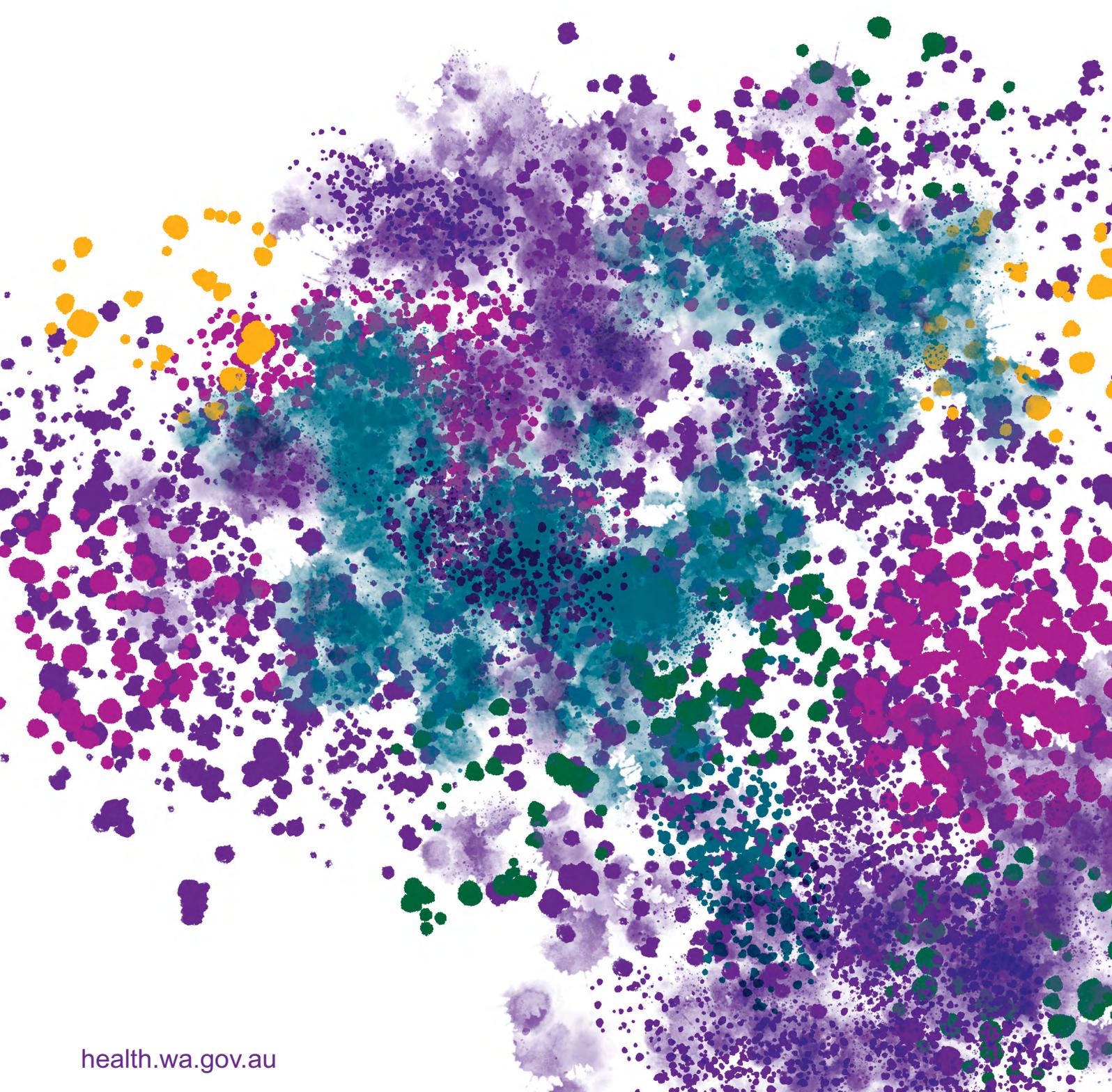




Government of **Western Australia**  
Department of **Health**

# Western Australian Optimal Paediatric Palliative Care Pathway

August 2021





## 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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## Foreword

The Optimal Paediatric Palliative Care Pathway has been developed with the aim of improving access, equity, outcomes and experiences for infants (including neonates), children, young people and their families who are living with a life-limiting condition in Western Australia (WA). The OPPCP has been developed in conjunction with the Western Australian Paediatric Strategy for End-of-Life and Palliative Care 2021–2028.

Paediatric palliative care focuses on providing care throughout the trajectory of a child's life-limiting condition and frequently includes a different disease and symptom profile to that occurring in adults. Many of these life-limiting conditions are rare with no definitive diagnosis, making accurate prognosis difficult. Potentially curative treatment may be part of the child's 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 across a wide range of services including tertiary, secondary and primary sectors. Care is likely to include periods of symptom management and/or respite throughout this trajectory that may not be linked to end-of-life care.

