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Safety and Quality
in Health Care

DRAFT

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

National Consensus Statement

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Contents

1

Executive summary

Executive summary

The death of a baby, child or young person feels unnatural and is deeply distressing for everyone. It is tragic, confronting and can have a profound effect on parents, carers, siblings and family, friends, health professionals, and communities. End-of-life care is a specific phase of the palliative care journey. The health care that children with life-limiting conditions receive in the last years, months and weeks of their lives can help families and loved ones to manage the distress and grief associated with death and dying and maximise the child or young person's quality of life [3, 11-13]. Particularly when it is delivered with a culturally responsive approach that encompasses the child and families' spiritual needs, cultural protocols and end of life beliefs.

Effective communication and coordination of care is particularly critical at the end of a child or young person's life. Systems should be employed that support collaboration and shared care between healthcare services including general practitioners, acute services, specialist paediatric palliative care services, and social care agencies. The aim is to support care that is well coordinated and helps the child or young person receive end-of-life care in their preferred place.

The *National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care* (the Consensus Statement) provides healthcare services with a best practice, culturally responsive, and family-centred approach to caring for babies, children and young people who are approaching the end of their life. The Consensus Statement provides nine guiding principles that define safe and high-quality end-of-life care. These are followed by 10 essential elements that outline the key actions that should be applied by healthcare services providing end-of-life care.

Essential elements 1–5 describe how end-of-life care should be approached and essential elements 6–10 describe the organisational processes required for the effective delivery of safe and high-quality end-of-life care. However, the way the elements are applied will vary according to the local circumstances of the setting, the available resources, the cultural requirements and spiritual beliefs alongside the individual needs and preferences of the child receiving care, and their parents or carers.

Background

The Consensus Statement specifically covering 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 derived from experts, published evidence, partnership 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 the findings of two rapid literature reviews[8, 14], a paediatric rapid literature review [15] and additional consultation with the paediatric palliative care sector and those with expertise or interest in paediatric end-of-life care, 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.

Purpose

The purpose of the Consensus Statement is to describe the essential elements for delivering safe and high-quality end-of-life care to babies, children and young people in Australia.

Scope

The Consensus Statement applies to all services where health care is provided to children approaching the end of their life, including hospitals, hospices, residential care facilities and home settings.

The elements within the Consensus Statement are designed to apply to all babies, children or young people, and their parents. However, some population groups may have specific needs or considerations. These have been highlighted within the essential elements.

The guiding principles, elements and actions in the Consensus Statement may need to be applied over an extended period of time for some children or young people and their families. End-of-life care is complex and multi-dimensional, and it is likely that aspects of care need to be revisited as a baby, child or young person’s condition changes, and they move through different developmental phases.

The guiding principles, elements and actions in the Consensus Statement may need to be applied over an extended period of time for some children or young people and their parents and families. End-of-life care is complex and multi-dimensional, and it is likely that aspects of care need to be revisited with changes in the baby, child or young person’s young age, development phase, decision-making capacity and condition over time and as family, guardianship or kinship relationships evolve.

Audience

The Consensus Statement has been developed for:

- Healthcare workers who provide health care to babies, children and young people 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

Key Terms used in this Document

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

- End-of-life care refers to a specific phase of the palliate care journey. It generally refers to the final 12 months of life, including children whose death is imminent (expected within a few hours or days) and involves support of the family, including parents, siblings, and other caregivers when a child is approaching the end of life.
- Terms related to healthcare professionals, healthcare workers, clinicians and multidisciplinary teams are intended to be inclusive. It is not possible to mention all professional groups in this document. However, we acknowledge that there are many different professional groups that support safe and high-quality end-of-life care.
- Terms such as parent, family and carer have been used throughout the document. It is acknowledged that family structures in Australia are diverse and that where parents or family are mentioned, this document should be read as inclusive of all family structures and legal guardians.
- The terms neonate, baby, child, children and young people are used throughout the document and refer to anyone under the age of 18 years, including babies and neonates (neonates 0-4 weeks).
- First Nations is used to refer to babies, children and young people whose cultural status as an Aboriginal or Torres Strait Islander child is determined by a parent, relatives or other kin. In using the term First Nations, it is recognised that the cultural protocols, practices, customs, rituals and experiences of Sad News and Sorry Business are unique to each child, their family and kinship groups.

Application

The Consensus Statement provides a resource for the implementation of actions in the National Safety and Quality in Health Services (NSQHS) Standards and the National and Safety Quality Primary and Community Healthcare Standards, and provides recommended, rather than mandatory, practice. It also aligns with the third edition of the National Consensus Statement: Essential elements for recognising and responding to acute physiological deterioration [17]. 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 provides a useful reference framework.

Healthcare services need to tailor the guiding principles and the essential elements in the Consensus Statement to deliver timely, safe and high-quality end-of-life care suited to their setting, the needs of their population and available resources. They also need to align their work with relevant national, state and territory legislation or other programs. These should work in synergy with local processes for recognising and responding to acute physiological deterioration.

Parents have a special role as caregivers and decision-makers in ensuring the best interests for their child. Consideration should be given to the preferences of the child and their parents for both the place of care and place of death. It may be their wish for the child to die at home.

