Australian
Commission on
Safety and Quality
in Health Care

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

National Consensus Statement

June 2026

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We recognise that knowledge about healthy Country, community and culture has been developed by Aboriginal and Torres Strait Islander peoples over tens of thousands of years and has been shared for generations. We are committed to partnering with and learning from Aboriginal and Torres Strait Islander peoples through the work that we do.

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Executive summary

The death of a baby, child or young person is deeply distressing and can have a profound effect on families, carers, health professionals, and communities. End-of-life care refers to the healthcare provided to children in the final years, months, weeks and days of their lives.

When delivered in a child and family-centred, culturally safe way, this care can support the child's comfort, dignity and quality of life, and help families manage distress and grief. Effective communication and coordinated care are critical at the end of a child's life. Clinical and organisational systems should support collaboration and shared-care between healthcare workers and the broader care team, to enable well-coordinated care in the child's preferred place wherever possible.

Depending on each child's circumstances, their care team may include a range of people, including (but not limited to) general practitioners, acute care services, specialist paediatric palliative care services, critical care services, and social care agencies. School and community supports may also play an important role for children and families.

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 contribute to a best practice, culturally safe, child and family-centred approach to end-of-life care. The Consensus Statement upholds the rights of the child, consistent with the principles of the UN Convention on the Rights of the Child. It includes nine guiding principles that define safe, high-quality care, followed by ten essential elements that describe the key actions expected of healthcare services providing end-of-life care in Australia.

Essential elements 1–5 describe how end-of-life care should be approached, while essential elements 6–10 outline the organisational processes that support effective care delivery. The way these elements are applied will vary according to local context, available resources and the cultural, religious, spiritual and individual needs and preferences of the child, and their family or carers.

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.

Key terms used in this document

This document uses a range of terms to describe people, roles and aspects of care. A full list of definitions is included in the glossary at the end of the Consensus Statement.

- End-of-life care is care provided when a child is approaching the end of their life, including when death is imminent (expected within a few hours or days). It focuses on supporting the child's comfort, dignity and quality of life, and supporting the wellbeing of the family, including parents, siblings, and other caregivers.
- Child is used to describe neonates, babies, children and young people under the age of 18 years.
- Parent or parents are 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.
- Family is used to refer to parents, siblings, grandparents, loved ones, carers, kin and other people with a significant relationship to the child. It is acknowledged that family structures

in Australia are diverse, and where family is mentioned, this should be read as inclusive of all family structures.

- Healthcare workers and multidisciplinary teams are inclusive of a broad range of health professionals and types of teams. It is not possible to mention all professional groups. We acknowledge the important role of the broader care team that supports safe and high-quality end-of-life care, including, but not limited to, disability support workers, social workers, psychologists, Aboriginal and Torres Strait Islander health workers and liaison officers, other culturally specific workers, and school staff.
- First Nations children are those whose cultural status as an Aboriginal or Torres Strait Islander person is determined by a parent, relatives or other kin. Cultural protocols, practices, customs, rituals and experiences of Sad News and Sorry Business are unique to each First Nations child, their family, community and kinship groups.

Background

The Consensus Statement on end-of-life care for children was first released in 2016 by the Australian Commission on Safety and Quality in Health Care (the Commission) to support the nuanced and complex clinical decision-making at end-of-life in paediatrics. It was informed by experts, published evidence, and partnerships with carers, consumers, representatives from public and private hospitals and healthcare services, professional colleges, state and territory health departments, and other government agencies.

Evidence supporting safe and high-quality end-of-life care has evolved since the original Consensus Statement. This second edition incorporates updated literature, additional consultation with the paediatric palliative care sector, those with expertise or interest in paediatric end-of-life care, consumers, and expert committees that advise the Commission and the Australian public. Neonatal-specific end-of-life care considerations are also included in this second edition.

Scope

The Consensus Statement applies to all services where healthcare is provided to children approaching the end of their life, including hospitals, hospices, residential care facilities, home settings, general practice and Aboriginal Community Controlled Health Services.

The elements within the Consensus Statement apply to all children and their families. Some population groups may have specific needs or considerations, and these are highlighted within the essential elements. Factors such as disability, cultural background, rurality, socio-economic disadvantage or trauma may intersect, and services should consider the whole context of the child and family to tailor support accordingly.

Parts of the Consensus Statement are aspirational, particularly for services that do not routinely provide care for children with life-limiting conditions. In regional, rural and remote settings, paediatric end-of-life care is often delivered by generalist clinicians within a hub-and-spoke, networked system of shared-care between regional, community, adult palliative care, specialist paediatric clinicians, retrieval services and paediatric intensive care units (PICUs). These collaborative partnerships are crucial to safe and high-quality care.

When death occurs as a result of sudden and unexpected events, such as acute illness or trauma, care should, where possible, be aligned with the Consensus Statement. Many sudden deaths occur in the community, at home, during ambulance attendance, or within Emergency Departments (ED) or PICUs. These deaths may involve ambulance officers, paramedics, critical care and retrieval teams. Sudden deaths present unique challenges, and some elements of the Consensus Statement may not be appropriate in these circumstances.

For some children and families, the guiding principles, elements and actions may need to be applied over an extended period. End-of-life care is complex and multi-dimensional, and aspects of care need to be revisited as the child's condition changes, and as their developmental stage, decision making capacity and family or kinship circumstances evolve.

Audience

The Consensus Statement has been developed for:

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

Application

The Consensus Statement provides a resource for the implementation of actions in the National Safety and Quality Health Service (NSQHS) Standards[1] and the National Safety and Quality Primary and Community Healthcare Standards[2], and provides guidance for recommended practice, not mandatory requirements. It also aligns with the third edition of the National Consensus Statement: Essential elements for recognising and responding to acute physiological deterioration[3]. It is intended that these documents be applied together when appropriate. For services that are not required to be assessed to standards, the Australian Charter of Health Care Rights[4] provides a useful reference framework. Health services can further support the implementation of the Consensus Statement by utilising A Practical Guide to Palliative Care in Paediatrics (The Green Book)[5] and The Paediatric Palliative Care National Action Plan[6].

Healthcare services should adapt the guiding principles and essential elements outlined in the Consensus Statement to reflect their local context, population needs, and available resources. They are expected to align their work with relevant national, state and territory legislation and other programs, and integrate with local processes for recognising and responding to acute physiological deterioration.

