, a substitute decision-maker should be sought.
5. Providing for the cultural, spiritual, and psychosocial needs of people, and their families and carers, is as important as meeting their physical needs.
6. Recognising when a person is approaching the end of their life is essential to delivering safe and high-quality end-of-life care that is appropriate, compassionate, and timely. A person's transition to the terminal phase of life must be documented and communicated to them, their families, carers, and other healthcare workers.
7. The prognosis and the way that people respond to medical treatment will vary between individuals. This means that there is potential for ambiguity and uncertainty at the end of life. This must be honestly and openly acknowledged, and discussed with people who are dying, substitute decision-makers, families, and carers.
8. Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled, and experienced multidisciplinary teams.
9. Safe and high-quality end-of-life care requires effective communication, collaboration, and teamwork to ensure continuity and coordination between teams, within and between settings, during transitions, and across multiple episodes of care.
10. End-of-life decision-making should be shared between the person and the multidisciplinary team. Substitute decision-makers, families and carers should be involved, in accordance with the person's expressed wishes and/or legislation.
11. People have the right to refuse medical treatments. Decisions regarding treatment may be made in advance and remain valid unless the person (or substitute decision-maker, family, and carers) state otherwise.
12. It is unethical to harm people by providing burdensome investigations, treatments and transfers that can be of no benefit.
13. Unless required by law, doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the person's quality of life.
14. Care of the deceased person, and care for families and carers extends beyond the death of the person.

Essential Elements

The essential elements of this Consensus Statement are the features that are required in healthcare systems to ensure safe and high-quality care for people who are approaching the end of life. These elements do not prescribe how care should be delivered. Application of the elements will vary according to the local circumstances of the setting, the available resources, and the individual needs and preferences of the person receiving care.

This Consensus Statement contains 10 essential elements.

Section A (Elements 1–5) relates to the way in which end-of-life care should be approached. Section B (Elements 6–10) relates to structural and organisational prerequisites for the effective delivery of safe and high-quality end-of-life care. Section B should be contextualised to the service and some actions may not be applicable in primary health and community settings.

Each element begins with a brief introductory statement, which is followed by a list of requirements that describe the necessary processes and systems to effectively address the element.

Section A: Care processes

1. Recognising end of life
2. Person-centred communication and shared decision-making
3. Multidisciplinary collaboration and coordination of care
4. Comprehensive care
5. Responding to concerns

Section B: Organisational prerequisites

6. Leadership, governance and readiness
7. Care setting and bereavement
8. Support, education and training
9. Evaluation, audit and feedback
10. Systems to support high-quality care

Section A: Care processes

A fundamental step in providing safe and high-quality end-of-life care is to recognise people who would benefit from such care.¹¹ End-of-life care is comprehensive care - the coordinated delivery of the healthcare required by the person. Everyone involved in end-of-life care needs to work together effectively to provide comprehensive care and achieve a person's goals. All people have a right to dignity, comfort, and privacy, and to be cared for respectfully and with compassion. The prevention and relief of suffering is the highest priority.

[Shared decision making](#) is a critical part of making sure that people approaching the end of their lives are partners in their own care.¹²

Essential element 1: Recognising end of life

Routine use of simple trigger tools and questions can prompt healthcare workers to use their clinical judgment to make a holistic assessment of whether a person might benefit from end-of-life care.^{11, 13}

Recognising that a person is at end of life offers opportunities to identify their needs. This includes reviewing the [comprehensive care plan](#) to align care with the individual's expressed values, goals and wishes.

Predicting prognosis and the timing of dying can be difficult.¹⁴ For some people, it may be difficult to distinguish reversible from irreversible deterioration that is part of the normal dying process. In such cases, it may be appropriate to consider a trial of treatment for a defined period to assess reversibility of a person's deterioration.

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

Health service organisations providing end-of-life care should aim to identify people at two critical points:

- when a person 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 person is likely to die in the short term (i.e. within days to weeks) and clinical deterioration is likely to be irreversible.

Children

- Children die from a range of conditions not widely seen in the adult population. The diversity of conditions can lead to a variety of illness trajectories.
- Life-limiting conditions can be extremely rare and sometimes there is no definitive diagnosis².
- For some children with life-limiting conditions, a palliative approach may be appropriate for many years before the terminal phase.
- Conditions are sometimes familial. Other children in the family may be conceived with, lived with, or died from, the same condition.²

- 1.1** The 'surprise' question^{14, 15} is used by healthcare workers as a simple screening mechanism to recognise people who could benefit from end-of-life care interventions. Healthcare workers should ask themselves:
- Would you be surprised if this person died in the next 12 months?
 - Would you be surprised if this person died in the next days or weeks?
- 1.2** Referral to palliative care is triggered when the person or healthcare worker requests palliative care, or when family members or carers express concern or worry that the person is dying or has unmet end-of-life care needs.
- 1.3** Condition-specific mortality risk prediction tools or critical events trigger healthcare workers to consider end-of-life care, in the following circumstances:¹⁶
- Diagnosis of life-limiting conditions
 - Poor or incomplete response to medical treatment
 - Continued deterioration despite intervention, such as decline in the person's condition, or a clinical determination that they will not benefit from interventions such as surgery, dialysis, or treatment in intensive care
 - Development of new clinical problems
 - Repeated calls in an acute facility to the rapid response team, particularly if the person has been admitted for more than one week
 - Advanced age with increased frailty, reduced mobility, and increased dependence on others to assist in performing activities of daily living
 - Moderate to severe dementia
 - Multisystem comorbidities (cardiovascular, pulmonary, endocrine, etc.)
 - Limit of medical therapy reached
 - Multiple recent admissions to hospital for exacerbation of a chronic condition
 - Unexpected, multiple, or extended stays in hospital.

