



Government of **Western Australia**
Department of **Health**

Western Australian Paediatric Strategy for End-of-Life and Palliative Care 2021-2028

aligned to the
WA End-of-Life and Palliative Care Strategy 2018-2028





Statement of acknowledgement

WA Health acknowledges the people of the many traditional countries and language groups of Western Australia. It acknowledges the wisdom of Elders both past and present, pays respect to Aboriginal communities of today and acknowledges their continuing connection to the land, sea and community.

Use of the term Aboriginal within Western Australia

The term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. Aboriginal and Torres Strait Islander may be referred to in the national context and Indigenous may be referred to in the international context. No disrespect is intended to our Torres Strait Islander colleagues and community.

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The photographs profiled on the front and inside back covers are of children who have received end-of-life and palliative care services in Western Australia and are included with permission from their families.

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Foreword

I am honoured to introduce the *Western Australian Paediatric Strategy for End-of-Life and Palliative Care 2021-2028* (the Paediatric Strategy). The Paediatric Strategy is aligned to the WA End-of-Life and Palliative Care Strategy 2018-2028 and other state and national strategies, policies and frameworks. It will guide the WA health system, health services, healthcare professionals, community and education service providers in meeting the needs of children living with, and dying from life-limiting conditions, and their families.

The importance of this document cannot be overstated. It gives voice to the many children and their families whose lives are impacted by the diagnosis of a life-limiting condition. Caring for a chronically sick or dying child impacts families in many ways - emotionally, psychologically and financially.

Paediatric palliative care focuses on providing care throughout the trajectory of a child's life-limiting condition. It encompasses different diseases and symptoms to adults. Many of these life-limiting conditions are rare with no definitive diagnosis, making accurate prognosis difficult. Curative treatment may be part of the child and family's life, but not their entire focus. Care is provided based on the needs of the child and family, not based on the child's diagnosis. It typically involves multiple service providers and occurs across a wide range of services including tertiary, secondary and primary sectors. Care is also provided for periods of respite and symptom management throughout this trajectory that may not be linked to end-of-life care but best provided by those who specialise in palliative care and management.

In August 2020 Perth Children's Hospital Foundation, in partnership with the Child and Adolescent Health Service, announced funding for a new children's hospice in Perth. The hospice will have family accommodation suites, and will provide outreach support and bereavement care to children and families across WA.

The Paediatric Strategy includes six priority areas and nineteen associated building blocks. These aim to provide children and their families with person-centred, compassionate and best practice care wherever they live.

I would like to thank everyone who contributed to the Paediatric Strategy, including the many individuals from agencies and services who provided their professional expertise. Importantly, I would like to thank the families who shared their insight and wisdom based on their unique and personal experiences in caring for their children. By working in partnership, we can achieve the best possible paediatric palliative care in Western Australia.



Hon Roger Cook MLA
Minister for Health



Key terms

Clarity and agreement are often lacking about the meaning of key terms that are commonly used in end-of-life and palliative care. It is important for all those involved with a child and their family's care to have a common understanding of what such terms mean in practice.

This section defines key terms and their meanings **in the context of this document**. See also [Glossary of terms](#) for a full list of terminology used through this document.

Age range

The applicable age range for paediatric palliative care incorporates the antenatal period up to 18 years of age, with discretion for providers to continue treatment into young adulthood.

Child

Child or children includes infant/s (including neonates), child/ren and adolescent/s. In some instances, the age-specific term infant or adolescent may be used.

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end-of-life will be considered likely to die during the next 12 months.²

In paediatrics, end-of-life is the period when the child is clearly dying and the primary goal of care is comfort.⁵

Family and carers

The term 'family' includes people identified by the child as family and may include people who are biologically related such as siblings and grandparents, foster parents, people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets).

Carers may include family members and other members of their community (such as close friends and neighbours). For the purposes of this document, family includes reference to carers.

Life-limiting condition/illness

The term life-limiting or life-threatening illness describes illnesses where it is expected that death will be a direct consequence of the specified illness. The term *child living with a life-limiting illness* also incorporates the concept of the child actively living with the illness, often for long periods of time, not simply dying.

The term life-limiting illness also incorporates life-limiting conditions. For the purposes of this document, the term life-limiting condition has been used consistently throughout, with the intention that it covers children living with a life-limiting illness or condition who are expected to die in childhood. The main groups of life-limiting conditions are described at [Table 1](#).

Paediatric palliative care

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, the provision of short breaks for planned respite, care at the end-of-life and bereavement support.¹

Palliative care can be introduced at any point throughout a child's life; it is completely individual. Some children may require palliative care from birth, others may only require it as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed at cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-limiting condition or recognition that curative treatment for a life-threatening condition is not an option; however, each situation is different and care should be tailored to the individual child.³

Palliative care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.⁴

Parents/Guardians

The person, or persons, who have parental responsibility for the child.

Specialist paediatric palliative care

Specialist paediatric palliative care comprises services provided by clinicians and others who have advanced training in paediatric palliative care. The role of specialist paediatric palliative care services includes provision of direct care to patients with complex palliative care needs, and provision of consultation services to support, advise and educate others who are partnering in palliative care.⁵

It is recognised that the availability of advanced training in paediatric palliative care is relatively recent and for this reason, not all clinicians in specialist paediatric palliative care teams will necessarily have advanced training in paediatric palliative care, despite having considerable clinical experience in paediatric palliative care. It is expected that over time there will be increased availability of specialists with advanced training in paediatric palliative care.⁵



Introduction

Stakeholder consultation

The Paediatric Strategy was developed alongside extensive statewide consultation across a diverse range of stakeholders.

The Paediatric Palliative Care Project Group (led by CAHS), ran the consultation process from February to May 2020 via a range of methods including face-to-face and videoconference workshops with clinicians and staff in Albany, Broome, Bunbury, Geraldton, Kalgoorlie, Karratha, Northam and Perth Children’s Hospital. In addition, workshops, face-to-face meetings, videoconference and telephone conversations were held with consumers throughout the seven WA Country Health Service regions and the Perth metropolitan area, thus enabling a ‘safe space’ for consumers to provide comment on their experience of palliative and end-of-life care services.

The consultation aims were to:

- understand current available services and resources within each of the WACHS regions and Perth metropolitan area
- identify what would be necessary to provide a comprehensive paediatric palliative care service by families across the state, when required.

A total of 166 participants, including 39 consumers, were involved in the consultation process (93 from the Perth metropolitan area and 73 from regional WA). Consultation participants included:

- consumers
- clinicians and staff from CAHS
- clinicians and staff from Health Service Providers (NMHS, EMHS, SMHS, WACHS)
- primary health care providers, including General Practitioners
- the WA Cancer and Palliative Care Network, WA Health
- the Aboriginal Health Unit, WA Health
- key agencies involved in paediatric palliative care such as Silver Chain, Palliative Care Western Australia (PCWA) and Hannah’s House.

The consultation resulted in a vast amount of material to be transcribed, collated, thematically coded and analysed. An iterative approach was taken to identify the key themes and these were subsequently aligned to the six overarching priority areas of the WA End-of-Life and Palliative Care Strategy 2018-2028.