The OPPCP is not a clinical practice guideline but rather it represents the pathway for a child diagnosed with a life-limiting condition and their family. It outlines the distinct components of paediatric palliative care and promotes consistent quality care and patient and family experience. The infant, child or young person living with a life-limiting condition and their family are the constant in the patient journey. Care should be delivered in an appropriate, responsive and coordinated manner.

The WA Paediatric Palliative Care Service has had oversight of the development of the OPPCP which has been informed by consultation with professionals as well as past and present families who have been consumers of the services.



# Context

The Optimal Paediatric Palliative Care Pathway has been developed for all Western Australian infants, including neonates, children, young people and their families (furthermore referred to as children throughout this document) diagnosed with a life-limiting condition. It provides guidance for all WA health practitioners and service planners who support and care for children with a life-limiting condition, and their families, including:

- consumers
- specialist and non-specialist teams providing end-of-life care, and specialist palliative care teams, both paediatric and adult, 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
- staff in public, private, community and non-government organisations (including training, research and educational institutions including schools) in metro and country WA
- the wider community and advocacy groups.

Palliative care for children is an active and total approach to care, from the point of diagnosis or recognition of a life-limiting condition, throughout the child's life, death and beyond. It embraces physical, emotional, social, cultural 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 symptoms, the provision of short breaks for planned respite, care at the end-of-life and bereavement support.<sup>1</sup>



# Informing the OPPCP

A review of the literature was conducted to ensure the pathway reflected best practice and, where possible, evidenced based care. Extensive statewide consultation was also conducted with a diverse range of stakeholders to ensure local knowledge, experience and context.

The Paediatric Palliative Care Project Group, led by the Child and Adolescent Health Service, (CAHS) conducted a consultation process from February to May 2020 using a range of methods. Workshops, face-to-face meetings, videoconference and telephone conversations were held with consumers, clinicians and staff throughout the seven Western Australian Country Health Service (WACHS) regions and the Perth metropolitan area. Separate consultation with consumers provided a 'safe space' for them to discuss their experience of palliative and end-of-life care services.

The aims of the consultation process were to:

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

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

- consumers
- clinicians and staff from CAHS
- clinicians and staff from other Health Service Providers including North Metropolitan Health Service (NMHS), East Metropolitan Health Service (EMHS), South Metropolitan Health Service (SMHS) and WACHS (Albany, Broome, Bunbury, Geraldton, Kalgoorlie, Karratha and Northam)
- primary health care providers, including General Practitioners
- WA Cancer and Palliative Care Network, WA Health
- Aboriginal Health Unit, WA Health
- other key agencies involved in paediatric palliative care refer to [Appendix 1](#).

The consultation provided a significant amount of information to be transcribed, collated, thematically coded and analysed. An iterative approach was used to identify the key themes which were subsequently aligned to six overarching priority areas and used to also inform development of the Western Australian Paediatric Strategy for End-of-Life and Palliative Care 2021-2028.

The OPPCP and the Paediatric Strategy are separate but complementary documents.

These priority areas are:

- Priority One: Care is accessible to everyone, everywhere
- Priority Two: Care is child-centred and family-centred
- Priority Three: Care is coordinated
- Priority Four: Families are supported
- Priority Five: All staff are prepared to care
- Priority Six: The community is aware and able to care



# Epidemiology

Paediatric palliative care encompasses a wide range of diseases and symptoms. Some of these conditions are rare with no definitive diagnosis. The specific needs of children with life-limiting conditions are often overlooked due to small numbers<sup>2</sup>, uncertain illness trajectories<sup>3</sup> and variation in diagnosis compared to their adult counterparts.<sup>4,5</sup>

At the time of publication, there have been no studies undertaken in WA to describe the prevalence of children living with life-limiting conditions. It is nationally and internationally recognised that the number of children living with life-limiting conditions is growing.<sup>6, 7, 8</sup>

Published hospital admissions data for individuals aged 0-21 years with a life-limiting condition admitted to a Queensland hospital suggest a 29.6% increase in hospital admissions 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 is estimated at 43.2 per 10,000 population.<sup>9</sup>

Figures reported in England for years 2009/10, estimate the prevalence for children aged 0-19 years living with a life-limiting condition to be 32 per 10,000, which is more than double the estimate reported ten years ago.<sup>6</sup> Extrapolating this data suggests that there are approximately 2,000 children living with life-limiting conditions in WA.<sup>10</sup> Given concurrent advancement in diagnostic techniques, medical and surgical care, this number is likely to continue to increase.<sup>6</sup>



**Table 1**

**Main groups of life-limiting conditions for children<sup>11</sup>**

	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 if 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).



## 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.<sup>3,11,12,13,14</sup>

While there are similarities in the key principles of palliative care for children and adults, there are also significant differences.<sup>11,15</sup>

These include:

<b>Smaller numbers mean less familiarity</b>	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.
<b>Conditions are often very rare, and can be undiagnosed</b>	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.
<b>Prognosis can be difficult</b>	Making a prognosis can be difficult.
<b>Perinatal palliative care</b>	Perinatal palliative care may be provided alongside antenatal care that a mother receives from the obstetric team.
<b>Unpredictable trajectory</b>	Deterioration can be episodic and unpredictable.
<b>A child's developmental needs</b>	A child continues to develop physically, emotionally and cognitively, with unique and often complex clinical, social, emotional, developmental, cultural and spiritual needs.
<b>The school as part of their community</b>	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.
<b>A child's level of understanding</b>	A child's ability to communicate and understand varies according to their stage of development and underlying condition.
<b>Transition to adult services</b>	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.