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

Healthcare workers should communicate with people in a person-centred way to share decisions about care at the end of life. Significant events that may indicate that conversations about end-of-life care should occur are listed 1.3 as well as when a person is actively dying or expresses interest in discussing end-of-life care.

Having conversations about death, dying and the end of life requires compassion, knowledge, experience, sensitivity, and skill of the healthcare worker(s) involved. All communication processes should recognise and be responsive to the individual preferences and needs of the person at end of life. Plain language should be used, avoiding euphemisms (like “not doing well”), and taking into consideration cultural requirements.

The purpose of end-of-life care conversations will depend on the circumstances of the person. In some cases, the purpose will be to impart information and in other cases, there may be decisions about specific aspects of care to be made. Early referral to support services for Aboriginal and Torres Strait Islander peoples, people with disability, and people from diverse populations should be promoted to actively engage with families throughout the dying process.⁷

Health services should consider dignity of risk when developing end-of-life processes.

Maximising the input and voice of people in their care is an obligation of all healthcare workers particularly with those unable to participate fully in decision-making. The capacity of people to participate in decision-making may fluctuate and supported decision-making may be necessary. Supported decision-making means that healthcare workers maximise opportunities for participation. This might mean deferring decisions until the person is more able to participate. Where this is not possible, healthcare workers should work with carers and families to support the person to be as involved in decision-making as their capacity at the time will allow. Substitute decision-makers, families and carers should be included in decision making, according to the person’s expressed wishes, and state or territory legislative frameworks.

When opportunities for shared or supported decision-making are limited or impossible – for example, because the person is dying suddenly and unexpectedly – healthcare workers

should check that the person understands what has been discussed and the subsequent plan of care.

Children

Healthcare workers should involve children as much as possible in discussions about their own care, even when they are not able to make decisions on their own. The child's level of involvement in decision-making should be based on their age and capacity. Decisions relating to the care of a child must be made in the child's best interests in accordance with legislation.

It is critical to recognise the primary role of parents in decision-making, to consider their wishes about communication with their child, and to support them to involve the child in decision-making that is appropriate for their age and capacity.

In most cases parents hold legal responsibility for decision-making about their child's care and have the right to refuse medical treatments for their child provided such a decision does not go against the child's best interests.

LGBTQ+ people

The LGBTQ+ community have some specific needs and concerns when it comes to end of life care. Many LGBTQ+ people have experienced trauma, particularly in health and institutional settings, that may make them apprehensive about seeking aged care and palliative care. They fear stigma, discrimination, and a lack of understanding of the needs of the LGBTQ+ community. People are particularly concerned that their identities and relationships are respected.

Steps towards improving awareness and inclusion may include ensuring inclusive promotional material and website content across your practice or organisation, staff training on working with the LGBTQ+ community, and embedding inclusion into organisational policy and procedures.

- 2.1** Identify opportunities for proactive and pre-emptive end-of-life care discussions with the person, to increase the likelihood of delivering high-quality end-of-life care aligned with the person's values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations.
- 2.2** Work with the person to identify the substitute decision-maker, family spokesperson or other key contacts that the person wishes to be involved in discussions about their care.
- 2.3** Identify culturally appropriate decision maker(s) as early as possible so that strategies can be put in place for obtaining their input into discussions about end-of-life care as assumptions about death and dying, and about persons and families as decision-makers may not be correct.
- 2.4** Seek to understand, and be respectful, sensitive, and responsive to the individual preferences and needs of the person at end of life, including their identity, culture, religious belief, gender, or orientation, and loved ones (including family of choice)
- 2.5** Prepare for having conversations about end-of-life care. Necessary preparation may include:

- Discussions involving the person's general practitioner or care coordinator about prognosis and options to develop a coordinated approach to the planning and delivery of end-of-life care
 - Ensuring familiarity with the person's history and current condition, their family structure, and cultural needs and preferences
 - Arranging adequate time for uninterrupted discussion in a quiet and private environment
 - Ensuring that people have access to their regular communication aids
 - Arranging for the appropriate people to be in attendance – ideally, this will include the person, their substitute decision-maker, carers and family members, and other appropriate healthcare workers.
- 2.6** Provide the person with written information identifying the healthcare worker responsible for leading and coordinating their end-of-life care. Whenever possible, involve this healthcare worker in all discussions.
- 2.7** Ensure end-of-life conversations are person-centred and tailored to meet the health literacy needs of the person and any other participants.
- 2.8** The healthcare worker responsible for leading and co-ordinating care provides the person with an honest and straightforward summary, in plain language, of their clinical assessment of the situation, what they consider to be appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the person's condition improving in response to such treatment.
- 2.10** Be compassionate and sensitive to the person's situation. Allow adequate time for those involved to absorb, process, and react to information provided. Multiple discussions may be required.
- 2.11** Conduct end-of-life discussions routinely include information about organ and tissue donation for transplantation, in circumstances where donation is possible. Ensure these discussions are conducted with advice from the state or territory DonateLife agency and are led by healthcare workers who have attended the core Family Donation Conversation workshop.
- 2.12** Provide support to make decisions with people at end of life, their families, and carers. Extra support may be required for those with communication or decision-making needs.
- 2.13** Clearly document the content of the discussion and any agreed plan of care in the person's healthcare record and My Health Record if available. Document any unresolved issues along with a plan for follow-up.
- 2.14** Communicate the content of the discussion and plan of care, including any limitations of medical treatment to all healthcare workers involved in the person's care.

