

national consensus statement:

essential elements for safe and high-quality paediatric end-of-life care



Published by the Australian Commission on Safety and Quality in Health Care
Level 5, 255 Elizabeth Street, Sydney NSW 2001

Phone: (02) 9126 3600

Fax: (02) 9126 3613

Email: mail@safetyandquality.gov.au

Website: www.safetyandquality.gov.au

Print ISBN: 978-1-925224-62-7

Online ISBN: 978-1-925224-63-4

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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.

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introduction

A child's death can have a profound and lasting effect on their parents, siblings, carers, friends, health professionals, and communities. The health care that children with life-limiting conditions receive in the last years, months and weeks of their lives can help families to manage the distress and grief associated with death and dying, and maximise the child's quality of life.

The purpose of this *National consensus statement: essential elements for safe and high-quality paediatric 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 to children in acute care settings in Australia. Clinicians, health service executives and managers, policy-makers, educators and training providers can use the principles and elements of the Consensus Statement as a guide to improving the safety and quality of paediatric end-of-life care.

This Consensus Statement has been adapted from the *National consensus statement: essentials elements for safe and high-quality end-of-life care*, which was developed to guide the care of adults at the end of life. The philosophy that underpins both documents is similar, but there are additional considerations, principles and actions required to provide optimal care to children at the end of life. Decisions about end-of-life care for paediatric patients needs to reflect, and respond to, the patient's and family's needs and preferences, in the context of what is best for the child.

The Consensus Statement reflects the views of health consumers and carers, experts in the field, and the Australian Commission on Safety and Quality in Health Care (the Commission). It has been derived from expert experience and published evidence, and developed in partnership with carers and consumers, and representatives from public and private hospitals and health services, professional colleges, state and territory health departments, and other government agencies. Throughout this document the term 'parents' is used to refer to the person or people who legally carry parental responsibility for the child. This

may include birth or adoptive parents, or a legal guardian. Where there is doubt about who carries parental responsibility for a child, legal advice must be sought.

The term 'child' is used to describe babies, children and young people aged between four weeks and 18 years of age.

The term 'family' refers to siblings, grandparents and other people with a significant relationship to the child.



application

The Consensus Statement aligns with the National Safety and Quality Health Service (NSQHS) Standards, but provides recommended, rather than mandatory, practice. It also aligns with the *National consensus statement: essentials elements for safe and high-quality end-of-life care* and the *National consensus statement: essential elements for recognising and responding to acute physiological deterioration*. It is intended that these documents be applied together.

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

Effective communication and coordination of care with community care providers are critical considerations when planning and implementing systems in line with the Consensus Statement. Acute health services should consider how to work collaboratively with partners such as parents, schools, volunteers, general and sub-specialty paediatric services, specialist paediatric palliative care services, general practitioners, and social and community care agencies (including disability services). Such collaboration maximises the opportunities for children with life-limiting conditions to continue to live, be cared for, and die in their preferred place, and to optimise the coordination and delivery of end-of-life care.

Parents have a special role as caregivers for their children. Consideration should be given to the preferences of the child and their parents for both the place of care and place of death. Families may wish for their child to die at home.

This may mean that parents provide care to their child throughout the trajectory of a life-limiting condition and at the end of life. The Consensus Statement should be applied to support parents who provide this type of care.

The guiding principles, elements and actions in the Consensus Statement may need to be applied over an extended period of time for some children and their families. End-of-life care is complex and multi-dimensional, and it is likely that aspects of care will need to be revisited as a child's condition changes and they move through different developmental phases. For example, the preferred place of care, and psychosocial, cultural and spiritual care needs of the child may change over time, and must therefore be reviewed regularly.

Parts of the Consensus Statement are aspirational, particularly for services that do not routinely provide care for children with life-limiting conditions, such as small rural and remote health services. It is also likely to take time for health services to develop and implement systems that enable care to be delivered in accordance with all the principles and elements outlined in this document.

scope

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

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

- when a child 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 child is likely to die in the short term (i.e. within days to weeks, or during the current admission) and any clinical deterioration is likely to be irreversible.

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

The Consensus Statement is generally targeted at acute health services providing care to children, including intensive care and the emergency department. It applies in all types of public and private acute hospitals, from large tertiary hospitals to small district and community hospitals. The Consensus Statement also applies to situations where children are being cared for in other settings – for example, in remote clinics, ambulance services, patient clinics, hospital-in-the-home services, children's hospices or residential care facilities. Such services may need to be networked to specialist paediatric health services to facilitate the delivery of end-of-life care that aligns with the Consensus Statement.