This Consensus Statement describes recommended practice for paediatric end-of-life care and is intended as a guiding document. It does not replace clinical judgement, local policy, or legal requirements. Healthcare workers must practise in accordance with the laws and regulations of their jurisdiction. Where any inconsistency exists between this Consensus Statement and applicable legislation, the legislation prevails.

Guiding principles

Guiding principles

1. Be child and family-centred

Children and families should be supported to participate in care decisions whenever possible. The child's best interests are the primary consideration, and the family is recognised as the fundamental decision-making unit. Children and families should be involved as much as possible, in accordance with legislation.

2. Align with values, needs and wishes

End-of-life care should be guided by the child's expressed wishes, which may be communicated verbally or non-verbally, including their preferences for how and where care is received. These wishes and needs may change over time. Parents play a central role in supporting and interpreting their child's wishes. Their insights, values and cultural beliefs should inform shared decision-making, while ensuring the child's best interests remain the primary focus.

3. Provide children with information they can understand

Children should be provided with information about their health in ways they can understand, considering their age, developmental stage, communication needs and preferences. Parents, who hold legal responsibility for decision-making, should also be given clear and understandable information to support shared decision-making with the child wherever possible.

4. Consider cultural, religious, spiritual and psychosocial needs

Meeting the cultural, religious, spiritual and psychosocial needs of children and their families and carers is as important as meeting physical needs. This includes beliefs and practices related to death, dying and after-death care, recognising that time may be required to shape practices and processes accordingly. For First Nations peoples, this includes ensuring that connection with ancestors, kin, community, and Country is enabled in end-of-life and after-death care.

5. Include qualified, skilled and experienced multidisciplinary care

Effective communication, collaboration and teamwork are required to ensure continuity and coordination of care across disciplines, services and care settings.

6. Ensure the right to refuse medical treatment

Decisions regarding treatment may be made in advance and remain valid unless the child and/or their parents state otherwise. Parents have the right to refuse medical treatments for their child, provided such decisions do not conflict with the child's best interests, considering all the relevant circumstances, in accordance with applicable laws and guided by relevant ethical principles.

7. Not be burdensome or harmful

It is unethical to provide investigations, treatments or transfers of care that are burdensome, offer no benefit, or cause harm to the child.

8. Not offer unreasonable hope

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

9. Continue with care after a child has died

Care of a deceased child, and bereavement care for families, extends beyond the death. Services should also consider the wellbeing of staff involved in the child’s care.

Essential elements

Essential elements

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

A. Care processes

Delivering high-quality end-of-life care

1 Recognising end of life

2 Child and family-centred care and shared decision-making

3 Multidisciplinary collaboration and coordination of care

4 High-quality care

5 Responding to concerns

B. Organisational processes

Supporting high-quality end-of-life care

6 Leadership and governance

7 Support, education and training

8 Care setting

9 Evaluation, audit and feedback

10 Systems to support high-quality care

Section A: Care processes

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

The first step in providing safe and high-quality end-of-life care to children is to recognise children who need this care.[3] All children have the right to dignity, comfort and privacy, and to be cared for with respect and compassion.

Shared decision-making is a process that allows children, parents and healthcare teams to work together to reach decisions in the child's best interests in accordance with the *Family Law Act 1975*. Informed by various ethical concepts relevant to paediatric care, this process respects the child's developing autonomy and recognises the complexities of family decision-making.[1]

Clinicians routinely communicate, provide and support access to information that meets the needs of children and families at all stages of care. This supports shared decisions based on the best available evidence, the child's stage of development, the realities of the child's clinical condition and treatment options, and the values and preferences of the child and their family.

Essential element 1: Recognising end of life

Recognising end-of-life in children is often complex and uncertain. Prognosis can be difficult to predict, as children die from a wide range of conditions, many of which are uncommon in adults.[7] For some children, it may be hard to distinguish between potentially reversible deterioration and irreversible deterioration that is part of the normal dying process. In these circumstances, a trial of treatment for a defined period to assess the reversibility of a child's deterioration may be appropriate.

Recognising that a child may be approaching the end of their life creates opportunities to identify their needs and ensure care aligns with the child's and family's expressed values, goals and wishes.

Healthcare workers should be aware of the referral criteria, processes and pathways for accessing specialist paediatric palliative care and other support services. Recognition of end-of-life care needs may occur at different points along a child's illness trajectory, including earlier (medium term) phases where deterioration may be intermittent or potentially reversible, and later (short term) phases where deterioration is more likely to be irreversible. Earlier recognition creates opportunities for ongoing discussions with the child and their family about future care needs.

Actions

1.1 Use screening mechanisms to recognise children who could benefit from end-of-life care interventions.[7, 8] Ask yourself:

- Would you be surprised if this child died in the next 12 months (medium term)?
- Would you be surprised if this child died in the next days or weeks (short term)?

1.2 Use condition-specific mortality risk prediction tools and monitor critical events to consider and react appropriately to end-of-life circumstances such as[9]:

- Life threatening trauma or disease
- Life-limiting conditions
- Poor or incomplete responses to medical treatment
- Continued deterioration despite intervention. This may include a decline in the child's condition, or a clinical determination that they will not benefit from interventions such as surgery, dialysis or treatment in intensive care
- Repeated escalation to the rapid response team in acute services, particularly if the child has been admitted for more than one week
- Multisystem comorbidities (such as involving the cardiovascular, pulmonary or endocrine system)
- Reaching the limits of medical therapy
- Multiple recent admissions to hospital for exacerbation of a chronic condition
- Multiple or extended stays in hospital

Considerations for First Nations children

Support services, such as those provided by Aboriginal and Torres Strait Islander liaison officers, Aboriginal and Torres Strait Islander health workers or Aboriginal and Torres Strait Islander health practitioners should be offered to families early.

Regardless of the location in which First Nations people live, their worldview is founded upon connections to kin, community, ancestors, the land and their specific country which extends to traditional lands, ancestral country and/or a community of significance.

Some families of First Nations children who are likely to die within days or weeks may prefer to return home so the child can die on Country. It is essential to ensure smooth transitions and coordination of appropriate services.

Healthcare services should liaise with First Nations communities to support appropriate communication and involvement from, or collaboration with, the child's kinship system, Elders or specific Aboriginal and Torres Strait Islander Land Councils and community organisations to support appropriate communication and involvement.

Considerations for neonates

The potential need for end-of-life care for an unborn baby may be identified antenatally, for example when a diagnosis of a severe congenital anomaly is made. This can allow for anticipatory discussions and proactive, family-centred planning, including parallel planning for prognostic uncertainty, to support families through complex decisions and prepare for potential outcomes after the birth of the neonate.