Essential element 3: Multidisciplinary collaboration and coordination of care

An identified person should take overall responsibility for coordinating a dying person's care and ensuring effective communication and collaboration.¹⁷ This could be a family member, general practitioner, nurse navigator or someone else depending on the circumstances.

People often receive care from a range of organisations with different systems, roles, and approaches to managing end-of-life care. Healthcare workers involved in a dying person's care have varied experience, values and perspectives on planning and providing end-of-life care. Multidisciplinary collaboration is a process where healthcare workers from different disciplines and/or health services share clinical information to optimise the delivery of comprehensive care for a patient.

Care coordination reduces the risk of receiving discordant information and poorly coordinated care¹⁸ and improves personal satisfaction.¹⁹ It requires roles and responsibilities to be clear, and processes need to be in place for care planning and exchange of information. The person's goals of care and the comprehensive care plan need to be clear to all healthcare workers, so that care can be effectively coordinated. This includes ensuring effective communication and liaison between all health services involved in care, particularly at the interface between different services and teams such as between the hospital and community-based services, or between the treating team and after-hours care providers.

- 3.1** Clearly identify the healthcare worker with overall responsibility for leading and coordinating a person's end -of-life care. If the person is unable to speak for themselves, their substitute decision-maker must also be clearly identified.
- 3.2** Ensure the roles and responsibilities of all healthcare workers are clearly defined and understood by the person and all those involved in their care.
- 3.3** The healthcare team is responsible for:
 - Providing timely and accurate information regarding the person's condition, the severity or stage of their condition, the expected disease trajectory, the available treatments, and the likelihood of response to such treatments
 - Communicating information to support people (or substitute decision-makers, families, and carers) to make decisions about care, and to check that they understand the implications, consequences and risks associated with such decisions
 - Inviting people to participate in the process of advance care planning, and create opportunities for them to make decisions and to communicate their values, goals and wishes regarding their end-of-life care
 - Offering support, expert opinion, and advice so that people (or substitute decision-makers, families, and carers) can participate in fully informed, shared (or supported) decision-making
 - Identifying existing advance care plans and provide care in accordance with the person's expressed wishes

- Documenting, communicating, and handing over to other healthcare workers involved in the person's care, the agreed care plan, and any limitations of medical treatment.
- 3.4** Discuss the range of views for future treatment and the reasons with the person to ensure agreement and reduce ambiguity about options.
- 3.5** Ensure processes are in place to enable all healthcare workers to voice concerns, and act on the expressed preferences and consent of the person.

Consultation Draft

Essential element 4: Comprehensive care

The goal of healthcare workers providing end-of-life care should be to deliver comprehensive care that is appropriate to the needs and condition of the person and aligned with their expressed wishes. Goals and wishes for a person's end-of-life care should be sought early, and psychosocial, spiritual, cultural, and emotional support offered. Treatments that maintain or improve quality of life should be provided, and burdensome or unwanted investigations and treatments avoided. Palliative interventions may be provided in conjunction with curative treatment.

People have the right to refuse medical treatment.

Doctors are under no obligation to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the person's quality of life.²⁰ Specific medical decisions about treatments that could be provided in the event of deterioration may be recorded in the comprehensive care plan.

For many people approaching the end of life, there will be a long period of transition when treatment will continue for reversible complications or reversible episodes of deterioration. People at this stage may benefit from a palliative approach, in conjunction with active medical treatment of their illness.

Processes should be in place to support proactive, anticipatory, and individualised planning for end-of-life care. When treatments cease to provide benefit or become uncomfortable and burdensome, the comprehensive care plan should focus on providing comfort to both the dying person and their family and carers. The person's terminal care should be clearly documented in the comprehensive care plan, including plans for managing physical, psychosocial, emotional, cultural, and spiritual needs. Support should be offered to include cultural, spiritual, or religious practices.

Children

- Children should be supported to play, learn, and socialise with friends if they wish. For adolescents this could include a partner.
- Referral pathways to relevant adult health services should be available for children with life-limiting conditions who are likely to survive past 18 years of age

Dementia

Activities that enhance engagement with external stimuli have shown to reduce symptoms associated with dementia in people at end of life. The symptomatic benefits of Namaste Care in both the residential and home care settings have been reported.¹ Sessions provide ongoing opportunities to interact and engage, develop interpersonal trust and equip carers to cope more effectively with the challenging behavioural and psychological symptoms of dementia.

- 4.1 Discuss goals of care, comprehensive care plan and any limitations of medical treatment and make sure they are clearly documented in the person's healthcare record by the treating healthcare worker/s. Arrange this as early as possible, and ensure the information is routinely reviewed and updated.