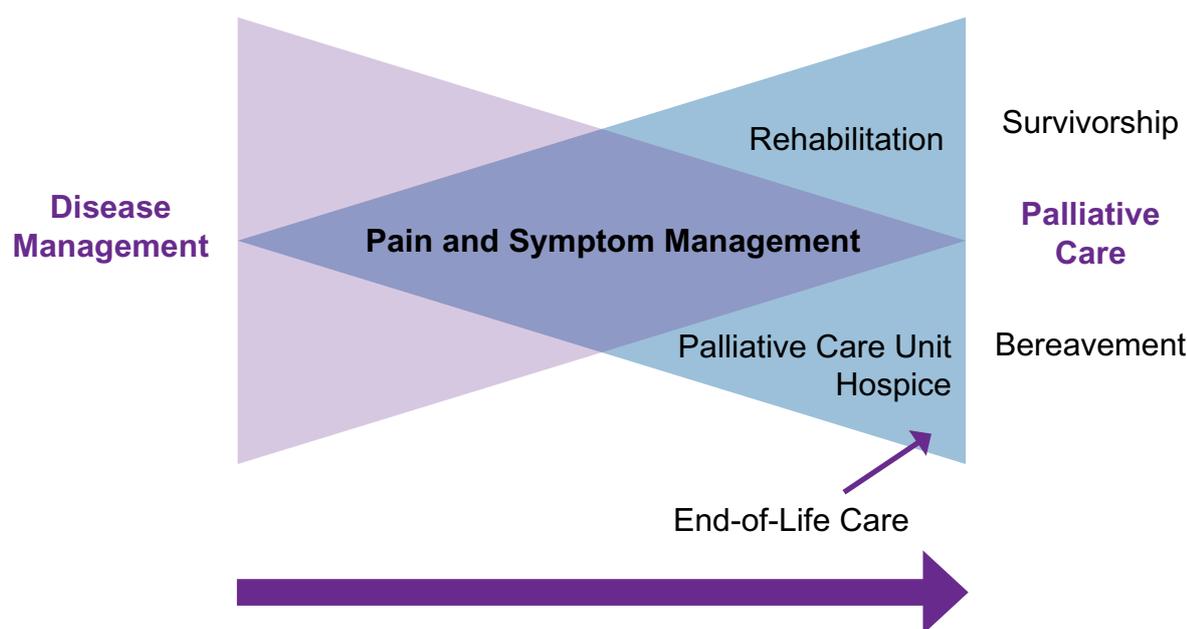


<b>Family involvement in decision-making</b>	The family has an increased role in decision-making and care for a child. This is quite dynamic and may change over time, with developmental growth and clinical deterioration.
<b>Family-centred care</b>	Care embraces the family within an ethos of child and family-centred care.
<b>Genetic counselling</b>	More than one child in the family may be affected, and there may be a need for genetic counselling.
<b>Siblings are vulnerable</b>	Siblings are vulnerable, with parents often providing care for them while providing 24-hour care to a child with a life-limiting condition.
<b>Financial demands</b>	There may be financial demands placed on families when parents withdraw partially or completely from the workforce to provide care for their child.
<b>Grief and loss evolves</b>	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.
<b>Defies the natural order of life</b>	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.
<b>Grandparent wellbeing</b>	The psychological wellbeing of grandparents may be affected, through 'doubled worry' – that is, worry about their grandchild as well as their own child.
<b>Consultative model</b>	Paediatric palliative care services may 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.
<b>Multiple settings of care</b>	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.



Palliative care can be introduced at any point throughout a child's life. 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 prolonging life. In practice, palliative care is best 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 and their family.<sup>12</sup>

The concept of parallel planning is important, where palliative care is offered in parallel with and alongside curative treatment, or treatment aimed at significantly prolonging life (refer to Figure 1). Effective palliative care is dynamic and responsive to the changing needs of children and their families. Paediatric services provide palliative care and children and families may dip in and out of utilising specialised paediatric palliative care services as their condition fluctuates. As children become more vulnerable to complications, palliative care becomes a more active element of their support package. This is particularly relevant for the growing number of technology-dependent children and those who are receiving experimental treatments for which there is a high risk of unknown side effects and complications.<sup>13</sup>



**Figure 1: Parallel planning for disease-directed alongside palliative care can be represented in the 'bow-tie' model** <sup>6, 16</sup>



## 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.

## Principles of optimal paediatric palliative care in Western Australia

There are several key elements of best practice which should be considered at each stage of the pathway. The principles outlined below have been adapted for the WA context from “A core pathway for children with life-limiting and life-threatening conditions” (Together for Short Lives, 3rd Edition).<sup>17</sup>

### Care is provided in the best interest of the child

- Confidentiality, consent and capacity issues must be addressed throughout the pathway.
- Children should receive coordinated care where services work together to deliver integrated, child-centred and family-centred life-long care to improve quality of life.
- The prevention of symptoms and symptom management are key elements.
- Care and support should be accessible 24 hours a day.
- Care should include the establishment of advance care planning and the establishment of Paediatric Goals of Patient Care (PGoPC).
- All treatment decisions must be made in the child’s best interest, based on the best scientific evidence available, the child’s clinical condition, treatment options, the child and their parents’ choices, values, needs, wishes and preferences.
- Social, play and education needs should be met.
- Recognition of ongoing grief and access to psychological and emotional support.

