

# Paediatric Addendum

Palliative Care Service  
Development Guidelines

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**PalliativeCare**  
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# Acknowledgements

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PCA would also like to acknowledge the contribution of all of those who have provided expert feedback through consultation and ongoing involvement, especially:

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# Foreword

I am excited to see the Paediatric Addendum – Palliative Care Service Development Guidelines bring to light some of the similarities and some of differences in working to provide palliative care to children. This Addendum will support the future design and development of paediatric palliative care services around Australia to ensure that we are providing services that meet the needs of children needing specialist palliative care and their families. This support may be for a very short period of time or we may work with people for many years, with them transitioning to adult services.

On behalf of Paediatric Palliative Care Australia and New Zealand (PaPCANZ), I would like to thank PCA for undertaking the work to develop this Addendum, as well as their broader support for PaPCANZ. We look forward to continuing to work towards a system that is able to support the provision of care to all children and their families that need palliative care.

## **Sara Fleming**

*Chair of Paediatric Palliative Care Australia and New Zealand*

On behalf of Palliative Care Australia (PCA), I would like to thank Liz Callaghan and the Members of the Working Group for their expertise and support to produce the Paediatric Addendum – Palliative Care Service Development Guidelines. These Guidelines outlined PCA's expectations for paediatric palliative care and complement the existing Palliative Care Service Development Guidelines, which articulate our view of the palliative care system and service design through a population-based approach.

Palliative Care Australia looks forward to continuing to work with, and support paediatric palliative care and the children and families they care for. On behalf of the Board of Palliative Care Australia, I commend this document to you and hope the information provided informs future paediatric palliative care service design and development.

## **Dr Jane Fischer**

*Chair of the Board, Palliative Care Australia*

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# 1. Purpose, definitions and a framework for the palliative care service system



## 1.1 Purpose

Palliative Care Australia (PCA) has produced this Paediatric Palliative Care Addendum (the Addendum) specifically as a stand-alone document to complement PCA's existing Palliative Care Service Development Guidelines.

The purpose of the Addendum is to communicate the expectations of PCA for:

- » The range of paediatric palliative care services that should be available to infants, children and adolescents living with a life-limiting condition and their families (Chapter 2); and
- » The workforce and system capabilities required to deliver an effective network of paediatric palliative care services using a population-based and geographic approach to service planning (Chapter 3).

The primary audience is:

- » State and Territory Governments with responsibility for planning and organising the provision of publicly funded paediatric palliative care services;
- » Private Health Insurers that provide reimbursement to palliative care services for privately insured patients, with these services being delivered by private or public providers;
- » Directors of specialist palliative care services; and
- » Other health professionals involved in providing paediatric palliative care in all service settings.

Development of the Addendum was informed by a literature review that explored the domains relevant to the Addendum. The literature review is available in the Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines on the Palliative Care Australia website. Input into the Addendum was sought from a 14-member, multi-disciplinary Working Group comprising clinicians and Commonwealth and State program representation. Additional consultation occurred with the Paediatric Palliative Care Australia and New Zealand (PAPCANZ) Association and PCA's National Policy Advisory Committee, as well as public feedback being sought online.

PCA notes other key resource documents relevant to the paediatric palliative care sector including:

- » The National Palliative Care Standards (5<sup>th</sup> edn – 2018) that have been recently updated by Palliative Care Australia;
- » The National Palliative Care Strategy that has been updated by the Australian Government Department of Health; and
- » The National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care produced by the Australian Commission on Safety and Quality in Health Care.

## 1.2 Terminology and Definitions

This section defines the key terms that are used throughout this Addendum, including:

- » Child;
- » Family and carers;
- » Parents / Guardians;
- » Age range;
- » Life-limiting illness/condition;
- » Palliative care;
- » Perinatal palliative care
- » Paediatric palliative care; and
- » Specialist paediatric palliative care.