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

Although neonates under the age of four weeks are excluded from the scope of the Consensus Statement, many of the principles and actions may also be relevant for neonates with life-limiting conditions.



intended audience

The Consensus Statement has been developed for:

- clinicians who are involved in the provision of acute health care to children
- health service executives and managers who are responsible for developing, implementing and reviewing systems for delivering patient care, including paediatric end-of-life care, in individual health services or groups of health services
- providers of clinical education and training, including universities and professional colleges
- health professional registration, regulation and accreditation agencies
- planners, program managers and policy-makers who are responsible for developing state or territory, or other strategic programs dealing with the delivery of end-of-life care.

Disclaimer

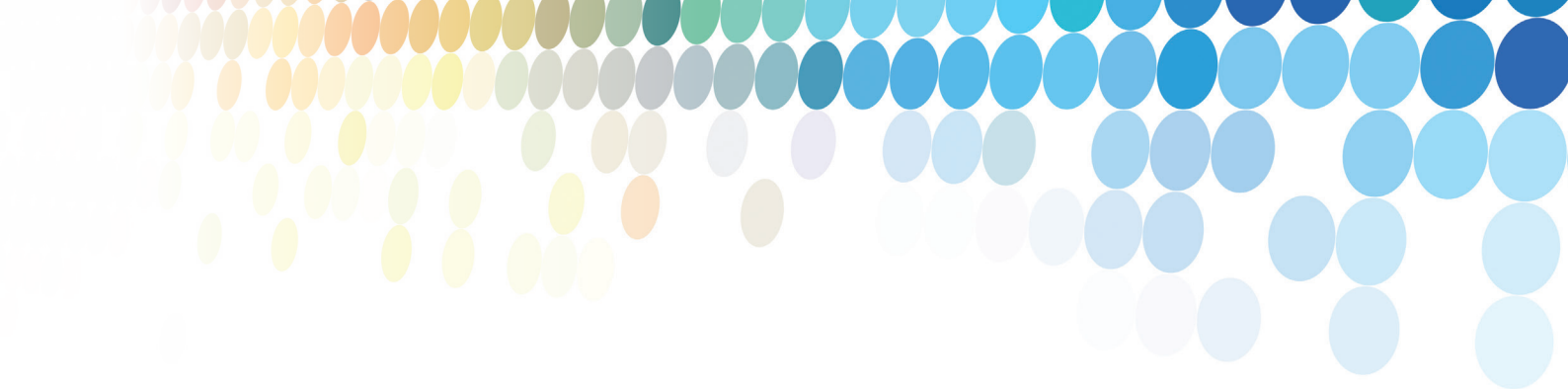
The Consensus Statement describes suggested practice for the provision of paediatric end-of-life care in settings where acute care is provided. It is a guiding document designed to inform clinicians and others of recommended practice. It is not a legal document, and clinicians must continue to be aware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

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

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

guiding principles

1. Dying is a human experience, not just a biological or medical event.
2. The death of a child is a traumatic event for their family and surrounding community.
3. The child and their parents must be empowered to contribute to decisions about the child's care.
4. Providing for the cultural, spiritual, psychosocial and developmental needs of children and families is as important as meeting their physical needs.
5. All children, including those with chronic or severe mental illness, intellectual or developmental disability, have the right to adequate pain relief and symptom control, and to the prevention and relief of suffering.
6. Care of the dying is urgent care. Recognising when a child is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care.
7. Prognosis and the way that a child responds to medical treatment will vary between individuals. The potential for ambiguity and uncertainty at the end of life must be openly and honestly acknowledged.
8. Safe and high-quality paediatric end-of-life care is family-centred. It should be aligned with the values, needs and wishes of the child, their parents and their family.
9. Safe and high-quality paediatric end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.

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10. Safe and high-quality paediatric end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care.
 11. The interdisciplinary team has a responsibility to provide timely, accurate and appropriate information about the child's clinical condition and care to the child and their parents in a form that is understandable to them.
 12. End-of-life decision-making should be shared between the interdisciplinary team, the parents and, where appropriate, the child.
 13. Decisions relating to the care of a child must be made in the child's best interests in accordance with legislation.
 14. Parents hold legal responsibility for decision-making about their child's care.
 15. Parents have the right to refuse medical treatments for their children provided such decisions do not go against the child's best interests.
 16. It is ethically important not to harm a child who is approaching the end of life by providing burdensome investigations and treatments that can be of no benefit.
 17. Doctors are not obliged to initiate or continue treatments that are not in the best interests of the child.
 18. Care of the child, and care for parents, siblings and other family members, extends from the time a child receives a life-limiting diagnosis through to the period after the child has died.

essential elements

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

This Consensus Statement contains 10 essential elements. The following sections provide information about each element. Each section begins with a brief introductory statement, which is followed by a list of actions that describe the necessary processes and systems to effectively address the element.

Elements 1–5 relate to the way in which paediatric end-of-life care should be approached and delivered. The actions within these elements are directed primarily to clinicians working in settings where acute care is provided to children.