- 
- Spiritual support.
  - Cultural care.
  - Access to specialist paediatric palliative care teams.
  - Access to care and transitions of care should be flexible and adaptable to rapidly changing needs.

### Additional needs of the adolescent

- It is important to provide opportunity for adolescents to express their views, hopes and fears.
- A young person may wish to be independent of their parents or have significant non-family members (such as boyfriend/girlfriend) included in discussions.
- Adolescents and young adults may want to choose and record the kind of medical treatment they want and do not want, how they would like to be cared for, information for their family and friends, and how their life is remembered.

### Caring for the family

- Families experience repeated uncertainty, grief and losses throughout their child's life. Some families may face multiple losses with more than one child affected by the same condition.
- Grief is individual and may be experienced differently by members of the same family. Grief and bereavement support should be made available to all members of the family.
- Families often experience isolation which may be improved by identifying supports and linking them with their local community.
- Emotional and psychological support is needed throughout the family's experience from diagnosis through to end-of-life care and bereavement. Families should be enabled to access support themselves.
- Spiritual support.
- Cultural support.
- Short breaks are beneficial to both the child and family provided by quality respite for the child.<sup>18</sup>
- Access to SPPC teams.<sup>18</sup>

### Caring for siblings

- The impact on siblings should be recognised and acknowledged and they should have access to their own health care team during the child's disease and into bereavement.
- Siblings may need assistance to thrive.
- Sibling support may include arranged activities and opportunities for networking with other siblings of children with a life-limiting condition.
- Respite support for the child may indirectly support siblings by providing them with quality time with their parents.



## Communication

- There should be an honest, open and timely approach to all communication with parents and carers, who should be treated as equal partners in discussions.
- A lead clinician should be appointed and available as the first point of contact for the family. This person may change, depending on the stage and progression of disease.

## Responsivity of health services and clinicians

- Palliative care can commence at any stage of illness and can run alongside curative treatment, allowing access to services as the child's condition fluctuates.
- Clinicians should recognise and be responsive to the individual preferences, giving families choices with a flexible 'can-do' attitude to support choice.
- Children and their families should receive coordinated care where services work together to deliver integrated, child-centred and family-centred care. Children with life-limiting conditions often receive care from a range of organisations with different systems, roles and approaches to managing end-of-life care and such services should be appropriately coordinated to best suit the child and family.
- Many transitions may occur during a child's illness and may include transition between services including into adult services. This should be child-centred and family-centred based on what is possible for a young person according to their developmental capabilities, needs and hopes for the future.
- Care should be equitable across the metropolitan, rural and remote areas with services working together to bridge the gaps imposed by location.
- All care should be culturally appropriate and respect diversity to maintain quality of family-centred care. Care should include recognition and understanding of specific cultural and spiritual practices around death, dying and bereavement to facilitate culturally appropriate care that supports the individual needs of families.
- Care should include recognition of the inequities often experienced by Aboriginal people, children and families including socio-economic factors, access to education, unemployment, isolation, increased morbidity and the high percentage of people living in rural and remote locations.
- Safe and high-quality paediatric care at the end of life, requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes and transitions of care.
- Timely and thorough planning with the young person and family to transition to adult services, should occur when appropriate.



## Care and support within the local community

- Service provision across various locations as well as being close to home.
- Collaboration between SPPC teams and primary paediatric care teams including community-based health care providers, general practitioners, community nursing services and other specialist palliative care services. These collaborations are particularly important in rural and remote locations to ensure 24-hour access to care.<sup>18</sup>
- Building the capacity of the local community and use of technology can partially bridge the gap of geographical location.

## Care of the team around the child

- Every member of the team around the child and family should receive support and an opportunity to talk about their experiences in a safe and confidential environment.
- Professionals should have access to support and clinical supervision.
- Professionals should have access to ongoing education.