The consultation also informed the development of the Optimal Paediatric Palliative Care Pathway (OPPCP).

Intended audience

The Paediatric Strategy informs public, private, community and non-government health sectors of the priority areas for paediatric end-of-life and palliative care to 2028. It acknowledges existing systems, services and programs that already contribute to these priority areas.

The Paediatric Strategy is applicable to all services in WA that support and care for children with a life-limiting condition, and their families, including:

- specialist and non-specialist teams providing end-of-life care, and specialist palliative care teams with recognised qualifications or accredited training in palliative care
- public, private, community, non-government and not-for-profit organisations, including primary healthcare teams and peak bodies
- administrators in public, private, community and non-government organisations (including training, research and educational institutions).

Importantly, we believe that the Paediatric Strategy will be invaluable to families and carers of children with a life-limiting condition, the wider community and advocacy groups.

What is paediatric palliative care?

Paediatric palliative care is care that aims to provide the best quality of life for children with a life-limiting condition, enabling them to live in an environment where curative treatment can be part of their life but not their entire focus. It provides a holistic approach which supports the physical, emotional, social and spiritual aspects of the child and their family. It requires the input of specialist health professionals specifically trained in paediatric palliative care. Paediatric palliative care can be integrated at any point along the illness trajectory.¹

See also [Unique characteristics of paediatric palliative care](#).

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks for planned respite, care at the end-of-life and bereavement support.³

Palliative care can be introduced at any point throughout a child's life; it is completely individual. Some children may require palliative care from birth; others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not an option. However, each situation is different and care should be tailored to the child.³



*The goal is to add life to the child's years,
not years to the child's life¹*



Unique characteristics of paediatric palliative care

Paediatric palliative care has evolved as a distinct speciality and service model to meet the specific needs of children and their families.^{3, 5-8}

Whilst there are similarities in the key principles of palliative care for children and adults, there are also significant differences^{5, 9}.

These include:

Smaller numbers means less familiarity	The number of children dying is small in comparison to adults thus non-specialist health care providers may be less familiar with and have less experience in caring for a child with a life-limiting condition
Conditions are often very rare, and can be undiagnosed	The majority of children have non-malignant and/or rare conditions which are often not seen in adult practice; sometimes there is no definitive diagnosis
Prognosis can be difficult	Making a prognosis can be difficult
Perinatal palliative care	Perinatal palliative care may be provided alongside antenatal care that a mother receives from the obstetric team
Unpredictable trajectory	Deterioration can be episodic and unpredictable
A child's developmental needs	A child continues to develop physically, emotionally and cognitively, with unique and often complex clinical, social, emotional, developmental, cultural and spiritual needs
The school as part of their community	A child's school is a significant part of their community and collaboration with education providers is key to enhancing their development and quality of life
A child's level of understanding	A child's ability to communicate and understand varies according to their stage of development and underlying condition
Transition to adult services	A child may survive into early adulthood and require holistic care and multidisciplinary services over a long period of time, including transition from paediatric to adult services
Family involvement in decision-making	The family has an increased role in decision-making and care for a child. This is quite dynamic and may change over time, with developmental growth and clinical deterioration

Family-centred care	Care embraces the family within an ethos of child and family-centred care
Genetic counselling	More than one child in the family may be affected, and there may be a need for genetic counselling
Siblings are vulnerable	Siblings are vulnerable, with parents often providing care for them while providing 24-hour care to a child with a life-limiting condition
Financial demands	There may be financial demands placed on families when parents withdraw partially or completely from the workforce to provide care for their child
Grief and loss evolves	Numerous, evolving losses may be experienced throughout a child's illness trajectory, requiring grief and bereavement support for the child, their family, siblings and friends, prior to and following death
Defies the natural order of life	The death of a child defies what is often considered as the natural order of life, the loss of a child can lead to prolonged, and sometimes lifelong, grieving
Grandparent wellbeing	The psychological wellbeing of grandparents may be affected, through 'doubled worry' – that is, worry about their grandchild as well as their own child
Consultative model	Paediatric palliative care services <i>may</i> be structured differently from adult services. A child usually remains under the care of their primary treating team, with specialist paediatric palliative care services providing support through a consultative model
Multiple settings of care	Provision of care across a wide range of care settings and healthcare teams can add a level of complexity in relation to communication and care coordination.

Delivery of paediatric palliative care in Western Australia

Statewide specialist paediatric palliative care (SPPC) is provided by the WA Paediatric Palliative Care Service (WAPPCS), CAHS. This team of health professionals have specialist qualifications, extensive experience and skills in palliative care and it is their substantive role and area of practice. Working in close collaboration with specialist and non-specialist services, the WAPPCS provide care for children with life-limiting conditions and their families throughout their illness, end-of-life and in bereavement.

Paediatric palliative care is also delivered by all health services caring for children with life-limiting conditions, with appropriate specialist paediatric palliative care support, clinical advice and mentoring.

The provision of paediatric palliative care is supported by, but not limited to, the following services and settings:

- specialist paediatric teams including, but not limited to: rehabilitation, neurology, respiratory, oncology, cardiology, renal and metabolic medicine
- acute care settings
- primary care, including general practice
- community services
- community palliative care including Silver Chain Community Specialist Palliative Care Service and WACHS specialist regional palliative care teams
- respite care services
- not-for-profit agencies and organisations.

The delivery of equitable paediatric end-of-life and palliative care across WA can be challenging.¹⁰

Some of these challenges include:

- inequitable access to end-of-life and palliative care based on need, e.g. geographical isolation and distance from recognised specialist paediatric treatment facilities
- inequity between diagnostic groups
- rare diseases with small population groups and at times, no known diagnosis
- growing numbers of children being diagnosed with a life-limiting condition
- increasing complexity of children living with a life-limiting condition
- recognition at the time of diagnosis of a life-limiting condition and early referral
- complexities of family relationships and dynamics.

Overview of the priorities of the Paediatric Strategy

The Paediatric Strategy has been developed as a stand-alone document, however it is closely aligned to the [WA End-of-Life and Palliative Care Strategy 2018-2028](#)¹¹, which is the overarching Strategy for end-of-life and palliative care in WA.

The priorities of the Paediatric Strategy align with the six priority areas of the Strategy (shown at [Appendix 1](#)) and provide broad direction to enable local and statewide implementation and evaluation.

Achieving the key priority areas will enable children and their families to receive comprehensive care within an integrated, responsive, coordinated and collaborative system, regardless of where they live.

Each of the priorities describe what is already known in relation to this area of focus, as well as describing the building blocks required to achieve the priority. An overview of the priorities is shown at [Figure 1](#).

Figure 1: Overview of the priorities from the child's perspective*



*It is important to recognise the wider family/caregivers of each child; whilst this may vary considerably for each child, their involvement is implicit.

Overview of the building blocks to achieve the priorities

The priorities and building blocks are described in full [here](#).