This means 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.

120

Guiding principles

Guiding principles

1. Be family-centred

Children, young people and families have the right to make care decisions, whenever possible. Parents, families and carers should be involved, in accordance with legislation.

2. Align with values, needs and wishes

End-of-life care should consider the child or young person’s expressed wishes (which may be expressed verbally or non-verbally), regarding the circumstances, environment and place in which they wish to die. Their needs, goals and wishes for end-of-life care may change over time.

3. Provide children with information they can understand

Children and young people should be provided with health information that they can understand at the end of their life. Parents hold legal responsibility for decision-making about their child or young person’s care and should also receive health information that they can understand.

4. Consider cultural, spiritual and psychosocial needs

Meeting the cultural, spiritual and psychosocial needs of children and their families and carers is as important as meeting their physical needs. This may include considerations such as beliefs and practices around the end of a baby, child or young person’s life and dying, and after death care practices; taking into account the time it may take to shape practices and processes accordingly. For First Nations peoples, this extends to considering how 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 that ensures continuity and coordination of care between multidisciplinary and interdisciplinary teams, within and between care settings, during transitions of care, and across multiple episodes of care is required.

6. Ensure the right to refuse medical treatment

Decisions regarding treatment may be made in advance and remain valid unless the child or young person and their parents state otherwise. Parents have the right to refuse medical treatments for their children, provided such decisions do not go against what is objectively in the child’s best interests based upon all of the relevant circumstance and in accordance with applicable laws.

7. Not be burdensome or harmful

It is unethical to provide burdensome investigations, treatments and transfers of care to babies, children or young people that can be of no benefit or are harmful.

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 a baby, child or young person’s quality of life.

9. Continue after a baby, child or young person has died

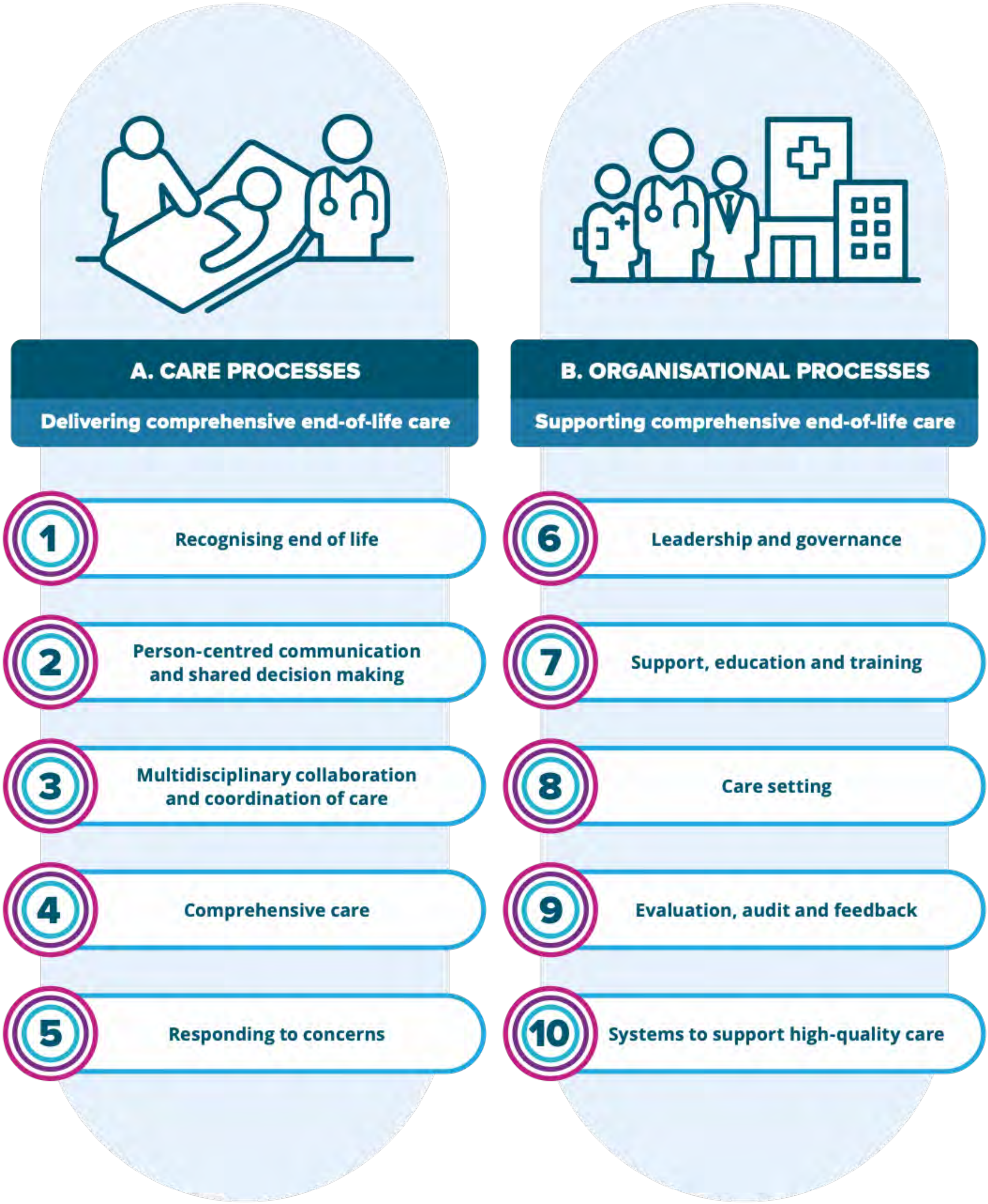
Care of a deceased baby, child or young person, and bereavement care for parents, carers, siblings, family and loved ones, extends beyond the death of the baby, child or young person.