Essential element 2: Child and family-centred care and shared decision-making

Healthcare workers should adopt a child and family-centred approach to communication and decision-making ensuring the child's best interests are the primary consideration. Child and family-centred care should be equitable and accessible, recognising that a child's ability to participate may vary over time, be decision-specific, and can be influenced by factors such as environment, culture, health literacy and previous interactions with healthcare providers.

Healthcare workers should be aware that various factors may intersect for a child and their family, including socio-economic disadvantage, trauma, race, religion, rurality and disability. The child's stage of development and capacity should be considered when involving them in decision-making, with children included in discussions about their care wherever possible.

Conversations about death, dying and the end of a child's life require compassion, knowledge, experience, sensitivity and skill. Communication should be tailored to the individual preferences and needs of the child and their family, using plain and clear language and avoiding euphemisms such as 'not doing well'. Conversations may need to be repeated, to ensure information has been understood.

The purpose of end-of-life care conversations will vary depending on the circumstances and may include sharing information or making decisions about specific aspects of care. Early referral to support services should be promoted to improve care experiences and actively engage the child at the end of their life, as well as their family.[10]

Actions

2.1 Identify the person/s with parental (or decision-making) responsibility.

2.2 Assess the capacity of the child to be involved in decision-making, in accordance with state legislation. This capacity may change across the course of the illness and over time. Include the child in discussions about their care wherever possible.

2.3 Identify opportunities for proactive and pre-emptive end-of-life care discussions with the child and their parents, to align care with their values, wishes, cultural, religious and spiritual care needs, and reduce the need for urgent, after-hours discussions in emergency situations.

2.4 Identify culturally appropriate decision-makers as early as possible so that strategies can be put in place for obtaining their input in discussions about end-of-life care. Cultural practices around death and dying, and about who should be involved in decision-making, should not be presumed.

2.5 Be respectful, sensitive and responsive to the preferences and needs of the child at the end of their life, including about their identity, culture, religious beliefs, gender identity, sexual orientation and loved ones (including family of choice).

2.6 Prepare to have conversations about end-of-life care that can include:

- Discussions involving the child's general practitioner or care coordinator about prognosis and options to develop a coordinated approach to planning and delivering end-of-life care.

- Familiarisation with the child's history and current condition, their family structure, communication skills, cultural, religious and spiritual needs and preferences.
- Organising enough time for uninterrupted discussion in a safe, quiet and private environment.
- Ensuring that the child and family have access to their tailored communication aids and are offered interpreters as required.
- Arranging for the appropriate people to be in attendance – ideally, this will include the child, their family, and relevant healthcare workers or teams, and may extend to religious, spiritual and cultural advisors for additional layers of support.

2.7 Early in the process, provide the child and parents with information, identifying the healthcare workers responsible for leading and/or coordinating end-of-life care. Whenever possible, involve these healthcare workers in discussions.

2.8 Ensure there are regular end-of-life conversations that are child and family-centred and tailored to meet the needs of the child, parents and any other participants.

2.9 Provide the child and parents with an honest and straightforward summary in plain language, including a clinical assessment of the situation, appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the child's condition improving in response to such treatment.

2.10 Be compassionate and sensitive to the child's situation. Allow enough time for those involved to absorb, process and react to information provided, to support informed decision-making about future care. Multiple discussions may be required.

2.11 Include information in end-of-life discussions about organ and tissue donation in circumstances where donation is possible. This extends to tumour, organ and tissue donation for scientific research. Ensure these discussions occur in collaboration with the relevant state or territory DonateLife agency and are led by healthcare workers or specialist donation personnel with appropriate expertise, in partnership with intensive care teams where relevant. These healthcare workers should know the processes involved and be able to answer questions for the family and staff.

2.12 Clearly document the content of discussions and any agreed plan of care in the child's healthcare record and My Health Record if available. Document any unresolved issues along with a plan for follow-up.

2.13 Communicate the content of the discussion and plan of care, including any limitations of medical treatment and resuscitation plans, to all healthcare workers involved in the child's care and prioritise the wishes of the child and their parents.

2.14 Discussions on memory-making - such as photos, hand and footprints, recording of a heartbeat, preservation of a lock of hair - and religious rituals or cultural ceremonies should occur in alignment with the wishes of the child and their family.

Considerations for First Nations children

Cultural approaches and expectations

It is important to ensure culturally safe care for First Nations children and their families at the end of their life including the provision of social, emotional and cultural supports. This includes respecting cultural protocols, decision-making structures, and connections to Country, kinship and community. Healthcare services should provide access to advice and support from Aboriginal and Torres Strait Islander health workers and/or liaison officers, and interpreters, or ensure appropriate community contact information is available.

Families should be offered the opportunity to include Elders and significant others for cultural and decision-making support. This may include support for cultural practices, spiritual needs and accommodation or adjustment to visitation practices to the extent that the family wishes.

Differences in communication styles, including the importance of silence and non-verbal cues, should be respected. There are many First Nations languages, and English may be a second or third language for some families.

Yarning and other culturally appropriate communication methods should be used to explain care options, explore values and beliefs, build trust and support decision-making. Aboriginal and Torres Strait Islander health workers and liaison officers can help guide culturally appropriate care and engagement and can assist clinicians to clarify the needs and preferences of the child at the end of their life.

Enabling culturally safe care through service delivery

Health services play a key role in enabling culturally safe care through flexible and respectful service delivery. Healthcare workers should introduce themselves in person to First Nations families and children wherever possible. At a minimum a video conference should be offered.

Clinicians should tailor their communication and engagement approaches to meet family preferences, using interpreters or cultural support where needed to ensure the information conveyed is appropriate and understood. Clinicians may be required to explain the child’s end-of-life plan (which may be better understood as an end-of-life story) to multiple people and may involve more than the child and their immediate family to ensure informed decision-making can occur.

Service models should accommodate large, extended family visitation due to First Nations family/kinship relationships and family-led decision-making. The best approach is to work with the family/spokesperson and First Nations health workers to coordinate care and visitation and ensure this is clearly communicated to all staff. Rooming-in options and access to cultural spaces should be supported where possible.