- 4.2 Offer or revisit [advance care planning](#) for people who are likely to die within the short or medium term.
- 4.3 Avoid unnecessary burdens associated with medical treatment. This includes non-beneficial investigation, interventions and medications and unnecessary observations.
- 4.4 Clearly communicate medical decisions, including the rationale, to discontinue or not instigate non-beneficial observations, investigations, or treatments with the person, and document them.
- 4.5 Reconsider the goals of care, comprehensive care plan and any limitations of medical treatment as necessary, when significant changes in the person's condition or circumstances occur. Provide the person the opportunity to request further discussion and a review of the comprehensive care plan at any time.
- 4.8 Ensure the comprehensive care plan is readily available to all healthcare workers involved in the person's care. The care plan must be specifically revised to meet the unique needs of the person.
- 4.9 Reassure the person at the end of life that, although care priorities may change, comprehensive compassionate care will continue.
- 4.10 Prioritise adequate pain relief and symptom control for the prevention and relief of suffering. Manage physical symptoms in alignment with the person's wishes, and review treatment regularly.
- 4.11 Ensure dying people are supported to receive food and drink for as long as they wish.
- 4.12 Liaise with other relevant services and provide referral, as necessary.

Essential element 5: Responding to concerns

There may be occasions when concern is raised about a person approaching the end of life or decision-making is particularly complex. In these circumstances, timely and appropriate assistance should be obtained from a suitably skilled healthcare worker or team.

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

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

- 5.1 Ensure the health service has a system to allow people to independently raise concerns about end-of-life care, including seeking a second opinion when needed.
- 5.2 Establish policies and procedures that clearly define criteria and processes for raising concerns about end-of-life care.
- 5.3 Support the person to understand the triggers and process for requesting an urgent review and how this will be provided.
- 5.4 Regardless of who raised it, a concern or worry that any person has unmet end-of-life care needs prompts a rapid healthcare review until a satisfactory resolution is achieved.
- 5.6 Provide healthcare workers rapid access, by agreed means, to specialist palliative care advice 24 hours a day and 7 days a week.
- 5.7 Avoid after-hours decisions to limit medical treatment or stop non-beneficial treatments. When after-hours decision-making is required because of sudden or unexpected deterioration in the person's condition, a review by the healthcare worker responsible for coordinating care should occur as soon as possible.
- 5.8 Ensure a medical officer or nurse practitioner of sufficient authority to make decisions about stopping non-beneficial treatments is available in emergency situations.
- 5.9 Communicate critical information to the healthcare worker responsible for care coordination in a detailed and structured way about the outcomes of the call for assistance, and the plan for follow-up or further review of the person.
- 5.10 Calls for assistance are used as a teaching and mentoring opportunity for other healthcare workers and students when appropriate.

Section B: Organisational prerequisites

Health services caring for people at the end-of-life must recognise and prioritise this care.⁷ They must be willing and able to work with other organisations and sectors to optimise care continuity and communication at transitions of care. Policies and systems need to guide the actions of the board, management, staff, volunteers, and students, to ensure a consistent and responsive approach. Consideration of families' needs to be individualised and culturally responsive.

Cultural responsiveness requires an organisation-wide approach to planning, implementing, and evaluating services for people of culturally and linguistically diverse backgrounds, including migrant and refugee communities. Meaningful consultation and participation strategies need to be embedded in the core business of the organisation.

Essential element 6: Leadership, governance, and readiness

End-of-life care should be included in the governance system for the health service and cultural change may be required to prioritise end-of-life care. A systematic approach and committed leadership are necessary to effect improvements in the experiences of people at end of life. It is recognised that roles that are embedded into an organisation are more likely to be successful and sustainable than time-limited roles.

Health services should provide proactive and practical support to prevent burnout of the health care workforce. Ongoing learning for healthcare workers who are responsible for delivering end-of-life care should also be provided.

Health services should use established systems and processes as required by the applicable Standards to deliver end-of-life care.

To become more culturally competent, a system needs to:

- Value diversity
- Have the capacity for cultural self-assessment
- Be conscious of the dynamics that occur when cultures interact
- Institutionalise cultural knowledge
- Adapt service delivery so that it reflects an understanding of the diversity between and within cultures

6.1 People at end of life are partners in the development and governance of the health service delivering end-of-life care.

6.2 A formal governance process (such as a committee) oversees the development, implementation, and ongoing review of systems for end-of-life care and includes:

- Appropriate delegated responsibilities and accountability for decisions and actions

- Consumer, family and carer, healthcare worker, manager, and executive representatives
- Regular review and advice on performance data including interventions, education, and training
- Regular review and advice about the allocation of resources.

6.3 A formal policy regarding end-of-life care addresses:

- Governance arrangements including reporting requirements
- Roles, responsibilities, and accountabilities for end-of-life care
- Processes for advance care planning, appropriate medical treatment, and dignity of risk
- Processes or tools for identifying people at end of life
- Alignment with systems for recognising and responding to deterioration
- Access to specialist palliative care advice and services
- Communication processes and tools
- Processes to ensure healthcare workers are not pressured to provide non-beneficial interventions
- Processes to ensure clear transitions of care and communication between health services and providers
- Clear dispute resolution processes, including access to mediation, bioethics, and legal support in situations of complex end-of-life decision-making or conflict
- Training and education requirements
- Access to professional clinical supervision to suit the varied needs of healthcare workers
- Access to formal and informal debriefing or counselling which includes strategies to mitigate moral injury for clinical and nonclinical staff
- Evaluation, audit, and feedback processes.

6.4 Apply the policy for end-of-life care across the health service and identify potential variations in its application that might exist in different circumstances (such as after-hours).

6.5 Policies and processes must be in place regarding advance care directives, organ and tissue donation, limitations of medical treatment and end-of-life decision-making to ensure that the care delivered in response to deterioration is consistent with appropriate clinical practice and the person's expressed wishes.