Priority One: Care is accessible to everyone, everywhere

- Improve equity of access for all children with palliative care needs, and their families
- Improve access to care for Aboriginal children with palliative care needs, and their families
- Improve access to care for culturally and linguistically diverse communities
- Improve access to care and support for children with condition-specific diagnoses and children with undiagnosed conditions, and their families
- Improve access to care for children and their families with risk factors for increased vulnerability, e.g. marginalised groups, refugees, under the care of the Chief Executive Department of Communities and/or have parents incarcerated in the judicial system.

Priority Two: Care is child-centred and family-centred

- Care is centred on the child and their family
- Children and their families co-design care with health teams, including:
 - culturally respectful and comprehensive care
 - timely referral to the Specialist Paediatric Palliative Care Service
 - opportunities to talk about improving quality of life
 - opportunities to talk about and plan for clinical deterioration, end-of-life care, death, and bereavement support for the family.

Priority Three: Care is coordinated

- Strengthen communication and collaboration between all providers of care and services
- Strengthen referral pathways to the Specialist Paediatric Palliative Care Service
- Ensure children and adolescents have access to education at all stages of their illness
- Support young adults and their families in their transition from paediatric to adult services
- Recognise end-of-life care as a time where optimal collaboration and coordination between services is vital
- Optimise a coordinated approach to grief and bereavement for all children with palliative needs and their families.

Priority Four: Families are supported

- Improve support to families (parents, siblings, grandparents and other significant family members) including practical, financial, emotional, social, cultural and respite support
- Improve opportunities for consumers to support consumers.

Priority Five: All staff are prepared to care

- Ensure staff have appropriate knowledge of paediatric palliative care, end-of-life care, and when to refer to specialist paediatric palliative care
- Build the capacity of specialist paediatric palliative care services.

Priority Six: The community is aware and able to care

- Improve community understanding of paediatric end-of-life and palliative care
- Engage the community to care.

Epidemiology

Paediatric palliative care encompasses a wide range of diseases and symptoms. Some of these life-limiting conditions are rare with no definitive diagnosis, which makes accurate prognosis difficult. The needs of children who are dying are often overlooked due to small numbers¹², variation in diagnosis compared to adults^{13, 14} and uncertain illness trajectories.⁷

At the time of publication, no studies have been undertaken in WA on the prevalence of children living with life-limiting conditions. It is recognised that the number of children living with life-limiting conditions is growing nationally and internationally.¹⁵⁻¹⁷

Published hospital admissions data for individuals aged 0-21 years with a life-limiting condition admitted to a Queensland Public Hospital or Health Service or private hospital suggest an increase in hospital admissions by 29.6% over a 5-year period from 2011 to 2016. The overall prevalence of life-limiting conditions for children and young people (0-21 years) living in Australia in 2016 and admitted to a Queensland hospital and health service provider is estimated at 43.2 per 10,000 population.¹⁸

Figures reported in England estimate the prevalence of children aged 0-19 years living with a life-limiting condition is 32 per 10,000, which is more than double the estimate reported 10 years ago.¹⁵ Extrapolating this data suggests that there are approximately 2,000 children living with life-limiting conditions in WA.¹⁹ It also suggests that this number will continue to increase; in addition to increasing complexities related to advancing technologies in medical and surgical care.¹⁵

Table 1**Main groups of life-limiting conditions for children⁵**

	Definition	Example
1	Life-threatening conditions for which curative treatment may be feasible but can fail.	Children with cancer when treatment fails. Irreversible organ failure where transplantation is not an option or where transplantation has failed.
2	Life-limiting conditions where premature death is inevitable. However, there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.	Examples include complex cardiac disease and Duchenne muscular dystrophy (DMD). Ongoing research and medication improvements have meant that some people with Cystic Fibrosis are surviving into their 40s and beyond. A similar trend is seen with DMD.
3	Life-limiting, progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.	Examples include neurodegenerative conditions (e.g. Batten disease), metabolic conditions (e.g. mucopolysaccharidoses) and neuromuscular conditions.
4	Irreversible but non-progressive life-limiting conditions causing severe disability, leading to susceptibility of health complications and likelihood of premature death. Complications that may cause death include severe recurrent pneumonias or intractable seizures.	Examples include severe cerebral palsy or multiple disabilities (such as following brain or spinal cord injury).

Policy snapshot

The Paediatric Strategy builds upon existing paediatric models of care and optimal care pathways in WA and aligns with national and state strategies and frameworks.

Figure 3: Policy snapshot

Optimal Paediatric Palliative Care Pathway (OPPCP)

WA End-of-Life and Palliative Care Strategy 2018–2028

WA End-of-Life and Palliative Care Strategy 2018-2028 Implementation Plan 1 (IP1)

Australian Commission on Safety and Quality in Health Care: National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care – 2016

WA Government: Sustainable Health Review
– Strategy 3 – Great beginnings and a dignified end-of-life
– Strategy 4 – Person-centred, equitable, seamless access

Palliative Care Australia: National Palliative Care Strategy – 2018

Palliative Care Australia: Paediatric Addendum – Palliative Care Service Development Guidelines – 2018

WA Aboriginal Health and Wellbeing Framework 2015–2030

Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer – 2018

Priority One

Priority One: Care is accessible to everyone, everywhere

My quality of life is valued and respected. I have access to high quality palliative care and, when needed, timely and appropriate end-of-life care regardless of who I am, where I live, or how I live my life.

What is already known:

- Paediatric palliative care aims to provide the best quality of life for children with life-limiting conditions.
- Every child and their family is unique, and no condition, child, family or situation is the same.
- The majority of referrals to paediatric palliative care are for non-cancer diagnoses and include conditions such as neurological, metabolic or chromosomal abnormalities.²⁰
- Gaps exist in the availability and access to care for children and families with condition-specific diagnoses.²¹
- Gaps exist in the availability of and access to care for identified populations, e.g. there is a need for increased support for Aboriginal families.²²
- Cultural beliefs may affect how a family thinks about illness and pain, attitudes to medications and nutrition, their understanding of dying and death, spirituality, burial, cremation and bereavement.⁶
- Patient and family experiences are improved when they receive the right care, at the right time, in the right place, delivered by the right team.



It is a massive stigma having a child with complex disability – made even harder by lack of equity.

Parent of a child with a life-limiting condition



Building blocks to realise Priority One

<p>Improve equity of access for all children with palliative care needs, and their families</p>	<p>All services provide care based on the needs of the child and family, not based on the child's diagnosis.</p> <p>All children in Western Australia with a life-limiting condition, and their families:</p> <ul style="list-style-type: none">• have access to timely end-of-life and palliative care if required, regardless of age, diagnosis, religion or ethnicity• have access to care in their preferred setting or location: home, hospice (including for respite), hospital, metropolitan, regional, rural or remote• receive seamless care through integrated partnerships and collaboration across and between services – including health, community, education, respite and disability• have access to appropriate information. <p>Children and their families living in rural and remote locations have access to, and are supported by, specialist paediatric palliative care services to remain within their community through collaboration with primary health care, local paediatric health care and community palliative care services.</p>
<p>Improve access to care for Aboriginal children with palliative care needs, and their families</p>	<p>Culturally respectful and appropriate care is provided to Aboriginal children, their families and communities, individualised to their needs.</p> <p>Health, community, education, respite and disability providers:</p> <ul style="list-style-type: none">• recognise the cultural diversity of Aboriginal children and their families• develop a greater understanding of the values and beliefs of Aboriginal children and their families, and how these may impact throughout the continuum of care, from diagnosis to bereavement• acknowledge and incorporate cultural systems of care where possible• work collaboratively with Aboriginal Health Workers, Aboriginal Community Controlled Health Services (ACCHS), and the community and its Elders, where appropriate• have access to culturally appropriate information in relevant formats and languages• have access to Aboriginal language interpreters, if required and if available.