162

Essential elements

Essential elements

Figure 1: Overview of the 10 essential elements for safe and high-quality end-of-life 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 babies, children and young people is to recognise children who would benefit from such care.[17] End-of-life care is comprehensive care delivered in a coordinated way. Everyone involved needs to work together to achieve the child's end-of-life goals. All children have a right to dignity, comfort and privacy, and to be cared for respectfully and with compassion. The prevention and relief of suffering is the highest priority.

Shared decision-making is a process that allows children, young people, parents and healthcare teams to work together to reach decisions in the child's best interests in accordance with the *Family Law Act 1975*, based on the scientific evidence available, the child's stage of development, the realities of the child's clinical condition and treatment options, and the choices, values and preferences of the child and their family.

Essential element 1: Recognising end of life

The first step in providing safe and high-quality end-of-life care is to recognise children who would benefit from such care [17].

Routine use of trigger tools and questions can prompt healthcare workers to use their clinical judgment to make a holistic assessment of whether a child might benefit from end-of-life care [17, 18]. Recognising that a baby, child or young person is at the end of their life offers opportunities to identify their needs. This includes ensuring the child's comprehensive plan for care aligns with their expressed values, goals and wishes.

Predicting prognosis and when a child will die can be difficult [19]. Children die from a range of conditions, with a significant percentage dying from conditions not widely seen in the adult population. For some children, it may be hard to distinguish reversible deterioration from irreversible deterioration that is part of the normal dying process. In such cases, it may be appropriate to consider a trial of treatment for a defined period to assess the reversibility of a child or young person's deterioration. Healthcare workers should be aware of the referral criteria, processes and timelines for accessing specialist paediatric palliative care services and other support services. Healthcare services delivering end-of-life care should:

- Aim to identify whether a baby, child or young person is likely to die within 12 months (the medium term), where it is possible episodes of acute deterioration may be reversible. This period can be a key opportunity to talk to the child and their family, carers and loved ones about advance care planning
- Aim to identify whether a baby, child or young person is likely to die within days or weeks (the short term), where acute deterioration is likely to be irreversible

Actions

1.1 Use screening mechanisms to recognise children who could benefit from end-of-life care interventions. Ask yourself [19, 20]:

- Would you be surprised if this child died in the next 12 months?
- Would you be surprised if this child died in the next days or weeks?

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 [21]:

- 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 Aboriginal and Torres Strait Islander babies, children and young people

Support services, such as those provided by Aboriginal and Torres Strait Islander Liaison Officers, 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.

Families of Aboriginal and Torres Strait Islander babies, children or young people likely to die within days or weeks will often prefer to return home so the baby, child or young person can die on Country. It is essential to ensure smooth transitions and coordination of appropriate services. Healthcare services should liaise with Aboriginal or Torres Strait Islander 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

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

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

Healthcare workers should adopt a family-centred approach to communication and decision-making and involve the child or young person in discussions about their own care, even when they are not able to make decisions on their own. Recognising the values, needs and wishes of children in their care is an obligation of all healthcare workers. However, family-centred care means that the family is involved in communication and recognised for decision-making in a child or young person's life. The child or young person's stage of development should be considered when involving them in decision-making and communication should be tailored to meet their needs. This is equally important for children and young people with developmental or intellectual disability.

Conversations about death, dying and the end of a child or young person's life require compassion, knowledge, experience, sensitivity and skill on the part of healthcare workers. All communication processes should recognise and be responsive to the individual preferences and needs of the child or young person and their family. Plain language should be used, avoiding euphemisms such as 'not doing well'.

The child's level of involvement in decision-making should be based on the child's age, assessed ability and state legislation. Consult with the parent or caregivers or the young person themselves to determine the best approach. In some cases, older children may be capable of decision-making if they have a sufficient understanding of their clinical condition and treatment options. The purpose of an end-of-life care conversation will depend on the circumstances of the child or young person involved. In some cases, the purpose will be to impart information. In other cases, decisions may need to be made about specific aspects of care. Early referral to support services should be promoted to improve care experiences and actively engage the child or young person at the end of their life, as well as their family [14].

Actions

2.1 Identify the person/s with parental responsibility.

2.2 Assess the ability of the child to be involved in discussions and decision-making about their care, in accordance with state legislation. This ability may change across the course of the illness and as the child develops.