For further information and the references relating to this section, please refer to the *Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

### 1.2.1 Child

For the purpose of this Addendum, the words 'child' or 'children' include infant/s, child/ren and adolescent/s. In some instances, the age-specific term infant or adolescent may be used.

### 1.2.2 Family and carers

The term family includes people identified by the child as family and may include people who are biologically related, 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 purpose of this Addendum, the word 'family' include reference to carers.

### 1.2.3 Parents/ Guardians

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

### 1.2.4 Age range

There is substantial variability in age group definitions used across different health and social service contexts and jurisdictions in Australia. For the purpose of the Addendum, 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.

### 1.2.5 Life-limiting illness/condition

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

In Palliative Care Australia's paediatric resources, the term life-limiting illness also incorporates life-limiting conditions (for example: Cystic Fibrosis; Down syndrome).

For the purpose of the Addendum, 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.

### 1.2.6 Palliative care

The World Health Organisation defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care Australia defines palliative care in the contemporary Australian context as follows:

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

### 1.2.7 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.

### 1.2.8 Paediatric palliative care

The following definition of palliative care for children, and their families, has been adapted from the World Health Organisation:

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

Palliative Care Australia defines paediatric palliative care as follows:

Palliative care for children with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

### 1.2.9 Specialist paediatric palliative care

Palliative Care Australia defines specialist paediatric palliative care as follows:

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.

## 2. Developing the paediatric palliative care service system



This chapter outlines the key elements of the paediatric palliative care service system from the perspective of children living with a life-limiting condition and their families.

It identifies Palliative Care Australia's expectations in relation to:

- » Who should be able to access paediatric palliative care services (Section 2.1);
- » When paediatric palliative care services should be provided (Section 2.2);
- » By whom paediatric palliative care services should be provided (Section 2.3);
- » Where paediatric palliative care services should be available (Section 2.4);
- » How and what paediatric palliative care services should be provided to children with a life-limiting condition (Section 2.5); and
- » What services and support should be accessible to the families of children with a life-limiting condition (Section 2.6).

### 2.1 Planning for children who require paediatric palliative care services

Palliative Care Australia expects that specialist paediatric palliative care services will be available to all children living with a life-limiting condition and their families on a needs basis.

The specialist paediatric palliative care services will provide input, when and as required, to support the role of the primary treating team in providing child and family-centred palliative care. The specialist paediatric palliative care services will operate through networked clinical and consultative service models.

Children and their families will:

- » Receive evidence-based paediatric palliative care according to their needs, from diagnosis through to bereavement;
- » Participate in decision-making and care planning throughout their care;
- » Receive coordinated care across all sectors of health and other agencies/organisations;
- » Receive coordinated care across other sectors, including education and disability; and
- » Receive care and support in their preferred setting.

There are unique characteristics of paediatric palliative care that differentiate it from adult palliative care that warrant special consideration for service planning and resource allocation. Some of these characteristics are:

- » **Care embraces the whole family** and uses a model of child and family-centred care;
- » The family has an increased **role in decision-making** and care for the child;
- » A substantial number of children have **non-malignant conditions**, many of which are specific to childhood;
- » Life-limiting conditions in children can be **extremely rare** and sometimes there is no definitive diagnosis;
- » The child usually always remains under the care of their **primary treating team**, with specialist paediatric palliative care providing support through a consultative model;
- » Perinatal palliative care may be provided **alongside the antenatal care** that a mother receives from the obstetric team;
- » Provision of care across a **wide range of care settings** and healthcare teams can complicate care coordination and communication;
- » Predicting a **prognosis can be difficult** and deterioration can be episodic and unpredictable;
- » The **number of children dying is smaller**; in turn, the lower volumes mean that non-specialist health care providers have less familiarity and experience in palliative care;
- » A **child is learning, growing and developing** along a continuum toward becoming a functional adult which requires social, emotional and spiritual needs;
- » A **child's ability to communicate and understand** varies according to their age or stage of development and underlying condition;
- » The provision of **education and play** is essential;
- » There may be **financial life-changing costs** to families when parents withdraw partially or completely from the workforce to become caregivers;
- » **Siblings are vulnerable**, with parents often providing care for them while providing 24-hour care to a child with a life-limiting condition;
- » **Grandparents are susceptible** to reduced psychological wellbeing through 'doubled worry': worry about the well-being of their grandchild as well as their own child (the child's parent);
- » **Conditions are sometimes familial**. Other children in the family may be conceived with, living with, or have died from, the same condition;
- » There can be **numerous, evolving losses** experienced throughout the illness trajectory requiring grief and bereavement support prior to death; and
- » The death of a child defies what is considered to be the natural order of life; parents do not expect to bury their children and this loss can lead to **prolonged, or even lifelong grieving**.