Essential element 7: Support, education, and training

An educated and suitably skilled and qualified workforce is essential to providing appropriate end-of-life care.²¹ Education should commence early in training programs and continue as part of healthcare workers' continuing professional development. All healthcare workers should have a shared understanding of the local terminology, policies, processes, and practices associated with end-of-life care. Education should include understanding [shared decision making](#), local referral and communication processes, and relevant legislation and other regulatory frameworks. It should also include training about how to have conversations about end-of-life care. Health services may consider accessing existing external training programs.

Dealing with death and dying can be challenging for healthcare workers, and can also affect other staff members such as administrative staff, food servers and cleaners. It can add considerably to workplace stress. Chronic unmanaged stress can erode empathy and potentially contribute to poorer experiences for people being cared for.²² It is important that systems are in place to facilitate access to peer support, mentoring and appropriate clinical supervision.

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

Children

For services that provide end-of-life care to children, end-of-life care education should include specific attention to paediatric issues.

For specialist paediatric services, education about paediatric end-of-life care should commence early in training programs and continue as part of healthcare workers' professional development.

- 7.1 Ensure a policy exists outlining supervision and support to healthcare workers who care for people who are dying.
- 7.2 Provide relevant education about recognising people at end of life and managing their care to all members of the workforce. Make sure this information is provided at the commencement of employment and as part of regular refresher training.
- 7.3 Ensure healthcare workers caring for people at end of life are provided with education and training to:
 - Identify people approaching end of life
 - Initiate interventions to support safe and high-quality end-of-life care, relevant to their scope of clinical practice
 - Support the cultural, spiritual and psychosocial needs of the person
 - Recognise disease-specific illness trajectories and changing care priorities including limitations of medical treatment, relevant to their scope of clinical practice
 - Understand the role of substitute decision-makers when providing care to patients who are unable to make decisions for themselves and use shared and supported decision making strategies

- Understand end of life ethical and medico-legal issues, including the relevant professional ethical frameworks, and the relevant legislation in the state or territory of practice
 - Support provision of end-of-life care in an appropriate environment
 - Document and communicate effectively
 - Escalate concerns in a timely manner.
- 7.4** Encourage healthcare workers providing end-of-life care to take up the learning opportunities offered by participating in discussions with patients and their families, multidisciplinary case reviews, reviews of patient records, mortality and morbidity meetings, and adverse event reviews.
- 7.5** Ensure education includes specific competencies for providing culturally safe end-of-life care to Aboriginal and Torres Strait Islander people, and to diverse people, and people with disability.
- 7.6** Offer ongoing formal training in communication skills to healthcare workers at all levels, as these skills are critical to the delivery of end-of-life care. This may include specific skills such as family donation conversations.
- 7.7** Ensure healthcare workers providing end-of-life care receive education about how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues. Provide information about how to seek help, if required.
- 7.8** Encourage and support people at end of life to participate in providing education through personal stories. These can be powerful tools for teaching.
- 7.9** Check that healthcare workers know how to access peer support, mentoring and clinical supervision. Provide this information at the start of employment and as part of regular refresher training. This may involve accessing external services for formal clinical supervision, counselling or debriefing.
- 7.10** Support healthcare workers to develop skills in self-care, reflective learning and providing peer support to colleagues. Experienced team members are responsible for developing the skills and capacity of other healthcare workers in relation to end-of-life care.

Essential element 8: Care setting and bereavement support

Health services caring for people at end of life should also support their families. Family members have associated lack of space and privacy with a feeling of being 'watched' and not being able to 'talk openly' with their loved ones.¹ The availability of physical spaces for privacy and gatherings contribute to the quality of care offered at the end of life. Spaces for cultural practices such as family congregations, chanting or other important rituals associated with end of life should be considered.

Bereavement support includes the emotional, psychosocial and spiritual support provided to family and loved ones before and after the death of a person to assist them with coping with issues related to grief, loss and adjustment.²³ It is important to recognise that in Australia, bereavement support may look different in different communities, based on lived experience and culture. For example, involvement of family in direct end-of-life care was found to be strongly preferred among patients and family from non-English speaking and culturally diverse backgrounds.¹ When providing end-of-life care, healthcare workers need to be supported to address family members' unique needs rather than as a proxy for the person at end-of-life.⁷

Bereavement support is fundamental for a good end-of-life care experience encountered by family members and friends. Early assessment and supportive measures to address bereavement needs of families should be taken to minimise adverse physical and emotional responses. Routine referrals to support such as Aboriginal liaison officers, spiritual or pastoral care may assist in responding to family concerns.

- 8.1** Establish systems to ensure that essential resources required for the provision of safe and high-quality end-of-life care (e.g. private space for family meetings, equipment and medications) are operational and available.
- 8.2** Health services work together to build capacity for people to be cared for in their preferred place of death (e.g. at home).
- 8.3** Ensure physical spaces that provide privacy are available to meet the individual needs of the patient.
- 8.4** Provide spaces for families to gather within services that provide end-of-life care.
- 8.5** Develop a policy that identifies local support resources for bereavement referrals and provide written information to bereaved family and carers about how to access support.
- 8.6** Establish partnerships with organisations that can provide ongoing bereavement care for families and healthcare workers.
- 8.7** Co-develop bereavement models of care according to clinical settings, for example, community health or paediatric and adult ICU models.

Essential element 9: Evaluation, audit and feedback

Care provided to people at the end of life should be reviewed on a regular basis to identify safety and quality improvements. In some health services, formal evaluations and audits may be required.