Elements 6–10 relate to structural and organisational prerequisites for the effective delivery of safe and high-quality paediatric end-of-life care. The actions within these elements are directed primarily to health service managers and executives who work in health services that provide care to children.

Figure 1 provides an overview of the essential elements and how they fit together within the Consensus Statement.

essential elements

a. processes of care

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

b. organisational prerequisites

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

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



part a

processes of care

1. family-centred communication and decision-making

key points

- The child, their parents and the interdisciplinary team should be partners in discussions and decision-making at the end of life.
- Clinicians recognise and are responsive to the individual preferences and needs of the child and their parents.
- Clinicians recognise the primary role of the parents in decision-making and take into account their wishes regarding the extent to which their child is involved in decision-making.
- Information is communicated to children about their care as appropriate and in a form that is understandable to them.
- Having conversations about death, dying and the end of life requires compassion, knowledge, experience, sensitivity and skill on the part of the clinician(s) involved.
- A series of conversations may be needed to elicit the goals, values and wishes of the child and their parents, and reach decisions about the appropriate plan for their care.

The child, their parents and the interdisciplinary team are all essential participants in discussions and decision-making about the child's care at the end of life. Depending on the needs and wishes of the child and their parents, other members of the child's family may also need to be involved in these discussions.

The purpose of conversations about end-of-life care will depend on the circumstances of the child. In some cases the primary purpose of communicating with the child and their parents will be to impart information. In other cases decisions about specific aspects of care, including care of the dying, may need to be made.

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

- the child or parent expresses interest in discussing end-of-life care
- a life-limiting condition is diagnosed
- a child who is likely to die in the short or medium term is admitted, or deteriorates during their admission
- a child living with a life-limiting illness has had recurrent, unplanned, recent admissions
- a previously well child who has suffered an acute life-threatening event or illness is admitted
- unexpected, significant physical deterioration occurs
- a child is dying.

The decision-making process should involve more than just providing information to children and their parents, or asking them questions to inform a clinically driven decision. It is a process that allows children, parents and interdisciplinary teams to work together to reach decisions in the child's best interests, based on the best scientific evidence available, the realities of the child's clinical condition and treatment options, and the child and their parents' choices, values and preferences.

Clinicians 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. When communicating information to children about their care it is important to use words and other communication methods that are understandable to the child.

The child's level of involvement in decision-making should be based on the child's age and capacity. In some cases older children may be capable of decision-making if they have achieved a sufficient understanding which allows them to fully appreciate their clinical condition and treatment options, this should be considered when communicating with patients and their families.

It is critical to recognise the primary role of parents in decision-making, to take into account 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. Doctors, nurses and other involved clinicians should use their clinical skills and experience, and their knowledge of the child and parents' values and preferences to make recommendations that inform the decision-making process.

Clinicians should always check that there is a clear understanding of what has been discussed and the subsequent plan of care.

actions

- 1.1 The interdisciplinary team should identify the person/s with parental responsibility.
- 1.2 Clinicians should assess the capacity of the child to be involved in discussions and decision-making about their care. This capacity may change across the illness trajectory and as the child develops.
- 1.3 Clinicians should take into account the wishes of the parents as to the extent of involvement of the child in these discussions, while at the same time providing support for the child to be involved as much as possible.
- 1.4 Clinicians should be respectful, sensitive and responsive to the preferences and needs of individual children and their families, regardless of aspects of identity such as culture, religious belief, gender or sexual preference.
- 1.5 Clinicians, the child and their parents should identify opportunities for proactive and pre-emptive end-of-life care discussions to increase the likelihood of delivering high-quality end-of-life care aligned with the child and their parents' values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations.
- 1.6 Whenever possible, clinicians should prepare for having conversations about end-of-life care. Necessary preparation may include:
 - reaching consensus among all of the teams involved in the child's care about the prognosis and what treatment options are appropriate to recommend
 - ensuring familiarity with the child's history and current condition (this may include discussion with key community care providers), their family structure, and cultural needs and preferences
 - arranging adequate time for uninterrupted discussion
 - arranging adequate time and an appropriate physical environment for uninterrupted discussion