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

2.4 Identify culturally appropriate decision-maker(s) as early as possible so that strategies can be put in place for obtaining their input in discussions about end-of-life care. Common assumptions about death and dying, and about children or young people and families as decision-makers may not be correct.

2.5 Be respectful, sensitive and responsive to the preferences and needs of the child or young person at the end of their life, including with regard to 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 or young person's general practitioner or coordinator of their care about prognosis and options to develop a coordinated approach to planning and delivering end-of-life care
- Familiarisation with the child or young person's history and current condition, their family structure, and cultural and spiritual needs and preferences
- Organising enough time for uninterrupted discussion in a safe quiet and private environment
- Ensuring that the child or young person and family has access to their tailored communication aids and offer interpreters as required
- Arranging for the appropriate people to be in attendance – ideally, this will include the child or young person, their parents and family, and other relevant healthcare workers or teams, and may extend to spiritual and cultural advisors for additional layers of support

2.7 Provide the 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 family-centred and tailored to meet the health literacy needs of the child, parents and any other participants.

2.9 Provide 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 baby, child or young person's condition improving in response to such treatment.

2.10 Be compassionate and sensitive to the child or young person's situation. Allow enough time for those involved to absorb, process and react to information provided. Multiple discussions may be required.

2.11 Include information in end-of-life discussions about organ and tissue donation for transplantation in circumstances where donation is possible and there is no identified cultural objection. This extends to tumour, organ and tissue donation for scientific research. Ensure these discussions are conducted with advice from the state or territory DonateLife agency and are led by healthcare workers who have attended the core Family Donation Conversation workshop.

2.12 Clearly document the content of discussions and any agreed plan of care in the baby, child or young person'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 ensure to prioritise the child or young person's and parents' wishes.

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 Aboriginal and Torres Strait Islander babies, children and young people

Cultural approaches and expectations

It is important to ensure culturally safe care for Aboriginal and Torres Strait Islander babies, children and young people and their families at the end of their life including provision of 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 liaison officers and health workers, 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 throughout the care journey. 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 nonverbal cues, should be respected. There are many Aboriginal and Torres Strait Islander 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 health workers and liaison officers can help guide culturally appropriate care and engagement and can assist clinicians to clarify the requirements of the baby, child or young person at the end of their life.

Enabling culturally responsive 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 Aboriginal and Torres Strait Islander 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 young person'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 individual and the immediate family to ensure informed decision-making can occur.

Service models should accommodate large, extend family visitation due to Aboriginal family/kinship relationships and family-led decision making. The best approach is to work with the family/spokesperson and Aboriginal and/or Torres Strait Islander 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 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-making roles 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 [6].

Families should be provided privacy. Being on a postnatal ward where there are also healthy newborns can be challenging for some families. Preferred care locations, including NICU, home or hospice, should be discussed and be aligned with parent and family wishes [9].

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 or young person'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 and carers 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 [22]. This responsibility could be allocated to a general practitioner, nurse, allied health professional, paediatric palliative care team, parent, family member or someone else depending on the circumstances. The appointed person should understand the requirements, have capacity to perform the role, and understand that they are part of a multidisciplinary team caring for the child at the end of their life.

Children often receive care from a range of organisations that have different approaches to managing end-of-life care. Multidisciplinary collaboration is a process where healthcare workers from different disciplines and/or healthcare services share clinical information to optimise the delivery of comprehensive care for a person. This includes ensuring effective communication and liaison between all healthcare services involved in care, particularly at the interface between different services and teams, such as between hospital and community-based services, or between the treating team and after-hours care providers[23]. Plans should specify how information, including provision of cultural support and access to spiritual support, at these transition points will be communicated to a child and their family, carers and other support people.

Coordinating care reduces the risk of a child at the end of their life receiving contradictory information and poorly organised care [24]. It also improves the experiences of care for children and their families [25]. Coordinated care requires clear and agreed roles and responsibilities for different people involved, and defined processes for care planning. The goals and wishes of a child at the end of their life should be included in the comprehensive plan for care. The plan needs to be accessible and clear to all healthcare workers so that care can be effectively coordinated.

Actions

3.1 Assign a person to lead and coordinate the baby, child or young person'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, person-centred and family-centred way, and sharing and supporting decision-making
- Identifying existing advance care plans and providing care in accordance with the child and family's expressed values, needs and wishes, including after death care
- Referring children with specific needs to appropriate services
- Documenting and communicating the agreed plan for care and any limitations of medical treatment when handing over care responsibilities to other healthcare workers involved in the child's care

3.4 Discuss the range of views around future treatment with the child and parents to minimise confusion and ensure that they understand their 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 and young people should be to deliver high-quality care that is culturally safe and appropriate to the needs, symptoms, goals and wishes of the child, and their family, at the end of their life. It should also be aligned with their expressed wishes and goals. These should be sought early, with appropriate psychosocial, spiritual, cultural, religious and emotional support offered in response [26].