All deaths should be routinely reviewed to determine whether the safety and quality of the person's end-of-life care were acceptable, and how they could have been improved. Evaluation should not just assess the potential preventability of death.

Evaluation, audit and feedback are important to implement and maintain ongoing performance of recognition and response systems. Quality metrics can optimise performance^{24, 25} and check that systems are operating as planned.^{3, 26, 27} The [End-of-life audit toolkit](#) is available to assist services in auditing.

Involvement in palliative care and end-of-life care data collection (*National Palliative Care Strategy 2018*, *National Palliative Care and End-of-Life Care Information Priorities 2022*) may aid in service planning. An example could see Primary Health Networks providing local data regarding numbers of those considered to be at the end of life to acute hospitals.

- 9.1 Collect, review and locally report data (including over time) about the effectiveness of processes and systems for delivering end-of-life care.
- 9.2 Ensure processes exist for healthcare workers to lead evaluation and audit, and disseminate aggregate, de-identified data to their colleagues and organisational leaders responsible for governance within the organisation (such as senior executives and relevant quality committees).
- 9.3 Develop monitoring and evaluation strategies that capture feedback about the quality of end-of-life care from multiple disciplines (e.g. medicine, nursing, social work, pharmacy), as well as from people receiving care.
- 9.4 Make sure evaluation and monitoring processes use routinely collected data and data linkage, where possible, and are simple, inexpensive and feasible.
- 9.5 Ensure measures of the safety and quality of end-of-life care include the following minimum data set for audit:
 - Patient demographics
 - The trigger used to identify the person is approaching the end of life
 - Documentation of shared decision making and the person's goals of care
 - Alignment of the person's expressed goals with actual care
 - Effectiveness of treatment of symptoms such as pain relief, secretion management, or agitation
 - Whether an advance care directive or plan was documented or received, and enacted
 - Whether specialist palliative care was accessed
 - Concordance with limitations of medical treatment
 - The category of death (expected/ unexpected/diagnosis)
 - The time lapse between recognition of end of life or referral to specialist palliative care and death

- Transfers of care in the last week of life (e.g. transfers to hospital from home, or from ward to intensive care).

9.6 Methods for collecting data could include:

- Retrospective audit of case notes
- Medication chart safety review
- Follow-up with healthcare workers and other staff involved in the person's end-of-life
- Feedback on their experiences from substitute decision-makers, families and carers of people who received end-of-life care
- Use of tools developed for specific settings
- Mortality and morbidity review meetings.

9.7 Use feedback obtained from healthcare workers about the barriers and enablers to safe and high-quality end-of-life care for system improvement.

9.8 Include information collected as part of ongoing evaluation, audit and feedback processes in the quality improvement process and ensure it is:

- Fed back to healthcare workers providing end-of-life care
- Reviewed to identify lessons that can improve clinical and organisational systems
- Used in education and training programs
- Used to track changes in performance of the system over time
- Reported with actions at local safety and quality meetings.

Essential element 10: Systems to support high-quality care

Health service organisations should seek opportunities to align their systems to support best practice and patient safety. End-of-life care should be integrated into existing organisational and safety and quality systems to support their sustainability and opportunities for organisational learning. Aligning systems for comprehensive care, end-of-life care and recognising and responding to deterioration will help to ensure coordinated and effective care for people at end of life.

Organisations should consider opportunities to systematise the approach to end-of-life care where this will support best practice. For example, developing consistent processes for accessing palliative medications might improve the timeliness of treatment for distressing symptoms.

Technological systems such as My Health Record may also provide benefits by improving communication between care providers and improving continuity and coordination of care. These systems should align with the requirements of the NSQHS Standards.

- 10.1** Provide systems that support healthcare workers to work with people to receive, prepare, review and/or update advance care plans and directives, according to the wishes of the person. Ensure these systems align with the NSQHS [Clinical Governance Standard](#) and the [Recognising and Responding to Acute Deterioration Standard](#), where these Standards apply.
- 10.2** Ensure systems provide healthcare workers with access to essential palliative medications 24 hours a day and 7 days a week. These systems should align with NSQHS [Medication Safety Standard](#), where this Standard applies.
- 10.3** Enable systems to provide timely access to specialist palliative care clinicians, when required for people with complex palliative care needs or as a supportive resource for other healthcare workers. This may include off-site access via videoconferencing or teleconferencing.
- 10.4** Make sure technological systems do not place a barrier between the healthcare worker and the person at end of life.
- 10.5** Implement processes to improve communication between health services at transitions of care. This includes processes for communicating the content of discussions about prognosis and advance care planning. Check these processes align with the NSQHS [Communicating for Safety Standard](#), where this Standard applies.
- 10.6** Put systems in place to work with other health services to communicate, access and share comprehensive care plans, advance care directives or plans developed in other settings.
- 10.7** Systems should facilitate appropriate documentation about end-of-life care, and reduce the burden of documentation and data collection when possible.
- 10.8** Implement technological systems and solutions where they will support safe and high-quality end-of-life care.