- ensuring that the child and their parents have access to their regular communication aids
 - arranging for the appropriate people to be in attendance – depending on the child and parents' individual preferences, this may include the child; their parents and family; the most senior doctor available; the nurse responsible for the child's care; and other members of the interdisciplinary team, such as interpreters, Aboriginal support workers, child life therapists, chaplains and/or social workers
 - ensuring that discussions can be held in an appropriately quiet and private environment.
- 1.7 Clinicians should provide parents with written information about which clinician is responsible for leading and coordinating their child's care. Whenever possible, this clinician should be directly involved in discussions about the child's end-of-life care.
- 1.8 Clinicians should assist parents in communicating information to their child about the outcomes of discussions about end-of-life care.
- 1.9 Clinicians should work with parents to ensure that key family members are present during end-of-life discussions or that appropriate follow-up meetings are offered. This will ensure that consistent messages are given about treatment options, their likelihood of success, risks and prognosis.
- 1.10 In some cultures, mainstream assumptions about death and dying may not be correct. Clinicians should work with parents to identify as early as possible any culturally appropriate decision-makers to include in discussions about end-of-life care.
- 1.11 Clinicians should provide an honest and straightforward summary of the clinical assessment findings, appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the child's condition improving in response to such treatment. Be compassionate and sensitive, use plain language, and avoid the use of medical jargon.
- 1.12 Clinicians should express empathy for the child and parents' situation. Allow adequate time for those involved to absorb, process and react to the information they are being given. Multiple opportunities for discussion may be required.
- 1.13 Clinicians should check that the child and their parents have been provided with sufficient support to make decisions. This includes support for children and parents who have communication difficulties, cultural, spiritual or linguistic needs, or decision-making difficulties associated with disability, mental illness or cognitive impairment.
- 1.14 Clinicians should clearly document the content of discussions and any agreed plan of care in the patient clinical record. Any unresolved issues that require further follow-up should be documented, along with a plan for follow-up.
- 1.15 Clinicians should communicate the content of the discussion and plan of care, including any limitations of medical treatment, to all teams involved in the child's care, including relevant community care providers.

2. teamwork and coordination of care

key points

- For a child's end-of-life preferences and needs to be fulfilled, members of the healthcare team(s) who are involved in their care need to work together effectively.
- The healthcare team includes: the interdisciplinary team in the health service; the child, their parents and other key support people; other specialists (e.g. paediatricians and palliative care); and community care providers, such as the child's general practitioner.
- Processes should be in place to support care coordination and continuity, particularly at the interface between different services and teams (e.g. between the hospital and community-based services, or between the treating team and after-hours care providers).

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

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

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

actions

- 2.1 The clinician with overall responsibility for leading and coordinating the child's care should be clearly identified.
- 2.2 The roles and responsibilities of different interdisciplinary team members should be clearly defined and understood by all those involved in the child's care, including the child (as appropriate) and their parents.
- 2.3 If members of the interdisciplinary team(s) are unable to reach agreement on appropriate treatment options, or there is ambiguity about options for future treatment, clinicians should discuss the range of views and the reasons for them with the parents and, where appropriate, the child.
- 2.4 Appropriate processes should be in place to enable all interdisciplinary team members, including junior clinicians, to engage with the broader healthcare team, voice concerns, and act on the expressed preferences and consent of the child and their parents.
- 2.5 Experienced interdisciplinary team members should provide supervision, leadership, support, mentorship and teaching to develop the skills and capacity of junior team members in relation to end-of-life care.

3. components of care

key points

- All children have a right to maintain their dignity, comfort and privacy, and to be cared for respectfully and with compassion.
- End-of-life care is every clinician's responsibility.
- Processes are in place to support proactive, anticipatory and individualised planning for end-of-life care.
- Active medical treatments and end-of-life care are not mutually exclusive. Many children may benefit from an approach in which medical treatments for their disease are provided in conjunction with palliative interventions to improve or maintain the best possible quality of life, and provide symptom relief.
- Decisions to withhold or withdraw treatment are made in the best interests of the child.
- For some children with life-limiting conditions, a palliative approach may be appropriate for many years before the terminal phase.
- Referral pathways to relevant adult health care services should be available for children with life-limiting conditions who are likely to survive past 18 years of age.

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

Decisions regarding a child's end-of-life care may be recorded in an advance care plan or directive. A plan may include preferences for future care such as decisions relating to care in the event of acute deterioration, preferred place of care, and agreed limitations of medical treatment.

Any decisions regarding the child's care, including withholding and withdrawing treatment, are to be made in the child's best interests. Parents have the legal right to make decisions for children, but clinicians are not obliged to initiate, continue or discontinue medical treatment if it is not in the best interests of the child. Identifying best interests can be difficult and clinicians should seek legal or clinical ethics advice if they are uncertain about how to proceed.

Children with life-limiting conditions may benefit from a long-term palliative approach, in conjunction with active medical treatment of their disease. This kind of dual care can provide support and improve comfort and symptom management to maximise quality of life for the child.