Building blocks to realise Priority One

<p>Improve access to care for culturally and linguistically diverse communities</p>	<p>Respectful and appropriate care is provided to children from culturally and linguistically diverse communities, and their families, individualised to their needs.</p> <p>Health, community, education, respite and disability providers:</p> <ul style="list-style-type: none"> recognise cultural diversity within the Australian population, including religious, ethnic and linguistic diversity recognise that culture, beliefs and values influence the child and family's experience throughout the continuum of care, from diagnosis to bereavement develop greater capabilities and application of paediatric palliative care clinical practice within the context of diverse cultural and religious groups demonstrate awareness of the impact of separated families and the context that extended relatives (both within Australia and/or overseas) may play in the palliative care experience. <p>Health, community, education, respite and disability providers have access to, and utilise:</p> <ul style="list-style-type: none"> appropriate interpreter services culturally appropriate information in relevant formats and languages to enable appropriate assessment and care for children and their families.
<p>Improve access to care and support for children with condition-specific diagnoses and children with undiagnosed conditions, and their families</p>	<p>Children with condition-specific diagnoses, and their families, receive timely, accurate diagnosis and appropriate, respectful, coordinated and integrated care, individualised to their needs.</p> <p>Children with undiagnosed conditions, and their families, receive optimised palliative care, individualised to their needs.</p> <p>Health, community, education, respite and disability providers have access to education and resources to optimise care provision.</p>
<p>Improve access to care for children and their families with risk factors for increased vulnerability, e.g. marginalised groups, refugees, under the care of the Chief Executive Department of Communities and/or have parents incarcerated in the judicial system</p>	<p>Appropriate and respectful care is provided to children and their families, irrespective of their culture, beliefs, values, social circumstances or personal characteristics.</p> <p>Health, community, education, respite and disability providers:</p> <ul style="list-style-type: none"> have an awareness of the broader socio-economic factors that impact on health and well-being, particularly in groups that have experienced significant trauma or adversity have access to education and resources to enable appropriate assessment and care for children and their families provide holistic, trauma-informed care for all families, regardless of cultural or religious backgrounds.

Priority Two

Care is child-centred and family-centred

I am an individual; wherever possible, my family and I are involved in honest discussions about my care. Our beliefs, values, needs, wishes, culture and spirituality are considered and respected and we receive individualised support and care.

What is already known:

- Safe and high-quality paediatric palliative and end-of-life care is family-centred and should be aligned with the values, needs and wishes of the child and their family.²
- The team(s) caring for the child have a responsibility to provide timely, accurate and appropriate information about the child's clinical condition and associated care to the child and their family, in a way that is understandable to them³.
- Better outcomes are achieved when the child and their family:
 - are introduced to paediatric palliative care services close to the time of diagnosis to establish therapeutic relationships⁵
 - are introduced to the concept of parallel planning, where palliative care can be offered to improve quality of life, alongside curative treatment or treatment aimed at significantly prolonging life³
 - are not perceived as passive recipients of professional services but as competent and leading partners in their child's palliative care⁶
 - are empowered to have a central role in the planning and decision-making process²³
 - are supported to think ahead about their goals of care; this may include a Paediatric Goals of Patient Care (PGoPC) discussion and completion of the PGoPC form.

When we discussed our son's goals of care, the discussion was cathartic – it gave us a leave pass and permission to live now, to make memories, to breathe again... we found it helped everyone in his team – they could understand us from the inside out, not just the outside in.

Parent of a child receiving care at Perth Children's Hospital

Building blocks to realise Priority Two

Care is centred on the child and their family

Children, together with their family:

- receive individualised support and care from providers who have the capacity and ability to anticipate and respond to their changing needs and preferences throughout the continuum of care, from diagnosis to bereavement
- receive holistic care which reflects their needs; this includes, but is not limited to, psychological support, pastoral care, allied health support, age-appropriate play, continuity of school and social communities.
- receive effective care that enables seamless transition across services in all settings, with the potential to reduce unnecessary/unwanted hospital admissions
- receive coordinated care where all providers work together across organisational, clinical and disciplinary boundaries to support care in the child and family's preferred location, including the use of digital health when required
- engage with and recognise the importance of the primary care providers who care for the whole family.

Children and their families co-design care with health teams, including:

- culturally respectful and comprehensive care
- timely referral to the Specialist Paediatric Palliative Care Service
- opportunities to talk about improving quality of life
- opportunities to talk about and plan for clinical deterioration, end-of-life care, death, and bereavement support for the family

Children, together with their family:

- receive flexible and responsive support and care, tailored to their individual needs, in partnership with care providers
- are involved as much as possible in discussions about their own care, according to their developmental capacity
- have sufficient information, support and confidence to be actively involved in the decision-making related to their care, and to make informed choices
- where appropriate, discuss and develop their PGoPC with other providers/services involved in their care, and share these with family consent.

Health, community, education, respite and disability providers have the skills and confidence to:

- recognise that Aboriginal family systems and networks can be significantly different from other family systems
- initiate open discussion regarding paediatric palliative care referral
- continue open discussion regarding treatment decisions and ongoing care
- where needed, contribute to the PGoPC to ensure appropriate care
- talk about and plan for death.

Priority Three

Care is coordinated.

I receive the right care at the right time, in the right place, from the right people. My care is provided seamlessly through a coordinated and collaborative approach involving all health and service providers, with support provided by the Specialist Paediatric Palliative Care Service, where required.

What is already known:

- Safe and high-quality paediatric end-of-life and palliative care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care³
- Quality of life and outcomes are improved for children and their families when they:
 - receive a multi-disciplinary approach to their care²²
 - receive efficient and effective transition of their care – within and across services
 - receive timely and appropriate referral to specialist palliative care
 - are supported to think ahead about their goals of care, including the completion of the Paediatric Goals of Patient Care (PGoPC) clinical document, where appropriate.
- The Optimal Paediatric Palliative Care Pathway (OPPCP) guides the delivery of consistent, safe, high-quality and evidence-based care.



A central point of contact for families is very important especially for families working with multiple teams.