Considerations for neonates

A collaborative approach is essential for end-of-life conversations in neonatal end-of-life care, involving key clinicians from various specialties. These can include midwives, obstetricians and maternal fetal medicine teams, and neonatal intensive care unit (NICU) healthcare workers including neonatologists, neonatal nurses, and neonatal allied health professionals. Conversations with the family’s general practitioner (GP) are also important, however in many situations the GP may know the family but may not have met the neonate.

Parenting a new baby with profound health concerns can be an overwhelming experience: comprehensive support for both parents' caregiving and decision-makers is vital. A Family-Integrated Care (FICare) approach, widely adopted in many NICUs, is highly valuable. This framework empowers families to actively participate in their neonate's care and parenting, fostering a sense of involvement and control during a challenging time.[11]

Families should be provided privacy. Being on a postnatal ward where there are also healthy newborns can be challenging for families. Preferred care locations, including NICU, home or hospice, should be discussed and be aligned with parent and family wishes.[12]

Discussions on memory-making - such as photos, hand and footprints, and naming ceremonies - should occur in alignment with parent and family wishes.

Considerations for children with communication difficulties

Communication difficulties at the end of a child’s life may impact a child’s ability to safely and readily express their thoughts and the decisions they make about care. Consideration should be made towards supporting children to effectively communicate, including asking parents about how their child prefers to communicate. Children may require tailored communication aids and supports to participate in care planning and decision-making due to difficulties with verbal communication or other factors, including cognition or fluctuating alertness.

Essential element 3: Multidisciplinary collaboration and coordination of care

Overall responsibility for coordinating a child's end-of-life care and ensuring effective communication and collaboration should be allocated to a person or team.[13] This role may be held by a general practitioner, general paediatrician or subspecialist, nurse, allied health professional, intensive care specialist, paediatric palliative care team, or another appropriate person or team depending on the circumstances. The appointed person should have the capacity to perform the role and understand their responsibilities as a part of a multidisciplinary team caring for the child at the end of their life.

Children often receive care from multiple services and sectors with differing roles and perspectives. Effective multidisciplinary collaboration across disciplines and services, particularly at transitions of care, is essential to reduce fragmented care, contradictory information and poorly communicated decision making, and to improve experiences of children and their families.[14] This includes coordinating care with disability services, carers and other members of the broader healthcare team to support safe and high-quality end-of-life care for children with disability.

Where available, PICUs and retrieval services may provide specialist consultation, care and shared problem-solving, particularly when escalation, de-escalation or transfer from smaller, regional and remote facilities is being considered. PICUs are an important specialist resource for both children with severe illness and for those receiving active treatment alongside palliative care. Clinicians should be aware of local procedures for contacting PICU for advice.

Actions

3.1 Assign a person to lead and coordinate the child's end-of-life care.

3.2 Explain the roles and responsibilities of all healthcare workers to the child, parents and those involved in their care.

3.3 Ensure all members of the multidisciplinary or interdisciplinary team are aware that they are responsible for:

- Communicating in a psychologically and culturally safe way, and providing care that is child and family-centred, supporting shared decision-making
- Identifying existing documented plans for care and providing care in accordance with the child and family's expressed values, needs and wishes, including care after death
- Referring children with specific needs to appropriate services
- Actively seeking, documenting and communicating relevant information from existing services involved in the child's care, including the agreed plan for care and any limitations of medical treatment, when handing over care responsibilities to others

3.4 Discuss the range of views around future treatment with the child and parents to minimise confusion and support understanding of available options.

3.5 Establish processes for healthcare workers and the child and their family, carers and other support people to voice concerns and respond accordingly.

Essential element 4: High-quality care

The goal of healthcare workers providing end-of-life care to children should be to deliver high-quality care that is culturally safe and appropriate to the child's needs. High-quality care should be person-centred, safe, effective, accessible, integrated, and provided in a way that is equitable, efficient and sustainable. Care should consider the whole context of the child and family and should be tailored accordingly. A child and family's goals and wishes should be identified early and revisited over time, with appropriate psychosocial, spiritual, cultural, religious and emotional support offered in response.[15]

For some children end-of-life care occurs alongside ongoing treatment for potentially reversible complications or episodes of deterioration. A palliative approach may be provided in parallel with active medical treatment. Parents have the right to refuse medical treatment, provided this does not conflict with the child's best interests. Clinicians are under no obligation to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the child's quality of life.[1, 5] Time limited trials of treatment and other agreed approaches may be documented to support shared decision-making during periods of uncertainty.

High-quality care requires proactive, anticipatory and individualised planning that can adapt to changes in the child's condition, including in situations of acute or unexpected deterioration. When treatments no longer provide benefit or become burdensome, care should focus on providing comfort to the child and support for their family. Bereavement care should continue beyond the child's death as required, noting that sudden death may increase the risk of psychological distress.[16] Services should also consider the wellbeing of staff involved in the child's care.

Actions

4.1 Discuss goals of care, the plan for care and any limitations of medical treatment early, including religious, spiritual and cultural needs and practices. Ensure these discussions are clearly documented in the healthcare record and routinely reviewed and updated.

4.2 Offer or revisit ongoing discussions about future care needs and preferences if the child is likely to die within 12 months, particularly when symptoms and needs fluctuate. These discussions may occur over multiple conversations with the child and their parents

4.3 Avoid unnecessary tests and treatments, to reduce the burden associated with medical treatment. This includes deprescribing medicines and avoiding non-beneficial investigations or interventions, and unnecessary observations.

4.4 Clearly communicate medical decisions, including the rationale, to discontinue or not instigate non-beneficial observations, investigations or treatments with the family, and document those decisions.

4.5 Reconsider the goals of care, the plan for care, and any limitations of medical treatment (including resuscitation plans) as the child's condition or circumstances change. Clinicians should lead families through "ceasing resuscitation" conversations, ensuring that families agree, rather than being forced to decide, when resuscitation is clearly not working.

4.6 Ensure the plan for care is readily available to all healthcare workers and other professionals involved in the child's care.

4.7 When care priorities change, reassure the child and family that comprehensive, compassionate care continues for children at the end of their life. Ensure comfort, and time to fulfill religious, spiritual and cultural practices.

4.8 Prioritise pain relief and symptom control to prevent and relieve suffering for all children. Manage physical symptoms and support psychosocial, emotional, social, religious and spiritual needs as part of care, and review symptom management regularly with the team.

4.9 Provide a plan for eating and drinking that supports dignity, quality of life and the enjoyment of food and drink for as long as the child wishes. Families may value continuing to offer food and drink as a meaningful part of caregiving and connection, and this should be supported wherever safe and appropriate.