## Considerations for children and their families in rural and remote Western Australia

- Every member of the team should consider the impact of distance, remoteness and isolation including:
  - the time it takes to travel to and from tertiary facilities
  - modes of transportation available to minimise the burden and cost on families
  - the time it may take to provide equipment and medications
  - challenges of transport availability which may be seasonal
  - availability, reliability and use of technology.
- Where possible, appointments should be coordinated to minimise trips away from home and disruption to the family and/or utilise technologies such as telehealth.
- Health professionals should consider the provision of a pop-up model of support to provide face-to-face support and education to the local health care team and community; and provide visiting health professionals with the opportunity to better appreciate and understand the local context and challenges.
- Care planning should consider use of respite services timed with visits to the metropolitan area, when necessary, to offer families the opportunity to take a break.
- Aboriginal children and families may live in very remote locations and are a diverse population strongly influenced by the Country on which they belong.
- A culturally secure approach to language difference is needed and Aboriginal language interpreters should be engaged when delivering palliative care services when appropriate and available. Palliative care resources should also be available in local language and dialects.

- Health professionals working in remote communities may need additional support and may be able to undertake a transdisciplinary approach whereby health professionals work across several roles.
- Access to supported death at home may not be possible in some remote communities.
- Detailed planning may be required to provide appropriate care of the child's body after death and that strategies are in place to provide appropriate care and funeral services.
- Death of a child in a small community may reverberate with greater depth than in larger towns or cities.

## Key stages of the child and family's paediatric palliative care journey

The OPPCP is based on the key stages of the child and family's palliative care journey (refer to Figure 2) and the care within each stage that should be considered, providing the opportunity for best care starting from the early stages of recognition of disease and complexity.



**Figure 2: Key stages**

Palliative care may be viewed as a thread that runs through the lives of children with a life-limiting or life-threatening illness and may begin at the diagnosis or recognition that curative treatment is no longer an option or is likely to fail.

Palliative care is optimal when health professionals are informed and able to recognise that the child has specific needs that may be discretely supported by paediatric palliative care services. Referral to specialist palliative care creates an opportunity to review the child's needs, refine or begin conversations about advance care planning and PGoPC to ensure that the child is receiving the best care to live well at each stage of their illness trajectory.

# Stage One

## Diagnosis or recognition of the life-limiting nature of the condition



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



Parent, PCH

### Presentation

Likely to be attendance at hospital for a parental or professional concern, or a critical event.

Prognosis of premature death may be at a different time to diagnosis of a health condition.

The common element will be deterioration to the extent that the long-term prognosis is poor, and the child's needs may be met by paediatric palliative care services.

### Specialist paediatric palliative care referral

Timing based on the nature of the disease and anticipated trajectory.

Barriers to referral include the understanding and acceptance of the child and family, and familiarity of health teams with the role of palliative care and how to introduce the concept to the child and their family.

### Clinical assessment

Likely to involve multiple investigations and contact with a number of different health professionals to provide accurate information.

Not all children will receive a diagnosis, rather it is recognition of clinical signs and symptoms that indicate a life-limiting or life-threatening condition.

### Care plan

Work in partnership with the child and family to identify the needs of the child and family to determine the care and support required.

- Consideration of place of care should be given.
- Quality of life should always be considered.
- Health professionals should work together within and across agencies to ensure seamless coordination and transitions of care.
- Where end of life is close to diagnosis a transfer plan from hospital to home should be agreed if required.
- Memory making should be part of the care plan for the child and the family.
- Parallel planning where palliative care is provided alongside curative treatment or treatment aimed at prolonging life.
- If appropriate consider discussing Paediatric Goals of Patient Care (PGoPC).

### Acknowledgement of grief

Recognition that grief starts at this stage.

Families need emotional, psychological and practical support.

Parental grief may continue throughout the child's life.

## Sharing significant news – working with families

Engage with the child and family to determine how they wish to be involved:

- Children and families need information provided in a way they can understand.

When sharing significant news families deserve:

- Honesty, respect and time from the health professionals.
- The opportunity to be together to receive significant information.
- Timely provision of written information that is disease specific (where possible) provided in an appropriate language which is culturally sensitive.
- Information and referral to support groups should be provided if available.
- Acknowledgement that they may be a long way from their usual support networks, particularly for rural and remote families.

Consider practical supports:

- Education and training
- Key contacts
- Practical support, equipment and transport needs
- Social support

Emotional support should be available.

Lead clinician appointed for family to contact with any questions.

## Child's needs

Engage with the child to determine how they want to be involved.

Comprehensive needs assessment and identification of the care team that will play a central coordination role.

Goal focused protocol for each aspect of clinical care including but not limited to:

- Quality of life
- Symptom management
- Medication
- Equipment

Develop relationships and service planning to provide equitable care irrespective of where the child and family live.

## Community capacity to care

Plan for community in-reach to the family in hospital in person if possible, or via telehealth.

A lead community health professional should be identified, and shared care plans implemented.

Identify important contacts for community care providers, respite, community support, education and school nurses.



*Above all, families need honesty, respect and time from the health professionals sharing the news.<sup>17</sup>*



# Stage Two

## Living with a life-limiting condition



*Some teams focus purely on cure, so they miss the palliative bit; this is still important, you can do both.*

Parent, PCH



### Family's needs

Families may need emotional and psychological support. Grief may be an ongoing element of their life.

Regular maintenance and review of:

- Quality of life
- Education and training
- Practical support
- Social support
- Respite care
- Financial support/funding/benefits
- Care in the community as much as is practical
- Psychological, emotional and spiritual support
- Cultural and religious needs
- Complementary therapies.