Health Professional, Perth Children's Hospital



Building blocks to realise Priority Three

<p>Strengthen communication and collaboration between all providers of care and services</p>	<p>Care and service provision for children and families is enhanced through effective communication, collaboration and seamless transition between all providers of care in all settings, including established coordination programs such as complex care and Aboriginal health services, by:</p> <ul style="list-style-type: none"> • ensuring that patient information is accessible across and between services via secure, efficient and effective systems • identifying a care coordinator/case manager for each child and their family, noting that this may change throughout the care continuum • strengthening communication and engaging with the local care team to support the family where they live • recognising the importance of identifying the child's goals of care and, where appropriate, contributing to the PGoPC to ensure appropriate care • identifying all members of the MDT • utilising MDT meetings as an effective communication method • liaising with all relevant government, non-government and not-for profit services and agencies, e.g. the National Disability Insurance Scheme • developing strong links between teams and the Emergency Department (ED) to minimise the distress of ED attendance.
<p>Ensure children and adolescents have access to education at all stages of their illness</p>	<p>Education providers:</p> <ul style="list-style-type: none"> • support the child's right to ongoing education. <p>Schools and support staff:</p> <ul style="list-style-type: none"> • receive the support and information necessary to best manage the child's health care and educational adjustments in their educational settings. • receive relevant communication to enable planning to support the transition through school or between school and other settings.
<p>Support young adults and their families in their transition from paediatric to adult services</p>	<p>The transition from paediatric to adult services occurs:</p> <ul style="list-style-type: none"> • through a coordinated and collaborative approach, with optimal support to the child/young adult and their family and effective communication across all care providers. • at a time of relative stability in the child's health.

Building blocks to realise Priority Three

Strengthen referral pathways to the Specialist Paediatric Palliative Care Service (SPPCS)

The SPPCS receives timely and appropriate referrals from treating teams and there is increased:

- recognition and awareness of the services provided by the SPPCS
- opportunity to build the capacity of individual staff members and teams in the concept of specialist paediatric palliative care, including staff within specialist paediatric teams (e.g. oncology, neurology, respiratory)
- awareness of the availability of flexible and responsive education from the SPPCS where required, e.g. pop-up and scheduled teaching
- understanding and knowledge of the referral pathways to the SPPCS
- understanding that palliative care begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease⁵
- increased recognition of conditions that are life-limiting
- recognition of the importance of the continuity of care
- recognition of the capacity of the SPPCS to support children in rural and remote locations through collaboration with partners, e.g. local paediatric services, General Practitioners, Regional Specialist Palliative Care teams, Aboriginal Medical Services etc
- recognition of the referral pathway to psychological support
- recognition of the value of pastoral care
- recognition of the value of the allied health team which may include art, music and pet therapy
- recognition of the value of age-appropriate play
- recognition of the value in school continuity
- recognition of the value of the continuity of social communities, e.g. school, sport, music, church, clubs.

Care and service provision for children with a life-limiting condition, and their families, is enhanced via the use of the Optimal Paediatric Palliative Care Pathway (OPPCP), which aims to:

- describe the key stages of paediatric palliative care
- guide health professionals in the provision of best-practice, comprehensive, coordinated and multi-disciplinary care.

Building blocks to realise Priority Three

Recognise end-of-life as a time where optimal collaboration and coordination between services is vital

Health, community, education, respite and disability providers work collaboratively to support the child and their family at end-of-life and at time of death, and:

- recognise the family's need for choice of place of death and meet their wishes wherever possible, including home (community services), hospice or hospital
- recognise the need for a rapid response to move between care settings
- recognise that culturally appropriate care for Aboriginal children may include the desire for a return to country
- recognise the need to engage with and respect the community in providing appropriate care for Aboriginal children, including communication with spokesperson(s) and elders, and working in collaboration with Aboriginal health leaders and ACCHS
- recognise the cultural or religious needs of the family, including beliefs and values, at the time of death
- ensure robust processes are established to support memory-making.

All staff involved with the child and their family's care are provided with active support, including peer support, mentoring and clinical supervision, at end-of-life and at the time of the child's death.

Optimise a coordinated approach to grief and bereavement for all children with palliative needs and their families

A child's death is recognised as a unique and rare experience that requires specialised support with a coordinated approach to bereavement, including:

- coordinated, intentional and dedicated grief and bereavement support to parents, siblings, extended families, school and social communities following an agreed plan
- recognition that the impact of anticipatory, ongoing, chronic and complicated grief for families can occur from the onset of their child's disease or diagnosis, and may continue throughout the child's life and beyond; and that families should be supported throughout this process
- coordinated and collaborative handover to relevant grief and bereavement services from the child's specialist medical and/or palliative team following death
- preference for an identified single point of contact for all families following the death of a child
- consideration, where possible, of opportunities for parents to meet with others with similar experiences
- recognition of the challenges that may be present following the death of child in a rural or remote setting.

Priority Four

Families are supported.

People close to me are supported and involved in my care. My family's involvement is recognised and valued by those providing care, including my family's need to be supported during and after my death.

What is already known:

- The family:
 - plays a critical role with the primary team(s) in supporting a child with a life-limiting condition²⁴
 - requires specific and considerable assistance to perform their caring role
 - has improved health and bereavement outcomes if their caring experience is positive⁶.
- Care of the child and their family should extend from the time a child receives a life-limiting diagnosis into the bereavement period.
- Ensuring families receive the appropriate care prior to and following their child's death is essential to their long-term wellbeing.^{25, 26}
- Planning is required to address the complexity of care, anticipate care needs and invest in strategies to reduce potentially avoidable hospital admissions.
- Funding models that recognise family values and needs are essential.
- Family support is vital if the child wishes to be cared for at home.
- Bereavement support requires additional resourcing, appropriate costing/funding and greater coordination across services.²⁷



You need to be listened to, to be taken very seriously because you are very vulnerable as a parent in this situation.

Parent of a child with a life-limiting condition



Building blocks to realise Priority Four

Improve support to families (parents, siblings, grandparents and other significant family members) including practical, financial, emotional, social, cultural and respite support

When caring for a child and their family, health, community, education, respite and disability providers:

- recognise and acknowledge the child and family's experiences and provide compassionate care
- recognise the child's family as a core element of the team and understand the importance of working with them to ensure that they are educated and informed
- have the skills and resources to identify the changing needs of the family throughout the continuum of care, from diagnosis to bereavement
- recognise diversity within families including identifying the key decision-makers and significant members of the family and engaging with them as required
- recognise that Aboriginal family systems and networks can be significantly different from non-Aboriginal family systems
- recognise the needs of both parents or guardians and facilitate their involvement and engagement, acknowledging that their visibility and availability may be different
- understand the possible financial burden to families
- explore the use of standardised assessment tools, where appropriate.

The child's family has equitable access to support and respite where required, including:

- information/resources about the child's disease specialist paediatric palliative care services
- specialist palliative care respite, e.g. in-home respite, hospice
- community palliative care services close to home
- a broad range of therapies
- support to engage in education
- support specific to the needs of siblings
- identify siblings who may be at risk and provide them with appropriate services
- support for grandparents or other significant family members.