4.10 Consider a process to determine the risks and benefits of transferring the child between services or to their home, in alignment with their family's wishes. Retrieval teams are a key resource in facilitating these transfers.

4.11 Develop and implement processes to provide tailored bereavement support that meets the immediate and ongoing needs of families. This includes identifying and offering referral to appropriate local and culturally safe bereavement supports and providing families with accessible information about how to access further support, including support for funerals, cultural ceremonies or rituals where relevant.

4.12 Establish and maintain partnerships with organisations that can provide ongoing bereavement care and support for families and healthcare workers, as needed.

Considerations for First Nations children

Healthcare workers should support First Nations children and families to determine the care that is right for them at the end of life. End-of-life care for First Nations children should respect First Nations ways of knowing, being and doing, be culturally safe, and align with identified individual needs of the child. Note that what is culturally appropriate care in one family community may differ to that of another.

It may be important to include additional family or community members. Elders are highly valued and can provide decision-making support and advice regarding cultural practices and care that are important at end-of-life.

Best practice is to engage with the child and their family alongside significant others (Elders and kin) to determine cultural needs and respect specific cultural obligations.

Consideration should be given to supporting children at the end of their lives to return to Country and providing end-of-life care on Country whenever possible, in alignment with the family's wishes.

Referral to rural services or remote clinics to ensure a smooth transition between services should include plans, the family's preferences and bereavement support requirements. This may require a facilitated introduction or handover or collaborative outreach care. Broader referral pathways should be considered for First Nations families to support culturally appropriate burials and bereavement practices.

Considerations for neonates

Assessment using validated neonatal-specific tools and observations of non-verbal cues can be used to assess discomfort or distress. Discomfort and distress can often be effectively managed with non-pharmacological comfort measures, including minimal handling, facilitated tucking, swaddling, non-nutritive sucking, and kangaroo care (skin-to-skin). Some parents may wish to provide comfort feeding for their baby. Pharmacological management is also often appropriate, using appropriate dosing and routes.

Parents and families may wish to engage in memory-making and parent-bonding activities and supports should be offered to facilitate this. Many neonates may not have the opportunity to ever be at home. Consider empowering the family to bring elements of their outside-of-hospital life into their baby's hospital space, if they wish to do so.

The Stillbirth Clinical Care Standard[17] provides additional guidance to support best practice care for bereavement care following perinatal loss.

Considerations for children with disability

End-of-life care for children with disability can be associated with a change in their physical care needs. Providing reassurance to parents, families, and carers can support their involvement in comfort-focused care.

Healthcare professionals should:

- Plan for reasonable adjustments to ensure the needs of children with disability, their families, and carers are met
- Understand the child and the disability
- Communicate directly with the child and their family and carers
- Act to provide required care

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

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

Bereavement support

Bereavement support includes the emotional, psychosocial, religious and spiritual support provided to families before and after the death of a child. This support is designed to help people cope with grief, loss and adjustment.[18] In Australia, bereavement support will vary between communities, depending on the lived experiences and cultural backgrounds.

Bereavement support is fundamental for families to have a good end-of-life care experience. Care extends beyond the death of the child, and abrupt cessation may be detrimental. Early assessment and supportive measures to address the bereavement needs of families minimises adverse physical and emotional responses. Support services that provide spiritual, pastoral, or culturally specific counselling may assist some families to grieve, and referral to such services should be offered to families as early as possible. Referral to partner organisations may also be required.

Essential element 5: Responding to concerns

When concerns are raised about a child approaching the end of their life, or decision-making is complex, timely and appropriately skilled support is essential. This may include additional consultation with specialist paediatric palliative care or consultants. Physical, psychosocial, cultural, religious or spiritual distress requires rapid assistance by suitably skilled healthcare workers, with additional support accessed as appropriate.

Responding to concerns may require the support of additional healthcare workers, or the use of videoconferencing or teleconferencing to access off-site help. A person skilled in clinical ethics, mediation and/or the law should be available for managing conflict, complex family dynamics or ethical issues.[5]

Actions

5.1 Ensure there are clear systems and processes that enable children and families to raise concerns about end-of-life care and request an urgent review or a second opinion when needed, and that families understand how these processes operate.

5.2 Undertake a rapid healthcare review if a concern regarding unmet end-of-life care needs is raised.

5.3 Provide healthcare workers, the child, and their family with rapid access to specialist paediatric palliative care advice by agreed means.

5.4 Ensure a medical officer, nurse practitioner, or other appropriately trained and authorised healthcare professional is contactable when a rapid response to acute deterioration is required. These healthcare workers should have sufficient expertise and authority to support ethical shared decision-making with families regarding withdrawal of non-beneficial treatment, including options for redirection of care to comfort-focused care and memory making.

5.5 When after-hours decision-making is required because of a sudden or unexpected deterioration in the child's condition, a review by the healthcare worker responsible for coordinating care should occur as soon as possible.

5.6 Communicate critical information to the person responsible for coordinating care in a detailed and structured way. This should include the outcomes of any call for assistance, and the plan for follow-up or further review of care options for the child.

5.7 Recognise that emotional and spiritual distress may accompany concerns at the end of a child's life and ensure timely access to psychosocial and spiritual support.

Section B: Organisational processes

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

Healthcare services delivering care to children at the end of their life should recognise and prioritise this care.[10] This includes working with organisations or sectors to optimise care continuity and communication between different service providers, particularly during transitions of care. Organisational policies and systems should guide the actions of boards, executives, managers, healthcare workers and other employees, volunteers, and students, to ensure a consistent and responsive approach. Healthcare services should also ensure the workforce is equipped to identify when end-of-life care is required and to provide comfort-focused, culturally safe and spiritually responsive care.

Essential element 6: Leadership and governance

Clinical governance is central to providing the best outcomes for patients. It is the combination of culture, systems and structures that enable everyone in a health service to deliver care that is consistently high-quality and improving. To achieve high-quality care, governance processes should aim to ensure early identification of vulnerable families and to provide proactive, accessible, service coordination.

A systematic approach and committed leadership are necessary to improve the experiences of a child at the end of their life. Cultural change may be required to prioritise end-of-life care for children in some healthcare settings.

Qualified and skilled healthcare workers are required to provide safe and high-quality end-of-life care to children. Permanent positions can be more successful than time-limited roles. Ongoing learning and support should be provided. Healthcare services should provide practical support to address moral distress, and prevent moral injury and burnout of healthcare workers, including support when clinicians are under pressure to provide non-beneficial interventions.