Glossary

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

Term	Description
Actively dying	The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks.
Acute healthcare facility ²⁸	A hospital or other healthcare facility providing healthcare services to persons for short periods of acute illness, injury or recovery.
Advance care directive ²⁹	A voluntary, person-led document completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity. In some states, these are known as advance health directives.
Advance care plan ²⁹	A document that captures an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).
Advance care planning ²⁹	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require capability to facilitate these conversations effectively. The National Quality Standards for aged care, general practice and health services all promote advance care planning. Individuals can also choose to engage in advance care planning with other non-health practitioners, such as friends or family.
Carer ⁹	A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged. An individual is not a carer merely because they are the spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care.
Clinician ⁹	A healthcare provider, trained as a health professional, including registered and nonregistered 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.
Dignity of risk ³⁰	The legal right of a person to make their own choices even if those decisions may increase risk.

Diversity ³¹	The varying social, economic and geographic circumstances of consumers who use, or may use, the services of a healthcare service, as well as their cultural backgrounds, disability status, religions, beliefs and practices, languages spoken, sexual orientation, gender identity and gender expression, and sex characteristics.
End of life ¹	<p>The period when a person is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown.</p> <p>This period may be years in the case of persons with chronic or malignant disease, or very brief in the case of persons who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.</p>
Frailty ³²	A state of age-related deficits recognising the heterogeneity in health status of people as they age
Goals of care ⁹	Clinical and other goals for a patient's episode of care that are determined in the context of a shared decision making process.
Healthcare worker	A person working in health, community and aged care settings providing direct care to people at end of life. This includes registered health practitioners, other health practitioners, carers. Support staff in these settings (such as those in administration or cleaning) are not considered healthcare workers in this consensus statement.
Multidisciplinary team ¹	A team of providers who work together to develop and implement a plan of care. Membership depends on the services required to identify and address the expectations and needs of the person, carers and family. A multidisciplinary team might typically include one or more doctors, nurses, social workers, spiritual carers, pharmacists and personal care workers. Other disciplines may be part of the team, depending on the needs of the person and the resources available. Volunteers, persons, carers, and family members may also be considered as part of the multidisciplinary team. Members of the multidisciplinary may work for different services and different locations.
Limitations of medical treatment	<p>Medical decisions that may be made to limit the treatments that are, or could be, provided when they will not benefit the person. A decision to not attempt cardiopulmonary resuscitation if a person suffers a cardiopulmonary arrest is one example of a limitation of medical treatment.</p> <p>Similar terms that are in common use include withdrawal or withholding of medical treatment.</p> <p>Decisions to limit medical treatment may avoid prolongation of dying but will not cause a person's death. This is quite different from the practice of euthanasia, where death is deliberately and purposefully hastened.</p>
Nonbeneficial treatment	Interventions that will not be effective in treating a person's medical condition or improving their quality of life. Nonbeneficial treatment may include interventions such as diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Nonbeneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.
Palliative care ² or palliative approach	An approach to treatment that improves the quality of life of persons and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial, and spiritual).

Person	The primary recipient of care.
Resuscitation orders/ plans	<p>Documents completed by a doctor to outline the plan of care in relation to emergency treatment of severe clinical deterioration.</p> <p>Not for resuscitation (NFR) and do not attempt resuscitation (DNAR) orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the person has a cardiac or respiratory arrest. In some organisations, decisions about other specific limitations of medical treatment may also be listed as part of a resuscitation plan (e.g. decisions to call a medical emergency team or transfer a person to intensive care if they deteriorate).</p>
Specialist palliative care	Services provided by healthcare workers who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to persons with complex palliative care needs, and providing consultation services to support, advise and educate nonspecialist healthcare workers who are providing palliative care.
Substitute decision-maker ³	<p>A person appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-makers have legal authority to make these decisions; the relevant legislation varies between jurisdictions (states and territories).</p> <p>A document that appoints a substitute decision-maker to make health, medical, residential and other personal decisions (but not financial or legal decisions) is considered to be an advance care directive. More than one substitute decision-maker may be appointed under an advance care directive.</p> <p>There are three categories of substitute decision-makers:</p> <ul style="list-style-type: none"> • substitute decision-makers chosen by the person (e.g. one or more enduring guardians appointed under a statutory advance care directive, or a nominated substitute decision-maker in a common law advance care directive) • substitute decision-makers assigned to the person by the law in the absence of an appointed substitute decision-maker (e.g. family member, carer or 'person responsible') <p>substitute decision-makers appointed for the person (e.g. a guardian appointed by a guardianship tribunal).</p>
Supported decision making	<p>Enables a person with cognitive impairment to remain involved in decisions about their health care rather than having their decision-making capacity removed</p> <p>(Definition in Primary and Community Healthcare Standards, referencing NSQHS User guide for HSOs providing care for patients with CI or at risk of delirium.</p>
Terminal phase	The hours, days or, occasionally, weeks when a person's death is imminent. This is sometimes referred to as the period when a person is actively dying.