Additionally, when planning services, consideration must be given to Aboriginal and Torres Strait Islander children and families as well people from culturally and linguistically diverse backgrounds. For these children and their families, understanding palliative care can be difficult and the concept of palliative care may be unfamiliar or foreign. Paediatric palliative care services need to be culturally safe and culturally responsive. Further, the paediatric palliative care team must be able to access appropriate resources to educate themselves to ensure that they have a strong understanding about the personal, cultural and spiritual needs of the child and their family.

Life-limiting conditions in children have been categorised into four broad groups (see Table 2.1: Main groups of life-limiting conditions for children below). Categorisation of a life-limiting condition is not always easy. Some children can be classified by more than one group. Diagnosis is only part of the process –

the spectrum and severity of the condition, subsequent complications, and the needs of, and impact on the child and family need to be taken into account.

#### Background evidence and analysis\*

There is a wider variety of conditions that require palliative care in childhood, with cancer comprising a relatively lower proportion of paediatric palliative cases than for adult palliative care. More than half of all life-limiting conditions in children are broadly grouped as neurodegenerative disorders, metabolic disorders, genetic conditions and congenital anomalies, cardiovascular and respiratory diseases and acquired brain injuries.

*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

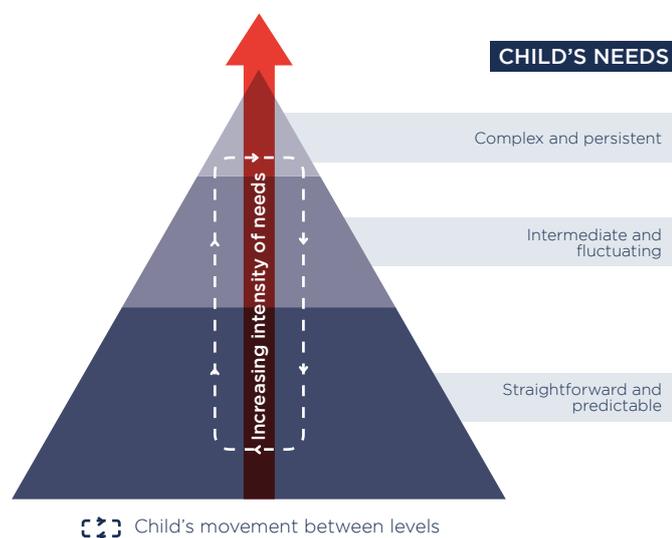
Table 2.1: Main groups of life-limiting conditions for children

	DEFINITION	EXAMPLE
1	Life-threatening conditions for which curative treatment may be feasible but can fail.	Children with cancer when treatment fails (e.g. stage 4 neuroblastoma). Irreversible organ failure (not amenable to transplantation or if transplantation is unsuccessful).
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 HIV, complex cardiac disease and Duchenne muscular dystrophy (DMD). Ongoing research and medical improvements have meant that some people with Cystic Fibrosis are surviving into their 40's 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 (e.g. spinal muscular atrophy type 1).
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).