For some children approaching the end of their life, there will be a long period of transition when treatment will continue for reversible complications or reversible episodes of deterioration. Children may benefit from a palliative approach in conjunction with active medical treatment of their illness. Parents have the right to refuse medical treatment, provided such decisions do not go against the child or young person's best interests, and clinicians are under no obligation to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the baby, child or young person's quality of life [27]. Specific medical decisions about treatments that could be provided in the event of deterioration may be documented in the health care record. These would include therapies that may be tried for a short time to test their ability to reverse deterioration and any other potential effects.

Processes should be in place to support proactive, anticipatory and individualised planning for end-of-life care. When treatments cease to provide benefit or become uncomfortable and burdensome, planning should focus on providing comfort to both the child and their family and carers. Bereavement care should continue for parents, carers, siblings, family and loved ones beyond the child's death as required.

Actions

4.1 Discuss goals of care, the plan for care and any limitations of medical treatment early, including cultural and spiritual needs and practices. Ensure these discussions are clearly documented in the healthcare record by healthcare workers. Ensure healthcare workers are aware of their roles and responsibilities to routinely review and update documentation.

4.2 Offer or revisit advance care planning [28] if the child is likely to die within 12 months, and particularly if symptoms and needs fluctuate and change. This may take multiple and ongoing meetings with the child or young person and their parents, where appropriate those who can offer decision-making and cultural support, and other health professionals involved in care.

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 baby, child or young person's condition or circumstances change. Provide the child or young person, parents and any others involved with the opportunity to discuss their treatment further, and to review the comprehensive plan for care at any time.

4.6 Ensure the comprehensive plan for care is readily available to all healthcare workers involved in the baby, child or young person's care.

4.7 When care priorities change, reassure the child or young person and family that comprehensive compassionate care continues for children at the end of their life, ensuring comfort, and time to fulfill spiritual and cultural practices associated with this time.

4.8 Prioritise adequate pain relief and symptom control to prevent and relieve suffering. Manage physical symptoms and provide for psychosocial, emotional, social and spiritual needs within scope of practice and in alignment with the child or young person's and parent's wishes and plan for care. Review treatment with the team regularly.

4.9 Provide a plan for eating and drinking that supports dignity, quality of life and enjoyment of food and drink for as long as the baby, child or young person wishes.

4.10 Consider a process to determine the risks and benefits of transferring the baby, child or young person between services or to their home, in alignment with their family's wishes.

4.11 Develop processes to tailor bereavement supports that meet the immediate needs of parents, siblings, family and loved ones and extend to meet their ongoing and future needs as required.

4.12 Identify local support resources for bereavement referrals and provide information to bereaved family and other loved ones about how to access ongoing information and support in a format they can use. In the immediate, this may include information and support about funeral arrangements, or other cultural ceremonies and rituals.

4.13 Establish partnerships with organisations that can provide ongoing bereavement care for parents, carers, siblings, families and healthcare workers.

Considerations for Aboriginal and Torres Strait Islander babies, children and young people

Priorities identified by First Nation families should be determined, and care should be culturally appropriate, respectful and align with identified individual needs. Noting that what is culturally appropriate care in one family community may differ to that of another.

It may be important to include additional family members and decision-makers from a baby, child or young person's community. 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 also 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 and in alignment with the family's wishes.

Referral to rural services or remote clinics to ensure a smooth transition between services should include plans and 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 Aboriginal and Torres Strait Islander 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). If safe to do so, 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 [7] 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. Reassurance for parents, families and carers to participate in comfort-focused cares can be helpful.

Healthcare professionals should:

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

A National Disability Insurance Scheme (NDIS) support coordinator may be part of the multidisciplinary team that cares for a child or young person 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 and spiritual support provided to families and loved ones before and after the death of a child or young person. It is designed to help people cope with grief, loss and adjustment [5]. In Australia, bereavement support may look different in different communities, depending on the lived experiences and cultural backgrounds of those involved. For example, some culturally and linguistically diverse communities may prefer to be directly involved in end-of-life care [8]. At the same time, it is important to recognise that there will always be different individual responses and preferences within any community.

Bereavement support is fundamental for families and loved ones to have a good end-of-life care experience. Care extends beyond the death of the baby, child or young person, and abrupt cessation may be detrimental. Some families are also at risk of prolonged or complicated grief. 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.

427

Essential element 5: Responding to concerns

When concerns are raised about a baby, child or young person approaching the end of their life or decision-making is particularly complex, timely and appropriate assistance should be obtained from a suitably skilled healthcare worker or team.

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

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

Actions

5.1 Ensure that there is a system in place for parents and carers to independently raise concerns about end-of-life care, or to seek a second opinion when needed.

5.2 Establish policies and procedures that clearly define criteria and processes for raising concerns about end-of-life care.

5.3 Support the child or young person at the end of their life, and their family and carers, to understand the triggers and process for requesting an urgent review of care and how this will be provided.

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

5.5 Provide healthcare workers and the child or young person and their family and carers with rapid access to specialist paediatric palliative care advice by agreed means.

5.6 Ensure a medical officer or nurse practitioner of 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 measures when withdrawing treatment, is contactable when a rapid response to acute deterioration is required.