Building blocks to realise Priority Four

Improve opportunities for consumers to support consumers

Health, community, education, respite and disability providers:

- recognise the unique experience of caring for a child with a life-limiting condition and the inherent knowledge, support and comfort that can be shared between consumers
- acknowledge that those with a lived experience of paediatric palliative care may offer comfort to families who are unfamiliar and fearful of the concept
- recognise that families may express a strong desire and actively seek opportunities to support and provide comfort to others, including other families
- are aware that specialist paediatric palliative care services may be able to facilitate opportunities for families to connect through one-to-one and group support
- recognise the need for additional support opportunities to be available, e.g. establishing support groups for fathers, non-primary care givers, grandparents and siblings
- explore the use of technology to enable the participation of families who are unable to attend support groups face-to-face, e.g. families living in rural and remote areas.

Priority Five

All staff are prepared to care.

Wherever and whenever I am cared for, all staff involved in my care should have expertise, empathy and compassion. All staff should provide sensitive, competent and skilful care across my continuum of care, from diagnosis to bereavement.

What is already known:

- Safe and high-quality paediatric end-of-life and palliative care requires the availability of appropriately qualified, skilled and experienced specialist interdisciplinary teams.
- End-of-life care is everyone's business, and quality end-of-life care can be delivered when health, community, education, respite and disability providers have the required skills and supports to do so.
- A competent workforce supports children, where appropriate, and their family to make informed decisions about end-of-life and palliative care.
- Gaps exist in the coordination and continuity of care for children and their family at end-of-life.¹⁰
- Health and community providers should be aware of when and how to refer to specialist paediatric palliative care.^{28, 29}
- Quality care at end-of-life supports the delivery of high-value health care.



Sometimes the focus is purely on cure and the opportunity for palliative care is missed; this is still important, you can do both.

Health Professional



Building blocks to realise Priority Five

<p>Ensure staff have appropriate knowledge of paediatric palliative care, end-of-life care, and when to refer to specialist paediatric palliative care</p>	<p>Health, community, education, respite and disability providers have the competence and capacity to:</p> <ul style="list-style-type: none"> ■ care for children with palliative care needs with access to specialist paediatric palliative care support ■ recognise gaps in paediatric palliative care knowledge and skills as it applies to clinical practice, and have access to appropriate education ■ embrace flexible and responsive upskilling from specialist paediatric palliative care services, where required, e.g. pop-up and scheduled teaching ■ ensure timely and compassionate discussions with the child, where appropriate, and their family, regarding possible referral to paediatric palliative care services ■ work collaboratively across all settings, including generalist and specialised services ■ recognise and reflect on their personal and cultural beliefs regarding disability, complex disease and palliative care ■ raise awareness of the frequency with which families must tell and re-tell their child's story. <p>Relevant graduate and undergraduate programs include paediatric palliative care curriculum content.</p> <p>The impact of childhood death and bereavement is acknowledged as a distressing event; and health, community, education, respite and disability providers should be provided with appropriate support, e.g. peer support, mentoring and clinical supervision.</p> <p>Funding models and strategies are established to address identified gaps and challenges.</p>
<p>Build the capacity of specialist paediatric palliative care services</p>	<p>The specialist palliative care workforce meets demand and improves equity of access for children and families with palliative care needs, through:</p> <ul style="list-style-type: none"> ■ access to appropriate resources, training and clinical supervision ■ provision of support to generalist, community, generalist paediatric and specialist paediatric staff to care for children with end-of-life and palliative care needs ■ delivery of coordinated statewide education and training via a range of methods (including education delivered through a 'pop-up' model) ■ identify the needs of the specialist workforce, e.g. leave cover, succession planning ■ increase in the Aboriginal workforce ■ support and encourage a diverse workforce – e.g. cultural, language, sexual orientation and gender identity ■ access to relevant research opportunities.

Priority Six

The community is aware and able to care.

I am supported by the community. The community understands what paediatric palliative care is and what it is not. The close community around me is aware of my needs and can support these needs, as well as the needs of those close to me.

What is already known:

- Raising awareness is required to increase community knowledge of end-of-life and palliative care and to view death as part of life.
- Increased knowledge assists and empowers families to make informed decisions in partnership with their child or on behalf of their child.



The best thing we had was a sheet we put on our fridge that told our friends and family how to best support us. We didn't need educating – they did ... everyone around us needs to be educated, to know how to be empathetic, how to understand how hard this is and how to support us.

Parent of a child with a life-limiting condition



Building blocks to realise Priority Six

<p>Improve community understanding of paediatric palliative care</p>	<p>Children and their families receive targeted education to improve their understanding of paediatric palliative care, including:</p> <ul style="list-style-type: none"> development of resources to support the family to share with the wider family, friends, the close community and service providers identification of the child's close community and those important to them, which may include their family, friends, health, community, disability, respite and education providers awareness of available non-government organisation and not-for-profit support. <p>The community surrounding the child and their family, and the wider community, has a better understanding of paediatric palliative care and children with life-limiting conditions, including:</p> <ul style="list-style-type: none"> the differences between paediatric and adult palliative care diversity of disease groups in paediatric palliative care myths and misconceptions about paediatric palliative care recognition of the broader socio-economic factors that may impact on the health and wellbeing of children and families, e.g. risk factors for increased vulnerability recognition of the unique strengths and challenges of rural/remote communities, including Aboriginal communities that some children will die, despite receiving the best care issues related to grief and bereavement after the death of a child, including unique cultural needs
<p>Engage the community to care</p>	<p>Explore established volunteer models including:</p> <ul style="list-style-type: none"> community volunteer models that actively support families with end-of-life and palliative care needs, with the development of paediatric specific processes as required strengthen and widen local volunteer models to include paediatric palliative care investigate successful models in use throughout Australia e.g. the Children's Hospital at Westmead Palliative Care Family Support Volunteer Program³⁰ and established community models. <p>Establish links to existing public health approaches to end-of-life and palliative care, e.g. via the Compassionate Communities Network³¹</p> <p>Explore access to collaborative partnerships to support continuity of education across settings.</p>



Implementation and evaluation

The Paediatric Strategy provides the strategic direction for end-of-life and palliative care from 2021 to 2028.

Successful implementation of the priorities and building blocks of the Paediatric Strategy requires the engagement, leadership, commitment and collaboration of key stakeholders across all services throughout the state, including specialist and non-specialist services and Health Service Providers.

Development of an Implementation Plan will commence in 2021, through a partnership with DOH WA and CAHS. The Implementation Plan will be informed by targeted consultation with key stakeholders and will set out the priorities for action, and how progress towards achieving the priorities and building blocks will be measured.

Stakeholders will be supported to connect and collaborate, to enable the provision of an integrated, coordinated and strategic approach to influence policy, purchasing, workforce and planning.

The collection of high-quality, accurate and timely data is essential to the efficient operation of the health system, including the implementation and evaluation of the Paediatric Strategy. Data influence funding, purchasing and resource allocation.

The Department of Health WA, in partnership with Health Service Providers, will provide statewide leadership and stewardship and monitor performance via systemwide trends and data collection.

Systems will be developed within the health service organisation to ensure that essential resources required for the provision of safe, high-quality specialist paediatric end-of-life and palliative care are always operational and available.

Through effective implementation and evaluation, a stronger and more sustainable approach to paediatric palliative care will be achieved, access to person-centred care and care coordination will be improved, children and families will receive optimal support, staff will be better prepared to provide optimal care, and the community will be empowered to care.