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

How people cope with grief varies; it is important that the child's family, including parents, siblings, close friends, girlfriends and boyfriends are supported to navigate the grieving process. Bereavement support can be provided in a variety of ways, including through provision of information, referral to services or support networks.

actions

- 3.1 Clinicians should assess the psychosocial, cultural and spiritual needs of the child. Support should be offered for families who wish to include cultural or religious practices in the care of the child, such as particular foods, singing, ceremonies or healing.
- 3.2 Clinicians should inform families about the process and purpose of advance care planning. This process should be undertaken using age-appropriate advance care planning documents where available.
- 3.3 Clinicians should avoid unnecessary burdens associated with medical treatment for dying children. For example, non-beneficial observations, surgical interventions, investigations, medications and treatments should not be prescribed or administered. Where a clinician feels pressured - by the family or another health professional - to provide such interventions, they should seek advice and support from an experienced colleague who is able to assist with a second opinion and sensitive discussion, or seek legal or clinical ethics advice where appropriate.
- 3.4 Clinicians should document the outcomes of the decision-making process in the child's clinical record. These outcomes include the goals of care, the agreed treatment plan, including prevention and relief of suffering, and any limitations of medical treatment.
- 3.5 Clinicians should revisit the goals of care, treatment plan and any limitations of medical treatment when significant changes in the child's condition, preferences, or circumstances occur – for example, when the child is in transition to the terminal phase.
- 3.6 Clinicians should clearly communicate the rationale for medical decisions to discontinue or withhold nonbeneficial observations, investigations or treatments to the parents and, where appropriate, the child.
- 3.7 Clinicians should enable the child and their parents to request further discussion and a review of the goals of care, treatment plan and any limitations of medical treatment at any time.
- 3.8 Information about the advance care plan, clinical treatment plan, goals of care, any limitations of medical treatment, and the child and parents' treatment preferences should be readily available to all clinicians involved in the child's care, including those involved in caring for the child in emergencies, after hours, through ambulance services and, where relevant, in the community.

- 3.9 The child and their parents should not feel abandoned by the healthcare team, or fear that care will be stopped or reduced, when the goals of care shift from cure to comfort. Clinicians should communicate openly about comfort care and what to expect in the terminal phase.
- 3.10 Clinicians should support dying children to receive oral food and fluids for as long as they wish.
- 3.11 Clinicians should manage physical symptoms in alignment with the child and their parents' wishes, and review treatment regularly.
- 3.12 Clinicians should explore and discuss alternatives to hospital-based care, when possible and appropriate, and as preferred by the child and their parents. This could include providing appropriate referrals, equipment and support to deliver care in the family home, the child's local hospital, a hospice or other palliative care facility.
- 3.13 Clinicians should liaise with, and provide referral to, other relevant services as necessary – for example, to children's hospice, specialist inpatient or community palliative care services.
- 3.14 Clinicians should support children to play, learn and socialise with friends. For adolescents this could include a boyfriend or girlfriend.
- 3.15 Clinicians should support parents and families to care for their dying child, and provide information about what to expect during the dying process.
- 3.16 Clinicians should provide information about organ and tissue donation for transplantation, in circumstances where donation is possible. Discussions should be conducted with advice from the state or territory DonateLife agency. Such discussions should preferably be led by clinicians who have attended the core Family Donation Conversation workshop. If families have previously expressed a wish for the child to die at home they should be informed that choosing organ donation may influence options for the place of death. The process of organ donation should not interfere with the family's wishes to be with their child for a period of time after death.
- 3.17 Clinicians should support parents, siblings and other family members to spend time with a dying child, including in the period immediately after death.
- 3.18 Clinicians should provide bereaved parents, siblings and other family members with written information about how to access bereavement support from the time the child receives a life-limiting diagnosis. This may include providing support to the child's friends or, for an adolescent, boyfriend or girlfriend.
- 3.19 Clinicians should consider whether the death of a child may need to be reported to the coroner. Clinicians should discuss this with the parents and other relevant health care providers prior to the death of the child.

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

key points

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

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

Predicting prognosis and the timing of dying can be difficult. Children die from a range of conditions and a significant percentage of children die from conditions not seen widely in the adult population. The diversity of conditions can lead to a variety of illness trajectories. A critically important trigger for assessment, discussion and consideration of referral to specialist palliative care is when the child, parents and family members, or other members of the interdisciplinary team request palliative care, or express concern or worry that the child is dying or has unmet end-of-life care needs.

For some children, it may be difficult to distinguish clinical deterioration that is reversible from deterioration that is irreversible and part of the normal dying process. In such cases, it may be appropriate to consider a trial of treatment for a defined period to assess reversibility of a child's deterioration.

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

actions

- 4.1 Clinicians should use the ‘surprise’ question as a simple screening mechanism to recognise children who may benefit from end-of-life care interventions. Clinicians should ask themselves:
- Would you be surprised if this child died as a result of this condition or problem?
 - Would you be surprised if this child died in the next 12 months?
 - Would you be surprised if this child died during this admission or in the next days or weeks?
- 4.2 Clinicians should consider other useful triggers for recognition and review of children who may benefit from end-of-life care interventions. Such triggers might be derived from condition-specific mortality risk prediction tools or from critical events, such as:
- presentation with life-threatening trauma or disease
 - diagnosis of life-limiting conditions
 - poor or incomplete response to medical treatment, continued deterioration despite medical treatment, and/or development of new clinical problems during inpatient admission
 - repeated calls to the rapid response team, particularly if the child has been admitted for more than one week
 - multi-system comorbidities (cardiovascular, pulmonary, endocrine, etc.)
 - maximal medical therapies already in place
 - decline in the child’s condition, or a clinical determination that they will not benefit from interventions such as surgery, dialysis or treatment in intensive care
 - unexpected or prolonged recent admissions to hospital for exacerbation of a life-limiting chronic condition
 - the child, parents and family members, or other members of the interdisciplinary team requesting palliative care, or expressing concern or worry that the child is dying or has unmet end-of-life care needs.