5.7 Where possible, ensure advance care planning conversations occur early and explore treatment pathways to alleviate suffering. Completed and current advance care planning documents improve the family's experiences and by minimising time-pressured decision making. It enables pre-determined timing to redirect futile and non-beneficial care to comfort measures and memory-making and avoids after hours and emergent decision-making regarding withdrawal of care.

5.8 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.

5.9 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 baby, child or young person at the end of their life.

5.10 Calls for assistance should be used as a teaching and mentoring opportunity for other healthcare workers and students when appropriate.

5.11 Recognise that children and their families can experience anticipatory loss and grief which is frequently accompanied by emotional and spiritual distress. Psychosocial and spiritual support and bereavement care is key to responding to distress.

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 babies, children and young people.

Healthcare services delivering care to children at the end of their life should recognise and prioritise this care [14]. This includes working with organisations or sectors to optimise care continuity and communication between different service providers particularly during transitions of care. Policies and systems need to guide the actions of boards, executives, managers, healthcare workers and other employees, volunteers, and students, to ensure a consistent and responsive approach

Healthcare organisations should ensure the workforce is equipped with the skills to identify when and how provide end-of-life care, provide comfort care and incorporate opportunities for making lasting positive memories specific to each family aligned with their cultural and spiritual beliefs.

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 processes that enables everyone in a health service to deliver care that is consistently high quality and improving. A systematic approach and committed leadership are necessary to improve the experiences of someone at the end of their life. Cultural change may be required to prioritise end-of-life care for children and young people 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 also provide practical support to address moral distress, prevent moral injury and burnout of healthcare workers.

Actions

6.1 Provide opportunities for families of babies, children and young people at the end of their life to partner with the healthcare service to improve care delivery.

6.2 Incorporate the development, implementation and ongoing review of systems for end-of-life care for children and young people into governance frameworks and include processes for:

- Appropriate delegation of responsibilities and accountability for decisions and actions
- Representation of families and carers of children at the end of their lives, healthcare workers, managers and executives
- Regular review of performance data, including completion and currency of advance care planning documentation, interventions, education, and training, and advice on potential for improvements
- Regular review of resource allocation, and advice on potential for improvements

6.3 Implement a policy regarding end-of-life care for children that addresses:

- Governance arrangements, including reporting requirements
- The roles, responsibilities and accountabilities of healthcare workers providing end-of-life care to children
- Provision of specialist palliative care services
- Processes for advance care planning and appropriate medical treatment
- Processes or tools for identifying babies, children and young people at the end of their life
- Alignment with systems for recognising and responding to deterioration
- Access to specialist paediatric palliative care advice and services
- Communication processes and tools
- Processes to ensure healthcare workers are not pressured to provide non-beneficial interventions

- Processes to ensure clear transitions of care and communication between healthcare services
- Cultural safety
- Dispute resolution processes, including mediation, bioethics expertise and legal support, in situations of complex end-of-life decision-making or conflict
- Training and education requirements for healthcare workers
- Access to professional clinical supervision to suit the varied needs of healthcare workers
- Access to formal and informal self-care planning, debriefing or counselling that includes strategies to mitigate moral injury and burnout of healthcare workers
- Evaluation, audit and feedback processes

6.4 Identify potential variations in the application of the end-of-life care policy that might exist in different circumstances (such as after hours).

6.5 Implement policies and processes that address advance care directives, organ and tissue donation, limitations of medical treatment, and end-of-life decision-making to ensure that the care delivered in response to deterioration is consistent with state legislation, appropriate clinical practice and the child or young person's and family's expressed wishes.

Considerations for Aboriginal and Torres Strait Islander babies, children and young people

Cultural safety creates an environment that is safe for Aboriginal and Torres Strait Islander people and aims to address interpersonal and institutional racism and discrimination. Cultural safety plans and policies for end-of-life care should be developed and reviewed in partnership with Aboriginal and Torres Strait Islander 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, particularly for children, are heavily influenced by cultural values and beliefs. Consideration of a family's needs should be individualised and culturally responsive.

Advance care planning discussions should be approached and delivered in accordance with cultural values and beliefs. Practices and expectations related to culture should be addressed and documented in the advance care planning documentation.

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 responsive care through provision of training, tools and resources (including time to become culturally competent).

Essential element 7: Support, education and training

An educated and suitably skilled and qualified workforce is essential to providing appropriate end-of-life care to children [29]. All healthcare workers should have a shared understanding of the healthcare services terminology, policies, processes and practices. Education should include:

- Decision-making, capacity and consent
- Shared decision making
- Advance care planning
- Local referral and communication processes, and relevant legislation and other regulatory frameworks
- Family-centred care informed by understanding of impact of the loss of child and experience of grief for parents, siblings, grandparents and kinship groups.
- Redirecting care for comfort and optimal family experience
- Condition-specific training as required
- How to have conversations about end-of-life
- Inclusion and diversity
- Cultural safety
- Moral distress and self-care, peer support and clinical supervision

Dealing with death and dying, particularly of a child, can be challenging for healthcare workers and can also affect other staff members such as administrative staff, food servers, porters and cleaners. It can add considerably to workplace stress. Chronic unmanaged stress can erode empathy and potentially contribute to poorer experiences for children and young people being provided end-of-life care [30]. It is important that systems are in place to facilitate access to peer support, mentoring and appropriate clinical supervision for healthcare workers and support staff.