Glossary of terms

The Strategy uses terms and definitions which encompass a range of services and disciplines. The following is an explanation of these terms.

Age range

The applicable age range for paediatric palliative care incorporates the antenatal period up to 18 years of age, with discretion for providers to continue treatment into young adulthood.

Bereavement

A broad term that encompasses the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one.³²

Child

For the purposes of this document, the words child or children include infant/s (including neonates), child/ren and adolescent/s. In some instances, the age-specific term infant or adolescent may be used.

End of life

End of life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end of life will be considered likely to die during the next 12 months.²

End-of-life care

End-of-life care includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death.

It encompasses a palliative approach to care and recognises that it is the responsibility of public, private, community and non-government health sectors to provide quality end-of-life care for their patients.^{33 34} It also recognises that support of people and their family is most effective with a team approach through a network of healthcare professionals.

End-of-life care includes connecting the person's primary treating team with specialist palliative care and enabling access to clear information and referral pathways if the person's complexity is beyond the scope of the professional or team.

Family and carers

The term 'family' includes people identified by the child as family and may include people who are biologically related such as siblings and grandparents, foster parents, people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets).

Carers may include family members and other members of their community (such as close friends and neighbours) who the child agrees to being involved in their care.

For the purposes of this document, family includes carers.

Multidisciplinary care

Professionals from a range of disciplines working together to provide comprehensive care that addresses as many of the patient's needs as possible. This can be delivered by professionals functioning as a team under one organisational umbrella or from a range of organisations, including private practice, and brought together as a unique team. As a patient's condition changes over time, the composition of the team may change to reflect the changing clinical and psychosocial needs of the patient.³⁵

Interdisciplinary team

For the purpose of this document, the interdisciplinary team refers to the Specialist Palliative Care Services team, as distinct from the multidisciplinary team providing 'usual' care to the child.

The interdisciplinary team may or may not include the child/family, but this will be dictated by the needs and circumstances of each child. It is recommended that the child and their family are included in interdisciplinary team reviews at least once each year, and that they are aware that the interdisciplinary team meets in the best interest of the child, as appropriate.

Life-limiting condition/illness

The term life-limiting or life-threatening illness describes illnesses where it is expected that death will be a direct consequence of the specified illness. The term child living with a life-limiting illness also incorporates the concept of the child actively living with the illness, often for long periods of time, not simply dying.

The term life-limiting illness also incorporates life-limiting conditions. For the purposes of this document, the term life-limiting condition has been used consistently throughout, with the intention that it covers children living with a life-limiting illness or condition who are expected to die in childhood. The four categories of life-limiting conditions are described at Table 1.

Optimal Paediatric Palliative Care Pathway

The WA Health Optimal Paediatric Palliative Care Pathway (OPPCP) aims to determine the best care for children with life-limiting conditions requiring palliative care. It aims to ensure appropriate referral to specialist palliative care and to address inequities, e.g. due to geographic location, disease category or cultural beliefs. It acknowledges that the needs of a child and their family requiring palliative care can be complex and may involve multiple providers across a range of settings.

Paediatric Goals of Patient Care

Paediatric Goals of Patient Care establishes the most medically appropriate, realistic, agreed goals of patient care that will apply in the event of clinical deterioration, during an episode of care. This clinical care planning process facilitates proactive shared discussion and decision-making between the clinician, the child and family.

Paediatric palliative care

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, the provision of short breaks, care at the end-of-life and bereavement support.³

Palliative care can be introduced at any point throughout a child's life; it is completely individual. Some children may require palliative care from birth, others may only require it as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed at cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-limiting condition or recognition that curative treatment for a life-threatening condition is not an option; however, each situation is different and care should be tailored to the individual child.³

Palliative care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.⁴

Parallel planning

Where palliative care is offered alongside curative treatment, or treatment aimed at significantly prolonging life.³

Parents/Guardians

The person or persons identified as having parental responsibility for the child.

Perinatal palliative care

Perinatal palliative care is a holistic approach to supportive and end-of-life care. The aim of perinatal palliative care is to ensure provision of best care during pregnancy, childbirth and the newborn period when a fetus is diagnosed with a serious fetal abnormality, or when a newborn is diagnosed with a life-limiting condition. Perinatal palliative care may be integrated with the care of the mother by the obstetric management team, particularly for early pregnancy loss, or provided concurrently with the obstetric management by a specialist paediatric palliative care team.⁸

Person and family-centred care

Person and family-centred care is an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families. A person-centred approach considers the diverse needs of all people, recognising the importance of their beliefs, culture, goals, wishes, concerns, spirituality, religious, emotional, social and special needs. It reflects the primacy of the person, placing them at the centre of care.²³

Specialist paediatric palliative care

Specialist paediatric palliative care comprises services provided by clinicians and others who have advanced training in paediatric palliative care. The role of specialist paediatric palliative care services includes provision of direct care to patients with complex palliative care needs, and provision of consultation services to support, advise and educate others who are partnering in palliative care.

It is recognised that the availability of advanced training in paediatric palliative care is relatively recent and for this reason, not all clinicians in specialist paediatric palliative care teams will necessarily have advanced training in paediatric palliative care, notwithstanding their significant experience in paediatric palliative care. Palliative Care Australia expects that over time there will be increased availability of specialists with advanced training in paediatric palliative care.⁵

Acronyms

ACCHS	Aboriginal Community Controlled Health Services
ED	Emergency Department
MDT	Multidisciplinary Team
OPPCP	Optimal Paediatric Palliative Care Pathway
PGoPC	Paediatric Goals of Patient Care
SPPCS	Specialist Paediatric Palliative Care Service



Appendix One

WA End-of-life and Palliative Care Strategy 2018-2028: Overview of priorities

1

Priority One: Care is accessible to everyone, everywhere

My quality of life is valued and respected. I have access to high quality palliative care and, when needed, timely and appropriate end-of-life care regardless of who I am, where I live, or how I live my life.

2

Priority two: Care is child-centred and family-centred

I am an individual. Wherever possible, my family and I are involved in honest discussions about my care. Our beliefs, values, needs, wishes, culture and spirituality are considered and respected and we receive individualised support and care.

3

Priority three: Care is coordinated

I receive the right care at the right time, in the right place, from the right people. My care is provided seamlessly through a coordinated and collaborative approach involving all health and service providers, with support provided by the Specialist Paediatric Palliative Care Service, where required.

4

Priority Four: Families are supported

People close to me are supported and involved in my care. My family's involvement is recognised and valued by those providing care, including my family's need to be supported during and after my death.

5

Priority Five: All staff are prepared to care

Wherever and whenever I am cared for, all staff involved in my care should have expertise, empathy and compassion. All staff should provide sensitive, competent and skilful care across my continuum of care, from diagnosis to bereavement.

6

Priority Six: The community is aware and able to care

I am supported by the community. The community understands what paediatric palliative care is and what it is not. The close community around me is aware of my needs and can support these needs, as well as the needs of those close to me.