This table has been adapted from the Children's Health Queensland Hospital and Health Service 2014, *A practical guide to palliative care in paediatrics*, Queensland Government, Queensland.

Children living with life-limiting conditions will have varying levels of need for palliative care throughout their illness trajectory. Those who are clinically unstable, deteriorating or dying are more likely to have more complex needs, as illustrated in Figure 2.1.

Figure 2.1: Conceptual model of level of need for paediatric palliative care for children living with a life-limiting condition



Palliative Care Australia expects that State and Territory Governments will adopt a population-based approach to the planning of palliative care services and this extends to paediatric palliative care.

In Australia, there is currently no reliable estimate of the extent of the population that may benefit from paediatric palliative care. Accurately estimating the need for paediatric palliative care is challenging, partly due to some of the unique characteristics of paediatric palliative care, such as the wide range and rarity of some life-limiting conditions and long illness trajectories, and partly due to disjointed health service activity and epidemiological data. To inform service planning, local research is required to determine the nature and extent of the patient population in Australia.

For the purpose of providing a guide to population-based planning in this Addendum, recent international research on the prevalence of life-limiting conditions in children, and the proportion of those with complex needs, has been applied to Australia's current population.

The estimated prevalence rate of children living with a life-limiting condition in the UK is 32 children per 10,000 population aged 0-19 years. This is likely to be a conservative estimate given the challenge of comprehensively identifying all children aged 0-19 with life-limiting diagnoses, as well as perinatal deaths for which palliative care is required. *The application of this prevalence rate to Australia's 2017 population translates to 9,535 children.*

The proportion of children with a life-limiting condition who have more complex needs is estimated to be 37.5% in high income countries such as Australia. *This means that based on 9,535 Australian children living with a life-limiting condition, 3,576 of these children would have complex needs.*

Although these estimates are derived from international research, they provide a baseline that can be used as a guide for the potential number of children living with and dying from life-limiting conditions in Australia.

### Background evidence and analysis\*

Most deaths of children aged 0-14 years occur in infants, in the first year of life (71% in Australia in 2012). Three-quarters (75%) of infant deaths from 2010-2012 were due to congenital anomalies or originated in the perinatal period, such as conditions related to short gestation and low birth weight, birth trauma and viral diseases acquired in utero.

*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

Palliative Care Australia expects research to be undertaken to enable accurate estimates of:

- » The prevalence of children living with a life-limiting condition in Australia;
- » The proportion of children with a life-limiting condition in Australia who may have complex needs; and
- » The prevalence of perinatal deaths in Australia for which specialist paediatric palliative care would be beneficial.

## 2.2 Early introduction of paediatric palliative care

Paediatric palliative care should be introduced early enough to allow the team to establish a relationship with the child and family. Consultations undertaken close to the time of diagnosis will allow the team to suitably develop paediatric palliative care management plans.

Palliative Care Australia expects that paediatric palliative care will be integrated with disease-modifying therapies and continued throughout the course of the illness or condition, regardless of outcome, as required in response to the changing needs of children living with a life-limiting condition.