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

Actions

7.1 Develop and maintain a policy that describes how supervision and support will be provided to healthcare workers who care for babies, children or young people at the end of their life.

7.2 Provide relevant education to all members of the workforce about recognising babies, children and young people 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 their life are provided with education and support to:

- Identify babies, children and young people approaching the end of their life
- Initiate interventions to support person-centred and family-centred, safe and high-quality end-of-life care for children that is relevant to their scope of clinical practice, including comfort care measures and memory-making strategies that alleviate discomfort and distress of the child and their family
- Support the cultural, spiritual and psychosocial needs of the baby, child or young person at the end of their life
- Recognise condition-specific illness trajectories and changing care priorities, including limitations of medical treatment that are relevant to their scope of clinical practice
- Understand the role of early advance care planning and the importance of revisiting conversations to retain currency of advance care planning documentation
- Understand shared and supported decision-making strategies
- Understand end-of-life ethical and medico-legal issues, including the relevant professional ethical frameworks and the relevant legislation in the state or territory of practice, including:
    - refusal of treatment
    - withholding and withdrawing treatment
    - non-beneficial treatment
- Support provision of end-of-life care in an appropriate environment
- Document and communicate effectively
- Escalate concerns in a timely manner

7.4 Encourage healthcare workers providing end-of-life care to participate and learn from discussions with children at the end of their life and their families, multidisciplinary and interdisciplinary case reviews, reviews of health records, mortality and morbidity meetings, and adverse event reviews.

7.5 Ensure healthcare workers are taught culturally safe approaches to providing end-of-life care to First Nations babies, children and young people and those from culturally and linguistically diverse groups, as well as appropriate approaches for children with disability.

7.6 Offer ongoing formal training in communication skills to healthcare workers at all levels, as these skills are critical to the delivery of end-of-life care. Training may include specific skills, such as communicating with children with varying communication abilities, children with neurodiversity, and skills offered by DonateLife on core and practical Family Donation Conversations.

7.7 Ensure healthcare workers providing end-of-life care are educated about how to recognise and develop strategies and self-care plans to cope with and resolve feelings of moral distress and burnout in themselves and their colleagues. Provide information and access to support services.

7.8 Encourage and support children and young people at the end of their life to participate in providing personal stories about their experiences. These can be powerful tools for learning, and quality and system improvement.

7.9 Ensure healthcare workers know how to access peer support, mentoring and clinical supervision. Provide this information at the commencement of employment and as part of regular professional development. This may include accessing external services for clinical supervision, counselling or debriefing.

7.10 Support healthcare workers to develop skills in self-care, reflective learning and providing peer support to colleagues. Experienced 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 visiting care settings 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 [8]. Access to private physical spaces for gatherings contributes to the quality of care offered at the end of a baby, child or young person's life. The provision of spaces for cultural practices such as family gatherings, chanting or other important rituals associated with end of life should be considered. Where possible, and where time and the child's condition permit, preferred location of death should be identified as early as possible (home, hospice, on Country, hospital) and coordination initiated.

Where possible, 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. Examples include private space for family meetings as well as appropriate equipment and medicines.

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

8.4 Ensure healthcare services can provide private physical spaces that meet the individual needs of the child and their family at the end of their life, including spaces for families, and others that the child or young person chooses, to gather.

8.5 Support families, carers, siblings and loved ones to visit the baby, child or young person 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 babies, children or young people where end-of-life care has been provided by a healthcare service should be routinely reviewed to assess the safety and quality of the baby, child or young person's end-of-life care and how care could be improved. Evaluation should not just assess the potential preventability of death.

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 – and feedback from children and young people receiving care and their family – 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 with the following minimum data set:

- De-identified demographics of children at end of life, including disaggregated Aboriginal and Torres Strait Islander data (where possible) to support directed improvement activity
- Triggers used to identify that a baby, child or young person is approaching the end of their life
- Assessment of documentation of shared decision making and the child or young person's goals of care
- Alignment of the child or young person's goals of care with actual care
- Effectiveness of the treatment of symptoms, including the use pain relief, and the management of secretions and agitation
- Assessment of investigations and interventions in the final 48 hours of life
- Evidence related to advance care directives or plans being documented or received, and enacted
- Access of specialist paediatric palliative care services
- Concordance with limitations of medical treatment and resuscitation plans
- The category of death: expected, unexpected, diagnosis
- The time lapse between recognition of end of life or referral to specialist paediatric palliative care and death, if appropriate
- Transfers of care in the last week of life – for example, transfers to hospital from home, or from ward to intensive care
- Bereavement support provided

- Barriers and enablers identified by healthcare workers to provide safe and high-quality end-of-life care

9.6 Methods for collecting data could include:

- Retrospective audit of case notes
- Review of medicines prescribed and administered
- Review of interventions and investigations
- Review of documentation of response to treatment (including medicines) for symptom management
- Follow-up with healthcare workers and other staff involved in the child's end-of-life care
- Feedback on experiences from substitute decision-makers, families and carers of children who received end-of-life care
- Data from mortality and morbidity review meetings.