5. response to concerns

key points

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

When concerns are raised about a child approaching the end of life it is important that timely and appropriate assistance is obtained from a suitably skilled clinician or team. This is even more important when a child is in distress, has a complex condition or difficult to manage symptoms, or when end-of-life decision-making is particularly complex.

The type of response may depend on the nature of the concern and the person who has raised it. For example, a different response may be needed for concerns raised by a family member about a child's physical pain or distress to that of the response required to resolve conflict or an ethical dilemma.

The initial response to concerns about end-of-life care issues may be provided by a member of the interdisciplinary team, such as the senior registrar or consultant, or by a member of another team, such as an after-hours medical registrar or specialist palliative care clinician.

In some health services, such as small rural hospitals, responding to concerns may require access to external clinicians (e.g. general practitioners) and the use of technology (e.g. videoconferencing) to access off-site help, such as intensive care, specialist paediatricians, or specialist palliative care. Public advocates, such as national and state children's commissioners and guardians, as well as clinical ethicists, may also be a useful source of assistance in cases involving conflict about what is in the best interests of the child.

actions

- 5.1 Members of the interdisciplinary team should escalate concerns as required and in line with relevant policies and procedures until a satisfactory resolution is achieved. This may include accessing a second opinion if there are concerns that end-of-life care needs are not being adequately recognised or addressed.
- 5.2 Clinicians should provide information to the parents and the child so that they understand how to request an urgent review if they are concerned about their child's care, and the process for responding to their request.
- 5.3 Clinicians should conduct an interdisciplinary review of the goals of care and the treatment plan when concerns are raised that a child has unmet end-of-life care needs including physical, psychosocial or spiritual distress. Plan and document required follow-up and ongoing communication with the child, parents, and other clinicians.
- 5.4 Clinicians should know how to get rapid access to specialist paediatric palliative care advice 24 hours a day and seven days a week. This may include access by telephone or videoconference.
- 5.5 When sudden or unexpected deterioration in the child's condition occurs, clinicians should inform the parents and the interdisciplinary team with primary responsibility for the child's care as soon as possible.
- 5.6 Clinicians providing assistance in emergency situations should:
- have access to support from a clinician of sufficient authority to make decisions about stopping nonbeneficial treatments and providing palliative care
 - document appropriate, detailed and structured information about the outcomes of the call for assistance, discussions with the child and their parents, and the plan for follow-up or further review of the child in the healthcare record
 - communicate with the responsible medical officer in an appropriate, detailed and structured way about the outcomes of the call for assistance, and the plan for follow-up or further review of the child
 - use calls for assistance as a teaching and mentoring opportunity for other clinicians and students whenever possible, although resolving the concerns of the child and their parents should be the first priority.

part b

organisational prerequisites

6. leadership and governance

key points

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

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

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

actions

- 6.1 The health service organisation should partner with families to develop and govern systems for delivering paediatric end-of-life care.
- 6.2 The health service executive should consider how best to allocate resources within the context of the organisation's strategic plan to support the delivery and effective functioning of systems for providing paediatric end-of-life care.
- 6.3 The health service organisation should create a formal organisational policy framework for paediatric end-of-life care which applies across the acute health service, including:
 - governance arrangements
 - roles and responsibilities
 - communication and documentation processes
 - processes for advance care planning and limiting medical treatment
 - alignment with systems for recognising and responding to acute deterioration
 - criteria and processes for accessing help for end-of-life issues that are causing concern (e.g. ethical or legal advice)
 - access to specialist paediatric palliative care advice and services
 - the interface with external services, such as community and social care providers, and external hospice providers
 - clear dispute resolution processes, including access to mediation, bioethics and legal support in situations of complex end-of-life decision-making or conflict

- training and education requirements
- access to professional clinical supervision, and formal and informal debriefing, to suit the varied needs of clinicians
- access to support and debriefing for non-clinical staff
- evaluation, audit and feedback processes, and reporting requirements.

6.4 The health service organisation should identify potential variations in the application of the policy framework that might exist in different circumstances (such as at different times of day or in satellite locations).

6.5 The health service organisation should establish policies and processes for advance care planning, organ and tissue donation, limitations of medical treatment, symptom management and end-of-life decision-making to ensure that the care delivered in response to deterioration is consistent with appropriate clinical practice, the child and their parents' expressed wishes, and the best interests of the child.