Memory making for the family.

### Sibling's needs

Independent emotional and psychological support should be considered and provided.

Identify school contact person as required.

### Child's needs

Engage with the child to determine how they want to be involved.

Goal focused protocol for each aspect of clinical and non-clinical care including but not limited to:

- Quality of life (social, play, education)
- Symptom management
- Medication
- Equipment
- Emotional and psychological support with recognition of the child's experience of grief
- Equitable access to care and services.

Memory making for the child and family.

### Advance care planning

Advance care planning is a process of shared decision making about the priorities of care between health professionals, the child and family. In WA, the common approach to paediatric advance care planning is via PGoPC. Effective PGoPC provides child and family-centred guidance about the best way to care for the child and documents the child's and family's wishes in the event of a sudden deterioration of the child's condition.

Planning provides an opportunity to commence discussions about the end of life. Plans should be documented and readily available for all who care for the child including the parents, family, school, community agencies and the emergency department where the child is likely to present.

### Ongoing multidisciplinary team assessment and dynamic management plan

Assess full range of medical nursing, practical, social, educational, psychological and spiritual needs.

Explore the wishes, feelings and concerns of the child and family to reach an understanding of the individual situation and impact on the family.

Explore options for local/community provision of care.

Agree and develop a written shared care plan.

Consider referral to specialist paediatric palliative care if not already involved.

Assessment should cover the needs of the whole family and others as identified by the child.

Detailed plan will provide:

- Details of professionals and services involved with the family
- Medical information
- Functional abilities of the child
- Nursing and personal care needs
- Allied health including therapy needs
- Emotional needs
- Educational/developmental needs
- Spiritual and cultural needs
- The family's home circumstances
- Equipment needs.

Consider transition to adult services as appropriate.

### Holistic multidisciplinary and multi-agency care

Palliative care is a holistic approach to care. Identify and build on the strengths and networks of the family.

- Work in partnership with the child and family to establish the needs of the child and family and determine the care and support required.
- Quality of life should always be considered. Health professionals should work together to ensure seamless coordination and transitions of care.
- Consider referral to a care coordination service.
- Develop relationships and service planning so that care is equitable irrespective of where the child and family live.
- Parallel planning where palliative care is provided alongside curative treatment or treatment aimed at prolonging good quality of life.



*The ultimate goal is for the child and family to have the best possible life.<sup>17</sup>*



# Stage Three

## Living with disease progression and deterioration



*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, PCH

### Child's needs

Establish priorities with and for the child including:

- Creating experiences
- Recognise the importance and provide ongoing education, social and play activities
- School community supported and engaged for children attending school
- Facilitate school work/attendance for as long as desired
- Respite care available
- Symptom management admissions.

### Care planning and Paediatric Goals of Patient Care

Management of more frequent episodes of acute illness, increased symptoms and hospital admissions:

- Assessment of quality of life
- Joint planning with the child and family
- Establish PGoPC.

Parallel curative and palliative care.

Possible transition from curative to palliative care.

### Family's needs

Parents may experience persistent stress, anxiety and isolation:

- Duality of joy of survival, hope and the emergence of fear of death and sorrow
- People close to the family are supported with their capacity to care
- Availability of equipment and transport is reviewed
- Education resources for family to share with others
- Consider use of complementary therapies such as music, play, storytelling and other activities
- Psychological, emotional and spiritual support
- Consider cultural and religious needs.

### Multidisciplinary team review

Parents/family are often able to recognise and report changes in their child that are impacting adversely.

Determine and understand family's needs:

- Maintain family's sense of control
- Establish family's preference for place of care and death as condition deteriorates.

Management of recurrent episodes of acute illness, increased symptoms and hospital admissions.

Assessment of quality of life.

Joint planning with the child and family.

Establish PGoPC:

- Parallel curative care and palliative care
- Possible transition of care from curative to palliative care.

Consider:

- Referral to care coordination if not previously done
- Referral to community palliative care services.

Recognition that palliative care may become a more active part of their child's care.

Flexible and responsive location of care that can accommodate rapid changes in the child and their family's need i.e. access to care at home, hospital and/or hospice.

### Community capacity to care

Community engaged and supported to care. Collaborations between paediatric, palliative care and local services.

Rural and remote areas – consider pop-up visits for additional support and education for local teams.

School community may be involved and informed.



*Uncertainty at this time should be communicated honestly, parallel planning, that is planning for death and for survival, can make it acceptable for families to hope for the best alongside preparing for the end of their child's life.<sup>17</sup>*



# Stage Four

## End-of-life care



*Recognising what happens at the end of life can have an enormous impact on parents' ability to cope, process, grieve and move on; they remember these moments forever.*



Parent, PCH

### Child's needs

Establish priorities with and for the child including:

- Their comfort
- Assessment of their symptoms and appropriate management (pharmacological and non-pharmacological)
- Emotional, psychological and spiritual support needs
- 24-hour access to paediatric palliative care services
- Facilitate school attendance for as long as desired
- Where they would like to die and who should be with them
- Provision of opportunities for legacy making
- Funeral planning
- Memory making
- Care of child's body after death.