9.7 Include audit and feedback in the quality improvement process for clinical improvement, education and service provision.

Using data to improve

Data from evaluation, audit and feedback can be used to improve performance of recognition and response systems [1, 2] and ensure that systems are operating as planned [3, 4].

Involvement in relevant national palliative care and end-of-life care data collections can also aid in service planning.

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 systems, and safety and quality systems to support sustainability and provide opportunities for organisational learning.

These systems should align with the requirements of the National Safety and Quality Health Service (NSQHS) Standards and the Primary and Community Healthcare Standards when 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 advance care plans and directives, according to the wishes of the person at the end of their life. Ensure these systems align with the Clinical Governance Standard and Recognising and Responding to Acute Deterioration Standard, 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, 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 health care.

10.4 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 health care.

10.5 Implement processes to improve communication between healthcare services at transitions of care in relation to prognosis, advance care planning, treatment and medicines. Check these processes align with the Communicating for Safety Standard, where applicable.

10.6 Ensure systems between healthcare services support safe, secure access and sharing of plans for care, advance care directives or plans developed in other settings.

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

749

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 directive [31] A voluntary, person-led document completed and signed by a competent person that focuses on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance care directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity.

In some states, these are known as advance health directives.

Advance care plan [31] 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).

Advance care planning [31] 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.

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.

Carer [23] 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, chronic or mental illness), or because they are frail and aged.

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

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

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

Clinician [23]A healthcare worker, trained as a health professional, including registered and non-registered practitioners. 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, pharmacists, technicians and others who provide health care, as well as students who provide health care under supervision.

Comprehensive care Healthcare 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 [32] A set of congruent behaviours, attitudes and policies that come together in a system, agency or among healthcare workers to enable that system, agency or those professionals to work effectively in cross-cultural situations.

Cultural safety [32] Identifies that health consumers are safest when clinicians have considered power relations, cultural differences and patients' rights. Part of this process requires clinicians to examine their own realities, beliefs and attitudes. Cultural safety is defined not by the clinician but by the health consumer's experience – the individual's experience of the care they are given, and their ability to access services and to raise concerns. The essential features of cultural safety are:

- An understanding of one's culture
- An acknowledgement of difference, and a requirement that caregivers are actively mindful and respectful of difference(s)
- Informed by the theory of power relations – any attempt to depoliticise cultural safety is to miss the point
- An appreciation of the historical context of colonisation and how racism at individual and institutional levels has impacted, and continues to impact, Aboriginal and Torres Strait Islander people's lives and wellbeing
- That its presence or absence is determined by the experience of the recipient of care and not defined by the caregiver

Diversity [33] The varying social, economic and geographic circumstances of consumers who use, or may use, healthcare 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.

Effective clinical communication Two-way, coordinated and continuous communication that results in the timely, accurate and appropriate transfer of information. Effective communication is critical to, and supports, the delivery of safe patient care.

End of life The period when a person 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 persons with chronic or malignant disease, or very brief in the case of persons who suffer acute and unexpected illnesses or events, such as sepsis, or trauma.

End-of-life care Includes physical, 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 or young person'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 [34] The term family includes people identified by the child or young person 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, and friends (including pets) may be identified by the child or young person as family.

Family-centred care [35] Care that embraces the whole family to include parents and carers and other family members, such as a child's siblings. Family-centred care recognises that parents are typically the most expert about their child.

Family Integrated care [6] 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.

Goals of care [23] 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, particularly as the child enters the terminal phase.

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 [33] A separately constituted organisation that is responsible for implementing clinical governance, administration and financial management of a service unit or service units providing health care to patients. It can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients' homes, community and primary healthcare settings, practices and clinicians' rooms.

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

Health literacy [23] The Australian Commission on Safety and Quality in Health Care separates health literacy into two components – 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.

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, 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 [36] 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.

Multidisciplinary team [23] Clinicians from multiple disciplines who work together to deliver comprehensive care that deals with as many of the patient's health and other needs as possible. The team may operate under one organisational umbrella or may be from several organisations brought together as a unique team. As a patient's condition changes, the composition of the team may change to reflect the changing clinical and psychosocial needs of the patient. 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 person'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 approach/ palliative care An approach to treatment that improves the quality of life of children, young people and their families facing life-limiting illness by preventing and relieving suffering. It involves early identification, and assessment and treatment of pain and other problems (physical, psychosocial, and spiritual). End-of-life care is a specific phase of the palliative care journey.

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 Aboriginal and Torres Strait Islander children is subject to section 61F of the *Family Law Act*.

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 and do not attempt resuscitation orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the person has a cardiac or respiratory arrest. In some organisations, decisions about other specific limitations of medical treatment may also be listed as part of a resuscitation plan (for example, decisions to call a medical emergency team or transfer a person 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 [23] A discussion and collaboration between a person and their healthcare worker that brings together the person'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 that person.

Supported decision-making [33] Enables a person with cognitive impairment to remain involved in decisions about their health care rather than having their decision-making capacity removed.

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1038

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