Actions

6.1 Provide opportunities for families to partner with the healthcare service to improve care delivery.

6.2 Incorporate the development, implementation and ongoing review of systems for paediatric end-of-life care within governance frameworks, including processes for:

- Clear delegation of responsibilities and accountability for decisions and actions
- Representation of families and carers, healthcare workers, managers and executives
- Regular review of performance, education and training, and opportunities for improvements

- Regular review of resource allocation, and service capability

6.3 Ensure organisational policies and governance arrangements support safe, culturally safe and ethically sound paediatric end-of-life care, including clarity about roles, decision-making, access to specialist advice, escalation pathways, and processes for managing concerns and resolving disputes.

6.4 Identify variations in the application of the end-of-life care policy that might exist in different circumstances (such as after-hours) and address findings when unwarranted variation is identified.

6.5 Implement policies and processes that support organ and tissue donation, limitations of medical treatment, and end-of-life decision-making in a way that is consistent with state legislation, appropriate clinical practice and the child's and family's values and wishes.

6.6 Ensure systems are in place to support coronial and statutory requirements following a child's death, including appropriate documentation, reporting, and support for family and staff.

Considerations for First Nations children

Cultural safety is determined by First Nations individuals, families and communities.

When care is delivered in a culturally safe way it improves the experience and outcomes of First Nations people. Healthcare organisations should ensure their approach to delivering culturally safe end-of-life care, including policies, procedures and models of care, are developed and reviewed in partnership with First Nations people, families and carers, Elders, communities, other support people and other services.

Cultural competence

Experiences of end-of-life care, including care expectations, religious and spiritual practices, and after-death customs are heavily influenced by cultural values and beliefs. Consideration of a family's needs should be individualised and culturally safe.

Discussions about future care should be approached in accordance with cultural values and beliefs. Cultural practices, expectations and preferences should be explored and documented as part of the child's care planning and ongoing conversations.

Capability to deliver culturally sensitive care requires an organisation-wide approach to planning, implementing and evaluating services for children from culturally and linguistically diverse backgrounds, including migrant and refugee communities.

To support cultural competence, a service or provider should:

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

Essential element 7: Support, education and training

An educated, suitably skilled and qualified workforce is essential to providing high-quality, child and family-centred end-of-life care to children.[19] All healthcare workers should have a shared understanding of relevant policies, processes and expectations, and access to education that supports safe, compassionate, culturally safe and developmentally appropriate care.

Education and support should enable healthcare workers to recognise end of life in children, communicate effectively with children and families, and provide culturally safe and developmentally appropriate care. It should also enable healthcare workers to manage symptoms, navigate shared decision-making and ethical challenges, and care for themselves and their colleagues. This includes mechanisms for specialist paediatric palliative care services to build capability and provide ongoing support to generalist hospital, community and adult palliative care services, particularly to enable care close to home. Providing end-of-life care for children can be emotionally challenging and may contribute to moral distress, burnout and reduced wellbeing across the workforce, including for non-clinical staff. Systems for peer support, mentoring, supervision and debriefing are essential to support staff wellbeing and maintain high-quality care.

Actions

7.1 Ensure systems are in place to provide supervision, peer and other appropriate support to healthcare workers who care for children at the end of their life.

7.2 Provide relevant education to the workforce about recognising children at the end of their life and managing their care. Make sure education is provided at the commencement of employment and as part of regular professional development.

7.3 Ensure healthcare workers caring for children at the end of life receive the education and support required for their role. This includes but is not limited to:

- Supporting the cultural, religious, spiritual and psychosocial needs of the child at the end of their life
- Understanding and using shared and supported decision-making strategies
- Initiating interventions to support person-centred, child and family-centred, safe and high-quality end-of-life care for children including comfort care measures and memory-making strategies that alleviate discomfort and distress of the child and their family
- Understanding end-of-life ethical and medico-legal issues, including the relevant professional ethical frameworks and applicable relevant legislation, such as:
    - refusal of treatment
    - withholding and withdrawing treatment
    - non-beneficial treatment
- Communicating effectively, verbally and in writing
- Escalating concerns in a timely manner

7.4 Encourage healthcare workers providing end-of-life care to participate in reflective learning activities, including discussions with children and their families, multidisciplinary and interdisciplinary case reviews, mortality and morbidity meetings, reflective practice, and adverse event reviews, including following sudden, unexpected or traumatic deaths.

7.5 Ensure healthcare workers are taught culturally safe approaches to providing end-of-life care to First Nations children.

7.6 Ensure healthcare workers are taught culturally safe approaches to providing end-of-life care to culturally and linguistically diverse children.

7.7 Ensure healthcare workers are taught appropriate approaches to providing end-of-life care to children with disability.

7.8 Offer ongoing formal training in communication skills to healthcare workers at all levels, as these skills are critical to the delivery of end-of-life care. Training may include specific skills, such as engaging with children with varying communication abilities, children with disability or neurodiversity.

7.9 Ensure healthcare workers providing end-of-life care are educated about how to recognise moral distress and burnout in themselves and their colleagues. Provide mitigation strategies, information and access to support services.

7.10 Support healthcare workers to develop skills in self-care, reflective learning and providing peer support to colleagues. Experienced healthcare workers may help develop the skills and capacity of other healthcare workers.

Essential element 8: Care setting

The care setting is an important consideration for both a child at the end of their life and their family. When care is provided outside the home, family members may experience a lack of space and privacy, reporting feelings of 'being watched' and not being able to talk openly with their loved ones.[5, 20] Access to private physical spaces contributes to the quality of care offered at the end of a child's life, including spaces for cultural practices such as family gatherings, chanting or other important rituals associated with end-of-life. Where possible, and where time and the child's condition permit, the preferred location of death (home, hospice, on Country, hospital) should be identified as early as possible and coordination initiated.

Out-of-hospital care is a distinct, complex and often time-critical end-of-life care setting, and includes ambulance attendance, retrieval services, acute deterioration at home, planned home deaths, and unscheduled or after-hours care. Paramedics, ambulance services and emergency responders are often the first healthcare workers present during deterioration, crisis or death. Encounters may be brief, intense and highly emotional, and there may be limited background information about the child. These factors increase the likelihood of rapid, high-impact decisions being made without full knowledge of previously agreed care plans or family preferences. In these settings, access to clear information about goals of care, limits of treatment, and specialist support is essential to reduce burdensome transfers and support care in line with the child's and family's wishes.