### Care plan

Symptom management plan.

Ensure PGoPC established, and reviewed as needed.

Anticipatory medication prescribing.

Ensure inclusion of cultural and religious needs.

Location of death with flexibility to change rapidly:

- Seamless transitions between home, hospital and hospice.

Plan for what the family would like to do at the time of death and immediately following:

- Who should be present
- Who to contact
- What will happen with the child's body.

Inclusion of and considerations required for siblings and the extended family.

School community may be significantly affected.

- Support may be required.

Equipment needs may change rapidly as needs increase and may be specific to end-of-life care.

### Recognition that the end of life is approaching

Health changes can be subtle.

Facilitate discussions around signs that dying is imminent.

Support family to look back over a period to clarify the deterioration in their child's health.

## Family's needs

Families having some control is important:

- Family supported to make choices
- Supporting feelings of hope, including refocussing of hope
- Family supported to communicate with family and friends, consider appointing one main contact if appropriate
- Health professionals are available and accessible
- Psychological, emotional and spiritual support
- Provision of rest and breaks as needed
- Ensure discussion of cultural and religious needs
- Consider use of complementary therapies such as music, play, storytelling and other activities
- Care of siblings and grandparents
- Be prepared that death may not happen as planned and honest discussions of "what to do" in the immediate period following the death of a child, including who to contact for support
- Information and support about symptoms their child may experience and reassurance support that these can be managed
- Explanation of the physical symptoms and emotional changes likely to happen as death approaches and what death looks like
- Funeral planning.

## Multidisciplinary team

Recognition of end of life, that disease progression cannot be halted or reversed.

Determine and understand family's needs:

- Joint planning with families
- Establish family's preference for place of care and death
- Discussion with family regarding funeral planning, where appropriate, and identify available grants and funds.

Local care providers require 24-hour access to paediatric palliative care services.

Recognition that PPC may become the most active part of their child's care.

## Location

Respect and facilitate the family's choice for the location of care at the end of life.

Flexibility and ability to change location rapidly as required.

## Support for staff

Support and clinical supervision of staff involved and reminders of boundaries.

# Stage Five

## Care after death



*No one can anticipate how they will feel or react after the death of their child and continued support is required to assist families to stay in control, to create safe memories of this time and have space and privacy to grieve.<sup>17</sup>*



### Family's needs

Time and privacy with their child.

Parents should retain control and choice of how to care for their child's body.

Parents should be aware of what they can do at this time, including, but not limited to photographs, bathing and dressing the child, taking locks of hair, handprints.

Cultural and religious beliefs and rituals should be respected.

Recognise the needs of those not present.

Ensure family are aware whom to contact if they have queries.

Ensure family are aware when next contact will be made and by whom.

Provide written information to family regarding grief including services available.

### Care of the deceased child

The child should be cared for with dignity and respect.

Attention should be paid to a child's prior wishes and preferences post death.

Recognise that a child continues to exist in the context of a family.<sup>9</sup>

Ensure adherence to cultural and religious requirements, including involvement of religious or spiritual supports.

Ensure family are aware of whom to contact when a child dies at home.

### Sibling's needs

Provide opportunities to express their emotions and ask questions.

They should be asked if they wish to be involved with the care of the child after death (bathing, dressing, memory making) and where appropriate, in decisions about funerals.

Continued input from health and other professionals who have been supporting them over the duration of their sibling's illness.

Friends and/or school community may be involved in supporting the family.

### Community

Recognise the need for care and support of community members that are a part of the family support network.

### Building and supporting positive memories

It is very important that families are supported to build positive memories of their child.

It is a time where parents especially need to reflect on their experience and feel safe to do so.

### Multidisciplinary team

Ensure all team members have access to relevant policy and procedures regarding care of the child's body.

Consider that the family may wish to move the child to an alternate location, ensure processes are established prior to the child's death in order to allow this.

Recognise hospital and health teams may have formed a significant part of the family's support network.

Ensure all teams involved in the child's care are aware of death and give indication of appropriateness of contacting family.

Ensure rapid notification of the death via hospital system to ensure no further administrative correspondence is sent.

Provide notification of the death to all relevant providers.

### Environment

Support the family regarding their wishes of when and where to move the child's body.

Return/remove any equipment when the family is ready.



*The needs of the child and family will fluctuate, and every child and family should have a team that uses key working principles to coordinate the plan.*

(source not known)



# Stage Six

## Bereavement Support



*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, PCH

### Family's needs

The death of a child is not the end of the care pathway for the family.

Bereavement is unique to every person.

Provide the family with a plan for bereavement follow-up that identifies whom to contact at defined points in time.

Ensure all affected family members have access to bereavement support, including siblings and grandparents.

Consider the unique needs of families for example those who have experienced multiple deaths, and those who have had their only child die.

Consider (where appropriate) opportunities for parents and family to engage with other families who have experienced a similar loss for both their support and when/if able to support others.