References

1. Rawlings D, Damarell R, Chakraborty A, Devery K, J. T. Rapid review of the literature on end-of-life care in aged care and community settings. Sydney: ACSQHC; 2022.
2. Palliative Care Australia. Palliative Care Service Development Guidelines. Canberra: 2018.
3. Hoerger M, Greer JA, Jackson VA, Park ER, Pirl WF, El-Jawahri A, et al. Defining the Elements of Early Palliative Care That Are Associated With Patient-Reported Outcomes and the Delivery of End-of-Life Care. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2018;36(11):1096-1102.
4. Becqué YN, Rietjens JAC, van Driel AG, van der Heide A, Witkamp E. Nursing interventions to support family caregivers in end-of-life care at home: A systematic narrative review. *International Journal of Nursing Studies*. 2019 2019/09/01/;97:28-39.
5. Donnelly S, Prizeman G, Coimín DÓ, Korn B, Hynes G. Voices that matter: end-of-life care in two acute hospitals from the perspective of bereaved relatives. *BMC Palliative Care*. 2018 2018/10/19;17(1):117.
6. Ziegler LE, Craigs CL, West RM, Carder P, Hurlow A, Millares-Martin P, et al. Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. *BMJ Open*. 2018;8(1):e018284.
7. Rawlings D, Devery K, Tieman J, Tait P, Chakraborty A. Rapid review of the literature on end-of life care. Sydney: ACSQHC; 2021.
8. Rawlings D, Damarell R, Chakraborty A, Devery K, Tieman J. Rapid review of the literature on end-of-life care in aged care and community settings. Sydney: ACSQHC; 2022.
9. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Sydney: ACSQHC; 2021.
10. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential elements for recognising and responding to acute physiological deterioration. 3rd ed. Sydney: ACSQHC; 2021.
11. Jennings KS, Marks S, Lum HD. The Surprise Question as a Prognostic Tool #360. *J Palliat Med*. 2018;21(10):1529-1530.
12. Hoffmann T, Jansen J, Glasziou P. The importance and challenges of shared decision making in older people with multimorbidity. *PLOS Medicine*. 2018;15(3):e1002530.
13. Mudge AM, Douglas C, Sansome X, Tresillian M, Murray S, Finnigan S, et al. Risk of 12-month mortality among hospital inpatients

using the surprise question and SPICt criteria: a prospective study. *BMJ Supportive & Palliative Care*. 2018;8(2):213-220.

14. White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. *BMC Medicine*. 2017 2017/08/02;15(1):139.

15. Burke K, Coombes LH, Menezes A, Anderson A-K. The 'surprise' question in paediatric palliative care: A prospective cohort study. *Palliative medicine*. 2018;32(2):535-542.

16. Cuvillo A, Yip C, Battles H, Wiener L, Boss R. Triggers for Palliative Care Referral in Pediatric Oncology. *Cancers*. 2021;13(6):1419.

17. Dy SM, Apostol C, Martinez KA, Aslakson RA. Continuity, coordination, and transitions of care for patients with serious and advanced illness: a systematic review of interventions. *J Palliat Med*. 2013 Apr;16(4):436-445.

18. Zonneveld N, Driessen N, Stüssgen RAJ, Minkman MMN. Values of Integrated Care: A Systematic Review. *Int J Integr Care*. 2018;18(4):9-9.

19. Wang MC, Mosen D, Shuster E, Bellows J. Association of patient-reported care coordination with patient satisfaction. *J Ambul Care Manage*. 2015 Jan-Mar;38(1):69-76.

20. ELDAC. End of Life Law in Australia: An Overview for the Aged Care Sector. [Internet] Canberra: ELDAC; 2021 [updated June 1, 2021] Available from: <https://www.eldac.com.au/tabid/5277/Default.aspx>.

21. (ACN) ACoN. Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN Canberra: 2019.

22. 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. *Palliative medicine*. 2016 Oct;30(9):825-833.

23. Bereavement services definition. [Internet] 2022 [cited July 7] Available from: <https://www.lawinsider.com/dictionary/bereavement-services>.

24. Subbe CP, Bannard-Smith J, Bunch J, Champunot R, DeVita MA, Durham L, et al. Quality metrics for the evaluation of Rapid Response Systems: Proceedings from the third international consensus conference on Rapid Response Systems. *Resuscitation*. 2019 Aug;141:1-12.

25. Clinical Excellence Commission. Between the Flags Project: Interim Evaluation Report 2013. Sydney: CEC; 2013.

26. Peberdy MA, Cretikos M, Abella BS, Devita M, Goldhill D, Kloeck W, et al. Recommended guidelines for monitoring, reporting, and conducting research on medical emergency team, outreach, and rapid response systems: an Utstein-style scientific statement. *A Scientific*

Statement from the International Liaison Committee on Resuscitation; the American Heart Association Emergency Cardiovascular Care Committee; the Council on Cardiopulmonary, Perioperative, and Critical Care; and the Interdisciplinary Working Group on Quality of Care and Outcomes Research. *Resuscitation*. 2007 Dec;75(3):412-433.

27. Peberdy M, Cretikos M, Abella B, Devita M, Goldhill D, Kloeck W et al. Recommended guidelines for monitoring, reporting, and conducting research on medical emergency team, outreach, and rapid response systems: an Utstein-style scientific statement. A Scientific Statement from the International Liaison Committee on Resuscitation; the American Heart Association Emergency Cardiovascular Care Committee; the Council on Cardiopulmonary, Perioperative, and Critical Care; and the Interdisciplinary Working Group on Quality of Care and Outcomes Research. *Resuscitation*. 2007 75(3):412–433.

28. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. Sydney: ACSQHC; 2011.

29. Australian Government. National framework for advance care planning documents. In: Health Do, editor. Canberra: Australian Government; 2021.

30. Woolford MH, de Lacy-Vawdon C, Bugeja L, Weller C, Ibrahim JE. Applying dignity of risk principles to improve quality of life for vulnerable persons. *Int J Geriatr Psychiatry*. 2020 Jan;35(1):122-130.

31. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Primary and Community Healthcare Standards. Sydney: ACSQHC; 2021.

32. Rockwood K, Howlett SE. Fifteen years of progress in understanding frailty and health in aging. *BMC Medicine*. 2018 2018/11/27;16(1):220.