References

1. Palliative Care Australia and The Australian and New Zealand Paediatric Palliative Care Reference Group. Position Statement, 2015. [Available from: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/04/Paediatric-Palliative-Care-Position-Statement.-2015-pdf.pdf.]
2. Australian Commission on Safety and Quality in Health Care. National consensus statement: Essential elements for safe and high-quality end-of-life care Sydney, NSW 2015 [Available from: <http://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-ConsensusStatement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>.]
3. Together for Short Lives. A Guide to Children's Palliative Care Bristol, UK 2018 4th edition. [Available from: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/TfSL-A-Guide-to-Children's-Palliative-Care-Fourth-Edition-FINAL-SINGLE-PAGES.pdf>.]
4. World Health Organization. WHO Definition of Palliative Care 2021 [Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.]
5. Palliative Care Australia. Palliative Care Service Development Guidelines: Paediatric Addendum 2018. [Available from: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/PalliativeCare-Paediatricaddendum-2018_web.pdf.]
6. Children's Health Queensland. A practical guide to Palliative Care in paediatrics Queensland. Australia 2014 [Available from: <https://www.caresearch.com.au/QuoCCA/Portals/6/Documents/A-Practical-guide-to-Palliative-Care-in-Paediatrics.pdf>.]
7. Western Australian Department of Health. Paediatric and Adolescent Palliative Care Model of Care. Perth, Western Australia 2009. [Available from: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Health-Networks/Palliative-care/Paediatric-Adolescent-Palliative-Care-MOC.pdf>.]
8. Western Australian Department of Health. Perinatal Palliative Care Model of Care. Perth, Western Australia 2015 [Available from: <https://ww2.health.wa.gov.au/~/-/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/Perinatal-Palliative-Care-Model-of-Care.pdf>.]
9. International Children's Palliative Care Network. What is Children's Palliative Care? Assagay, South Africa: International Children's Palliative Care Network; 2015 [Available from: <http://www.icpcn.org/about-icpcn/what-is-childrens-palliative-care/>.]
10. Western Australian Child and Adolescent Health Service. The Paediatric Palliative Care Project: Consumer and Stakeholder Consultation Report. Perth, Western Australia: Perth Children's Hospital; 2020.
11. Western Australian Department of Health. WA End-of-Life and Palliative Care Strategy 2018-2028. Perth, Western Australia: WA Cancer and Palliative Care Network; 2018 [Available from: <https://ww2.health.wa.gov.au/-/media/Corp/Documents/Health-for/End-of-Life/WA-End-of-life-and-Palliative-Care-Strategy-2018-2028.pdf>.]

12. Meier DE, Beresford L. Pediatric palliative care offers opportunities for collaboration. *J Palliat Med.* 2007;10(2):284-9.
13. Goldman A. ABC of palliative care. Special problems of children. *BMJ.* 1998;316(7124):49-52.
14. Hutchinson F, King N, Hain, RDW. Terminal care in paediatrics: where are we now? *Postgraduate Medical Journal.* 2003;79:566-8.
15. Fraser LK, Lidstone V, Miller M, Aldridge J, Norman P, McKinney PA, et al. Patterns of diagnoses among children and young adults with life-limiting conditions: A secondary analysis of a national dataset. *Palliative Medicine.* 2014;06(28(6)):513-20.
16. Hynson JL, Sawyer SM. Paediatric palliative care: distinctive needs and emerging issues. *Journal of Paediatric Child Health.* 2001;37:323-5.
17. Fraser LK, Miller M, Hain RDW, Norman P, Aldridge J, McKinney P, et al. Rising national prevalence of Life-Limiting Conditions in children in England. *Paediatrics.* 2012;129:923-9.
18. Bowers AP, Bradford N, Chan RJ, Herbert A, Yates P. Analysis of health administration data to inform health service planning for paediatric palliative care. *BMJ Support Palliat Care.* 2020.
19. Australian Bureau of Statistics. Census QuickStats 2016. [Available from: https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/5.]
20. Siden H. Paediatric Palliative Care for Children with Progressive Non-Malignant Diseases. *Children.* 2018;5(2):28.
21. Aoun SM, Gill FJ, Phillips MB, Momber S, Cuddeford L, Deleuil R, et al. The profile and support needs of parents in paediatric palliative care: comparing cancer and non-cancer groups. *Palliat Care Soc Pract.* 2020;14:2632352420958000.
22. Western Australian Department of Health. Models of Care Review 2015-2016. WA Cancer and Palliative Care Network. Perth, Western Australia 2016.
23. Australian Commission on Safety and Quality in Health Care. Patient-centred care: Improving quality and safety through partnerships with patients and consumers Sydney, Australia: Australian Commission on Safety and Quality in Health Care; 2011 [Available from: https://www.safetyandquality.gov.au/sites/default/files/migrated/PCC_Paper_August.pdf.]
24. Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L, et al. The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS One.* 2015;10(4):e0123012.
25. O'Leary N, Flynn J, MacCallion A, Walsh E, McQuillan, R. Paediatric palliative care delivered by an adult palliative care service. *Palliative Medicine.* 2006:433-7.
26. Jennings P. Providing Paediatric Palliative Care through a Paediatric Supportive Care Team. *Paediatric Nursing.* 2005;31:195-200.
27. Rosenwax LK, McNamara BA, Murray K, McCabe RJ, Aoun SM, Currow, D. Hospital and emergency department use in the last year of life: A baseline for future modifications to end-of-life care. *The Medical Journal of Australia.* 2011;194(11):570-3.

28. Western Australian Department of Health. The Palliative Care Model of Care. WA Cancer and Palliative Care Network. Perth, Western Australia 2008.
29. Western Australian Department of Health. The End-of-Life Framework. Perth, Western Australia 2016. [Available from: <https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/End%20of%20Life/PDF/The-End-of-Life-Framework.ashx>.]
30. New South Wales Health. Volunteer at Sydney Children's Hospital, Randwick Sydney. New South Wales 2021, [Available from: <https://www.schn.health.nsw.gov.au/supporters-volunteers/become-a-volunteer/volunteer-at-sydney-childrens-hospital-randwick>.]
31. Compassionate Communities Network. Compassionate Communities: Public Health Palliative Care, 2021 [Available from: <http://www.compassionatecommunities.net.au/>.]
32. Field MJ, Behrman, RE. When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. Washington DC, USA: National Academies Press, USA; 2003.
33. Victoria Government. Victoria's end of life and palliative care framework: A guide for high-quality end of life care for all Victorians. Melbourne, Victoria 2016.
34. Bartel R. Conversations: Creating choice in end-of-life care. Melbourne, Victoria: Australian Centre for Health Research; 2016 [Available from: <https://apo.org.au/sites/default/files/resource-files/2016-03/apo-nid62025.pdf>.]
35. Mitchell GK, Tieman JJ, Shelby-James TM. Multidisciplinary care planning and teamwork in primary care. Med J Aust. 2008;188(S8):S61-4.

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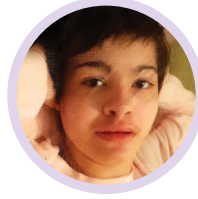
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Sukayna



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