### Child

Recognise that a child still exists in the context of a family.

### The child's legacy and meaning making

Recognise significant dates for the child and family, including anniversary of death and birthdays.

Consider (where appropriate) opportunities for parents and families to engage with and contribute to their child's health and community services including advocacy, consultation and consumer input.

### Multidisciplinary team

Recognise that health carers, hospital and health teams may have formed a significant part of the family's support network.

Offer the family a meeting with the child's medical team to discuss their thoughts, concerns and queries.

Bereavement support should engage with the family as early as possible to build relationships that will support the family following the death of their child.



### **School community**

May be significantly impacted and education systems should include a process for supporting children, young people and staff through end of life and bereavement.

Ensure schools are enabled to provide ongoing care and support to the child's siblings.

May provide opportunities for the child's parents to return to the school.

### **Community**

Where possible consider ways in which the child's life can be memorialised, including school, clubs and the local community.



## 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**.

### Age range

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

### Child

Child or children includes infant/s (including neonates), child/ren and adolescent/s up to the age of 18 years. In some instances, the age-specific term infant or adolescent may be used.

### End of life

In paediatrics, the period when the child is clearly dying and the primary goal of care is comfort.<sup>11</sup>

### 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 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](#).<sup>11</sup>



## Paediatric Goals of Patient Care (PGoPC)

Paediatric Goals of Patient Care establishes the most medically appropriate, realistic, agreed goal 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 (PPC)

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, cultural 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.<sup>18</sup>

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 also vary as to whether they wish to pursue treatments aimed at cure or significantly prolonging life. In practice, palliative care should be offered from recognition 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.<sup>18</sup>

## 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.<sup>20</sup>

## Parents/Guardians

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

## Specialist Paediatric Palliative Care (SPPC)

Specialist Paediatric Palliative Care comprises services provided by clinicians and others who have advanced training and clinical practice in paediatric palliative care. The role of SPPC 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 SPPC 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 of all disciplines with advanced training in paediatric palliative care.<sup>11</sup>



# Resources for Service Providers and families

1. <https://pch.health.wa.gov.au/our-services/palliative-care>
2. <https://palliativecare.org.au/>

## 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](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/04/Paediatric-Palliative-Care-Position-Statement.-2015-pdf.pdf).]
2. Meier DE, Beresford L. Pediatric palliative care offers opportunities for collaboration. *J Palliat Med*. 2007;10(2):284-9.
3. 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>.]
4. Goldman A. ABC of palliative care. Special problems of children. *BMJ*. 1998;316(7124):49-52.
5. Hutchinson F, King N, Hain RDW. Terminal care in paediatrics: where are we now? *Postgraduate Medical Journal*. 2003;79:566-8.
6. Fraser LK, Lidstone V, Miller M, Aldridge J, Norman P, McKinney PA, Parslow RC. 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.
7. Hynson JL, Sawyer SM. Paediatric palliative care: distinctive needs and emerging issues. *Journal of Paediatric Child Health*. 2001;37:323-5.
8. Fraser LK, Miller M, Hain RDW, Norman P, Aldridge J, McKinney P, Parslow RC. Rising national prevalence of life-limiting conditions in children in England. *Paediatrics*. 2012;129:923-9.
9. 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.
10. Australian Bureau of Statistics. Census QuickStats 2016 2016. [Available from: [https://quickstats.censusdata.abs.gov.au/census\\_services/getproduct/census/2016/quickstat/5](https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/5).]
11. 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](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/PalliativeCare-Paediatricaddendum-2018_web.pdf).]



12. Together for Short Lives. A Guide to Children's Palliative Care Bristol, UK 2018 4<sup>th</sup> 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>.]
13. 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-Paediatics.pdf>.]
14. 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](https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/Perinatal-Palliative-Care-Model-of-Care.pdf).]
15. 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/>.]
16. Hawley P. The bow tie model of 21<sup>st</sup> century palliative care. Pain and Symptom Management 2014; 47 (1) 2-5.
17. Widdas D, McNamara K, Edwards F. A core pathway for children with life-limiting and life-threatening conditions. Together for Short Lives 2013. [Available from: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Core-Care-Pathway.pdf>.]
18. Virdun C, Brown N, Phillips J, Lockett T, Agar M, Green A, Davidson PM. Elements of optimal paediatric palliative care for children and young people: An integrative review using a systematic approach. Collegian. 2015;22(4):421-31.
19. 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-for-safe-high-quality-end-of-life-care.pdf>.]
20. World Health Organization. WHO Definition of Palliative Care 2021. [Available from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.]



## Appendix One: Key Agencies Consulted

- Cancer Council
- Community Hospices (Bunbury, Busselton, Albany)
- Compassionate Communities
- Department of Education
- DonateLife
- Epilepsy Action
- Hannah's House
- HeartKids
- NDIS Support Coordination
- Palliative Care Western Australia (PCWA)
- Silver Chain
- St John of God Hospital Bunbury





This document can be made available in alternative formats on request for a person with disability.

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