Schools are also a place where children may receive health care and are important partners in care planning to support continuity of care and ensure the best outcomes for the child.

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

Actions

8.1 Build capacity for children to be cared for in their preferred place of death where possible – for example, at home or on Country. This could best be accomplished by healthcare services working together.

8.2 Establish systems to ensure that essential resources required for the provision of safe and high-quality end-of-life care are operational and available, including appropriate staffing, private spaces for families to gather, bereavement spaces, as well as appropriate equipment and medicines.

8.3 Establish systems and processes to support families to access care settings and support after-hours and when other circumstances impact healthcare services, such as during a pandemic.

8.4 Support families and loved ones to visit the child at any time during the last days of life – to the extent that the child and family wishes.

Essential element 9: Evaluation, audit and feedback

All deaths of children where end-of-life care has been provided by a healthcare service should be routinely reviewed to assess the safety and quality of care and how it could be improved. Evaluation should not focus solely on the potential preventability of death. Findings from evaluation, audit and feedback can be used to improve the safety, quality and coordination of care, including the performance of recognition and response systems, ensuring systems are operating as planned. Findings may also contribute to research, learning and innovation in paediatric end-of-life care, where appropriate.[21, 22] Further guidance to support evaluation and audit, including practical tools, is available through the Commission's End-of-Life Care Audit Toolkit[23] and related resources.

Actions

9.1 Collect, review and report data about the effectiveness of processes and systems for delivering end-of-life care.

9.2 Ensure processes exist for reporting data to inform governance and planning.

9.3 Develop monitoring and evaluation strategies that capture multidisciplinary and interdisciplinary feedback, as well as feedback from children receiving care and their families, about the quality of end-of-life care.

9.4 Routinely use collected data for evaluation and monitoring processes, and support data linkage where possible. Ensure systems are simple, inexpensive, feasible and fit for purpose.

9.5 Ensure measures of the safety and quality of end-of-life care are ethically collected, accessed, used and stored. The data collected should be determined locally and be proportionate to service capacity and context. Where evaluation is undertaken, considerations may include:

- Who end-of-life care is being provided to, including equity considerations and population characteristics
- How end-of-life care needs are recognised and responded to
- The alignment between the child's goals, values and wishes and the care that is delivered
- Effectiveness of symptom management and comfort care
- The use of investigations, treatments and transfers of care near end-of-life
- Access to, and involvement of, specialist paediatric palliative care services
- Care settings and transitions of care, including during acute or unexpected deterioration
- Bereavement support provided to families and carers
- Barriers and enablers to providing safe and high-quality end-of-life care

9.6 Include audit, feedback and review in quality improvement processes to support clinical improvement, education and service provision.

Essential element 10: Systems to support high-quality care

Organisations should consider opportunities to systematise the approach to end-of-life care, where this will support best practice. End-of-life care should be integrated into existing organisational safety and quality systems to support sustainability and organisational learning. High-quality end-of-life care should be supported across all care settings and circumstances, including expected and unexpected deaths, to ensure equity of care for all children regardless of location or mode of death.

These systems should align with the requirements of the National Safety and Quality Health Service (NSQHS) Standards[1] and the Primary and Community Healthcare Standards[2] where applicable. Aligning systems for comprehensive care with those for end-of-life care, including those related to recognition and response to acute deterioration, will help to ensure that children at the end of their life receive coordinated, appropriate and effective care from their multidisciplinary and/or interdisciplinary team.

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

Actions

10.1 Provide systems that support healthcare workers to receive, prepare, review and update documented plans for care and treatment decisions in line with the child's and family's wishes, and relevant legislation. Ensure these systems align with the Clinical Governance Standard[1] and Recognising and Responding to Acute Deterioration Standard[1], where these Standards apply.

10.2 Ensure systems appropriately identify essential palliative medicines and provide access to them for children at the end of their life, for example, provision for anticipatory prescribing. These systems should align with the Medication Safety Standard[1], where applicable.

10.3 Enable systems to provide timely access to specialist palliative care clinicians, where required, for children with complex palliative care needs or as a supportive resource for other healthcare workers. This may include off-site access via virtual care.

10.4 Implement processes to support safe and effective communication between healthcare services at transitions of care in relation to prognosis, future care planning, treatment and medicines in alignment with the Communicating for Safety Standard[1], where applicable.

10.5 Ensure systems support safe, secure and timely access to and sharing of plans for care and treatment decisions developed in other settings, with relevant professionals involved in the child's care, as appropriate.

10.6 Facilitate systems for accurate, efficient and appropriate documentation and data collection about end-of-life care.

Glossary

Glossary

Actively dying The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks.

Advance care plan A document that captures an individual's beliefs, values and preferences in relation to future care decisions, but which does not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date). *In paediatric care, advance care planning conversations occur within a broader shared and supported decision-making process and may be iterative. *

Advance care planning A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require skills to facilitate these conversations effectively. The national quality standards for aged care, general practice and healthcare services all promote advance care planning. Individuals can also choose to engage in advance care planning with people who are not health practitioners, such as friends or family.[1, 5] *In paediatric care, advance care planning conversations occur within a broader shared and supported decision-making process and may be iterative. *

Anticipatory prescribing When medicines are prescribed and dispensed in preparation for a time when a person needs them. They can be used to manage symptoms in the home, with the goals of rapid relief and avoidance of unplanned or unwarranted admission to a healthcare facility. Anticipatory prescribing is important in healthcare settings to enable ward staff to manage symptoms appropriately.

Broader care team People that provide care to a child who are not healthcare workers. They may be disability support workers or be part of education and community services.

Carer A person who provides personal care, support and assistance to another individual who needs it because they have a disability or medical condition (including a chronic or mental illness).

An individual is not a carer merely because they are parent, other relative or guardian of an individual, or live with an individual who requires care.

Child/children A person under the age of 18 years, including babies and neonates (0-4 weeks).

Clinical governance Central to providing the best outcomes for patients. It is the combination of organisational culture, systems and structures that enables everyone in a health service to deliver care that is consistently high-quality and improving.

Clinical supervision A formal professional relationship between two or more people in designated roles, which facilitates reflective practice, explores ethical issues, and develops skills.[25]

Clinician A trained health professional, including registered and non-registered practitioners, who provides direct clinical care to patients. Clinicians may provide care within a healthcare service organisation as an employee, a contractor or a credentialed healthcare provider, or under other working arrangements. They include nurses, midwives, medical practitioners, allied health practitioners, paramedics and other professionals who provide health care, as well as students who provide healthcare under supervision.