6.6 The health service organisation should establish a formal governance process to oversee the development, implementation and ongoing review of systems for end-of-life care. If a committee has this role, it should:

- have appropriate responsibilities delegated to it, and be accountable for its decisions and actions to the executive
- monitor the effectiveness of interventions and education
- have a role in reviewing performance data
- provide advice about the allocation of resources
- include consumers, interdisciplinary team members, managers and executives.

6.7 The health service organisation should develop systems to ensure that essential resources required for the provision of safe and high-quality paediatric end-of-life care (e.g. private space for family meetings, equipment and medications, memory making materials, access to toys and education resources) are always operational and available.

6.8 The health service organisation should work with local community-based service providers and families to build capacity for children to be cared for in the preferred place of care (e.g. at home).

7. education and training

key points

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

Having an educated and suitably skilled and qualified workforce is essential to providing appropriate end-of-life care. For general services that also provide end-of-life care to children, end-of-life care education and training 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 clinicians' professional development.

Education and training should cover elements 1–5 in the Consensus Statement, local referral and communication processes, and relevant legislation and other regulatory frameworks. It should also include training about how to have conversations about end-of-life care.

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

actions

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

8. supervision and support for interdisciplinary team members

key points

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

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

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

actions

- 8.1 The health service organisation should have a policy framework outlining how supervision and support are provided to clinicians and other staff members who are in contact with the child and their parents.
- 8.2 The health service organisation should ensure that clinicians and other staff members who are in contact with the child and their parents know when and how to access peer support, mentoring and clinical supervision. This information should be provided at the commencement of employment and as part of regular refresher training.
- 8.3 The health service organisation should ensure that clinicians know how to access support after particularly distressing or problematic episodes of care. This may involve accessing external services for formal clinical supervision, counselling or debriefing.
- 8.4 The health service organisation should support clinicians to develop skills in self-care, reflective learning and providing peer support to colleagues.

9. evaluation, audit and feedback

key points

- Ongoing monitoring of the effectiveness of end-of-life care systems and processes is essential for quality improvement.
- Evaluation should address the quality and safety of the end-of-life care provided, not just the potential preventability of death.
- Ongoing monitoring and evaluation of processes and systems for delivering end-of-life care are essential, to establish their efficacy, track performance over time and determine priorities for improvement.

actions

- 9.1 The health service organisation should collect, review and report locally (including over time) data about the effectiveness of processes and systems for delivering paediatric end-of-life care.
- 9.2 The health service organisation should ensure that clinicians lead evaluation and audit, and feed back aggregate, de-identified data to their peers and colleagues.
- 9.3 The health service organisation should develop monitoring and evaluation strategies to capture feedback about the quality of paediatric end-of-life care from multiple disciplines (e.g. medicine, nursing, social work), as well as from children and their families.
- 9.4 Evaluation and monitoring should be simple, inexpensive and feasible. The health service organisation should develop processes that use routinely collected data and data linkage, where possible.

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

- effectiveness of treatment of symptoms
- recognition of the child's disease trajectory
- documentation of the child and their parents' wishes, and alignment of these wishes with actual care
- real-time feedback on child and family experiences of care
- feedback on their experiences from families of children who received end-of-life care
- whether any existing advance care plan was enacted
- the category of death (expected/unexpected/diagnosis)
- the time lapse between deciding to palliate or referring to specialist palliative care, and death
- transfers of care in the last week of life (e.g. transfers to or from intensive care).

9.6 Methods for collecting data could include:

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

9.7 The health service organisation should implement processes to routinely review the safety and quality of all deaths and determine if end-of-life care could have been improved.

10. systems to support high-quality care

key points

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

Organisations should consider opportunities to systematise the approach to paediatric 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 to paediatric patients – for example, by improving communication with external care providers, and improving continuity and coordination of care as the child is transferred in and out of acute health services. These systems should align with the requirements of the NSQHS Standards.

actions

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

- 10.5 The health service organisation should work with community care providers to ensure that systems are in place for communicating and accessing advance care plans developed in community care settings.
- 10.6 The health service organisation should ensure that systems are in place to facilitate appropriate documentation about end-of-life care, and to reduce the burden of documentation and data collection when possible.
- 10.7 The health service organisation should implement technological systems and solutions where they will support safe and high-quality paediatric end-of-life care, in accordance with the essential elements in this Consensus Statement.

appendices

appendix a: terminology

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

Term	Description
Acute healthcare facility ¹	A hospital or other healthcare facility providing healthcare services to patients for short periods of acute illness, injury or recovery.
Advance care directive ²	<p>A type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care, and appoint a substitute decision-maker to make decisions about health care and personal life management.</p> <p>In some states, these are known as advance health directives.</p>
Advance care plan ²	An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care, and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.
Advance care planning ²	A process of planning for future health and personal care, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.
Best interests	What is objectively in the best interests of the child based upon all of the relevant circumstances and in accordance with applicable laws.
Carer ³	<p>A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged.</p> <p>An individual is not a carer merely because they are the spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care. 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.</p>
Child/Children	<p>A person between 0 and 18 years of age.</p> <p>NB: This document does not apply to neonates (children aged 0-four weeks)</p>
Clinician ¹	A healthcare provider, trained as a health professional. Clinicians include registered and nonregistered practitioners, or members of a team of health professionals providing health care who spend the majority of their time providing direct clinical care.