Comprehensive care Health care that is based on identified goals for the episode of care. These goals are aligned with the patient's and family's expressed preferences and healthcare needs, consider the impact of the patient's health issues on their life and wellbeing, and are clinically appropriate.

Cultural competence A set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals to enable that system, agency or those professionals to work effectively in cross-cultural situations.

Cultural safety Culturally safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities.

Culturally safe practise is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism.

Diversity The varying social, economic and geographic circumstances of consumers who use, or may use, health services, as well as their cultural backgrounds, disability status, religions, beliefs and practices, languages spoken, sexual orientation, gender identity and gender expression, and sex characteristics.

End of life The period when a child is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown.

This period may be years in the case of children with chronic or malignant disease, or very brief in the case of children who suffer acute and unexpected illnesses or events, such as sepsis, or trauma.

End-of-life care Includes physical, religious, spiritual and psychosocial assessment, and holistic and compassionate care and treatment delivered by healthcare workers. It also includes support of the family, including parents, siblings, and other caregivers when a child is approaching the end-of-life, and care of the child's body after their death.

A child is 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes children whose death is imminent (expected within a few hours or days) and those with:

- Terminal and/or life-limiting conditions
- 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 The term family includes people identified by the child as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, chosen family, street family for those experiencing homelessness, communities, and friends (including pets) may be identified by the child as family.[5]

Child and family-centred care Care that embraces the whole family to include parents and carers and other family members, such as a child's siblings. Child and family-centred care recognises that the child has agency, where possible, and their parents are the most experts in their care.[5]

Family integrated care A model that integrates families as partners in the neonatal intensive care unit care team and provides a structure that extends the implementation of family-centred care.[11]

Goals of care The aims for a child's medical treatment, as agreed between the child, their parents, family and the healthcare team in the context of a shared decision-making process. Goals of care will change over time.[5]

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.

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.

Healthcare service Used to describe acute, primary and community healthcare services, as well as other services involved in the delivery of health care. Healthcare services are delivered in a wide range of settings and vary in size and organisational structure. These range from owner-operated services, where a single clinician is also responsible for administrative and management operations, to complex organisations comprising of many clinicians, a supporting workforce, management and an overarching governing body.

Healthcare worker A person working in health or community settings. This includes registered health practitioners, other health practitioners, and carers. Support staff in these settings (such as those in administration or cleaning) are not considered healthcare workers in this consensus statement.

Health literacy There are two components to health literacy: individual health literacy and the health literacy environment.

Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action.

The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the healthcare system, which affect the ways in which consumers access, understand, appraise and apply health-related information and services.

Informed consent A process of communication between a child, their family and clinician about options for treatment, care processes or potential outcomes. This communication results in the child and their family's authorisation or agreement to undergo a specific intervention or participate in planned care, which may include watching and waiting. The communication should ensure that the child and family have an understanding of the care they will receive, all the available options and the expected outcomes, including success rates and side effects for each option.

Intensive care Intensive care is provided to patients who are critically unwell and require complex, multisystem life support such as mechanical ventilation, extracorporeal renal support, and invasive cardiovascular monitoring.[26]

Interdisciplinary team A team of providers who work together to develop and implement a plan of care. Membership depends on the services required to identify and address the expectations and needs of the patient, carers and family. An interdisciplinary team might typically include one or more doctors, nurses, social workers, religious and spiritual advisers, pharmacists and personal care workers. Other disciplines may be part of the team, depending on the needs of the patient and the resources available. Hospital volunteers, patients, carers and family members may also be considered as part of the interdisciplinary team.

Limitations of medical treatment 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.

Similar terms that are in common use include withdrawal or withholding of medical treatment.

Decisions to limit medical treatment may avoid prolongation of dying but will not cause a person's death.

Medicine A chemical substance given with the intention of preventing, diagnosing, curing, controlling or alleviating disease, or otherwise improving the physical or mental wellbeing of people. These include prescription, non-prescription, investigational, clinical trial and complementary medicines, irrespective of how they are administered.

Moral injury Persistent distress that arises from a personal experience that disrupts or threatens: (a) one's sense of the goodness of oneself, of others, of institutions, or of what are understood to be higher powers, or (b) one's beliefs or intuitions about right and wrong, or good and evil.[28]

Multidisciplinary team A team of clinicians from multiple disciplines who work together to deliver comprehensive care that deals with as many of the child's health and other needs as possible. The team may operate under one organisational umbrella or may be from several organisations brought together as a unique team. As a child's condition changes, the composition of the team may change to reflect the changing clinical and psychosocial needs of the child. Multidisciplinary care includes interdisciplinary care. (A discipline is a branch of knowledge within the health system.)

Non-beneficial treatment Interventions that will not be effective in treating a child's medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medicines, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Non-beneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.

Palliative care Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves providing support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres, and even in children's homes.[29]

Parent Defined under the *Family Law Act 1975* as the person or persons identified by law as having parental responsibility for the child.

Parental responsibility Defined under the *Family Law Act 1975* as all the duties, powers, responsibilities and authority which, by law, parents have in relation to children. The concept of parental responsibility in relation to First Nations children is subject to section 61F of the *Family Law Act*.

PICU A high specialised area in the hospital which provides advanced care for critically ill and injured infants, children and young people and their families, who require close monitoring, advanced medical treatment, and organ support.[30]

Reasonable adjustments Defined under the *Commonwealth Disability Discrimination Act 1992* as actions taken to prevent indirect or direct discrimination on the basis of disability.

Resuscitation orders/plans Documents completed by a medical officer to outline the plan of care in relation to emergency treatment of severe clinical deterioration.

‘Not for resuscitation’ (NFR), ‘do not attempt resuscitation’ (DNAR), and ‘allow natural death’ (AND) orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the child has a cardiac or respiratory arrest. In some organisations, decisions about other specific limitations of medical treatment may also be listed as part of a resuscitation plan (for example, decisions to call a medical emergency team or transfer a child to intensive care if they deteriorate).

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 non-specialist healthcare workers who are providing palliative care.

Shared decision-making Discussion and collaboration between a child, their family and their healthcare team that brings together the child and family’s values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, in order to reach the most appropriate healthcare decisions for the child and their family.

Virtual care Any interaction between a patient and clinician, or between clinicians, occurring remotely with the use of information technologies.

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