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

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

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

Term	Description
Dying	The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks. This is sometimes referred to as 'actively dying'.
End of life ⁴	<p>The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown.</p> <p>This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.</p>
End-of-life care ⁴	<p>Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death.</p> <p>People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:</p> <ul style="list-style-type: none"> • advanced, progressive, incurable conditions • co-existing conditions that mean that they are expected to die within 12 months • existing conditions, if they are at risk of dying from a sudden acute crisis in their condition • life-threatening acute conditions caused by sudden catastrophic events.
Family ⁵	Those who are closest to the patient in knowledge, care and affection. This may include parents, siblings, grandparents, aunts, uncles, cousins and friends.
Goals of care	<p>The aims for a child's medical treatment, as agreed between the child, their parents, family and the healthcare team. Goals of care will change over time, particularly as the child enters the terminal phase.</p> <p>Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying child.</p> <p>The child's goals of care may also include non-medical goals – for example, returning home or reaching a particular milestone, such as participating in a family event.</p>
Healthcare team	The healthcare team includes: the interdisciplinary team in the health service; the child and their parents; other specialists (e.g. paediatricians and palliative care); and community care providers, such as the child's general practitioner.

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

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

Term	Description
Interdisciplinary team ⁴	A team of providers who work together to develop and implement a plan of care. Membership depends on the services required to identify and address the expectations and needs of the patient, parents, carers and other family. An interdisciplinary team might typically include one or more doctors, nurses, social workers, spiritual advisers, pharmacists, allied health and personal care workers. Other disciplines may be part of the team, depending on the needs of the patient and the resources available. Patients, parents, carers, other family members and volunteers may also be considered as part of the interdisciplinary team.
Limitations of medical treatment	<p>Medical decisions that may be made to limit the treatments that are, or could be, provided when they will not benefit the patient. A decision to not attempt cardiopulmonary resuscitation if a patient suffers a cardiopulmonary arrest is one example of a limitation of medical treatment.</p> <p>Similar terms that are in common use include withdrawal or withholding of medical treatment.</p> <p>Decisions to limit medical treatment may avoid prolongation of dying but will not cause a patient's death. This is quite different from the practice of euthanasia, where death is deliberately and purposefully hastened.</p>
Non-beneficial treatment	Interventions that will not be effective in treating a patient's medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Non-beneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.
Palliative care ⁶ or palliative approach	An approach to treatment that improves the quality of life of patients and their families facing a life-limiting condition, 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).
Parent/s	The person or persons identified by law as having parental responsibility for the child.
Parental Responsibility	All the duties, powers, responsibilities and authority which, by law, parents have in relation to children.
Patient	The primary recipient of care.

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

Term	Description
Resuscitation orders/plans	<p>Documents completed by a doctor to outline the plan of care in relation to emergency treatment of severe clinical deterioration.</p> <p>Not for resuscitation (NFR) and do not attempt resuscitation (DNAR) orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the patient has a cardiac or respiratory arrest. In some organisations, decisions about other specific limitations of medical treatment may also be listed as part of a resuscitation plan (e.g. decisions to call a medical emergency team or transfer a patient to intensive care if they deteriorate).</p>
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.
Terminal phase	The hours, days or, occasionally, weeks, when a patient's death is imminent. This is sometimes referred to as the period when a patient is actively dying.

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

appendix b: contributing documents and web sites

Paediatric End-of-life Care Resources

General Documents

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appendix c: acknowledgements

This document is based on the *National consensus statement: essential elements for safe and high-quality end-of-life care* released by the Commission in May 2015.

Many individuals and organisations have freely given their time, expertise and documentation in the development of this paper. In particular, the Commission wishes to thank those who participated in the End-of-Life Care Paediatric workshop and the consultation process, for their time, enthusiasm and advice. The involvement and willingness of all concerned to share their experience and expertise are greatly appreciated.



Australian Commission on Safety and Quality in Health Care

Level 5, 255 Elizabeth Street, Sydney NSW 2000
GPO Box 5480, Sydney NSW 2001

Telephone: (02) 9126 3600 (international +61 2 9126 3600)

Fax: (02) 9126 3613 (international + 61 2 9126 3613)

mail@safetyandquality.gov.au

www.safetyandquality.gov.au