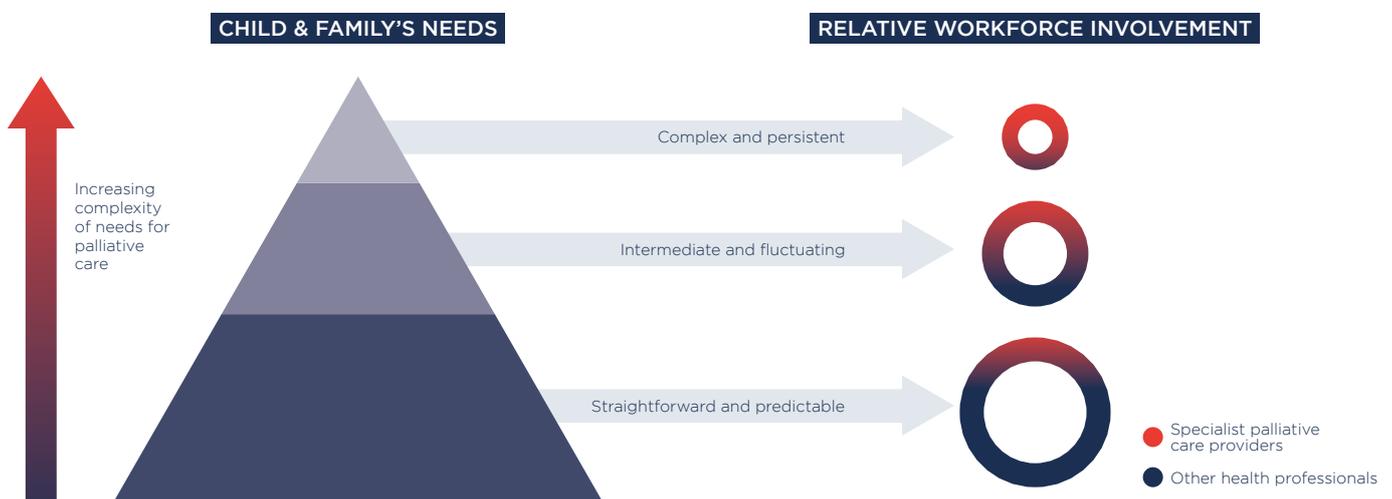
Perinatal palliative care can be planned and initiated early when a fetus is diagnosed with a serious fetal abnormality prior to birth, even if the expected outcome is uncertain. Perinatal palliative care would occur concurrently with obstetric management.

## 2.3 Providers of paediatric palliative care

In order to treat children living with a life-limiting condition, health professionals (who are not specialist paediatric palliative care providers) should have minimum core competencies to manage physical symptoms, to provide or refer to psychosocial support services, and to discuss the goals of treatment and a child's prognosis.

Figure 2.2: Builds upon the conceptual model of level of need for palliative care (Figure 2.1) to illustrate that as a child's needs become more complex, there should be increased involvement of specialist paediatric palliative care services in providing care.

Figure 2.2: Alignment of need for paediatric palliative care against workforce capability



## 2.4 Settings for the provision of paediatric palliative care

Children living with a life-limiting condition and their families need to be able to access paediatric palliative care services in a variety of hospital and community-based settings. This includes care provided by both specialist paediatric palliative care providers and by other health professionals.

Figure 2.3: provides a map of paediatric palliative care settings that illustrates that the child living with a life-limiting condition and their family should be at the centre of the service system and be able to access hospital or community-based care in different settings, depending on the complexity of their needs.

Palliative Care Australia expects that paediatric palliative care services will be provided in a wide range of hospital and community-based settings to meet the needs and preferences of children living with a life-limiting condition and their families. This should include the provision of specialist palliative care via consultancy to support children and their families and local treating teams, regardless of geographic location.

PCA acknowledges that many paediatric palliative care services are new or continually developing and seeks to highlight opportunities for optimal care provision within the following hospital and community-based settings.

### Critical care units

The role of specialist paediatric palliative care in the critical care setting, e.g. neonatal or paediatric intensive care units, is to enhance the child's quality of life through collaborative support of the treatment team's approach to pain and symptom management, communication and decision-making, advance care planning and grief and bereavement support. The specialist paediatric palliative care team would also provide input into complex situations, such as the transfer of patients who may wish to die at home and withdrawing or withholding life-sustaining medical treatment.

### Background evidence and analysis\*

International findings indicate that of the children who die in hospital, somewhere in the range of 80-91% die within a Neonatal or Paediatric Intensive Care Unit.

When the goals of care transition from curative to palliative, many life-limiting conditions can be managed outside the critical care environment, either on post-natal wards, in a hospital closer to home, at home, or in a paediatric hospice. Many families will opt for these settings of care if the appropriate support systems are available.

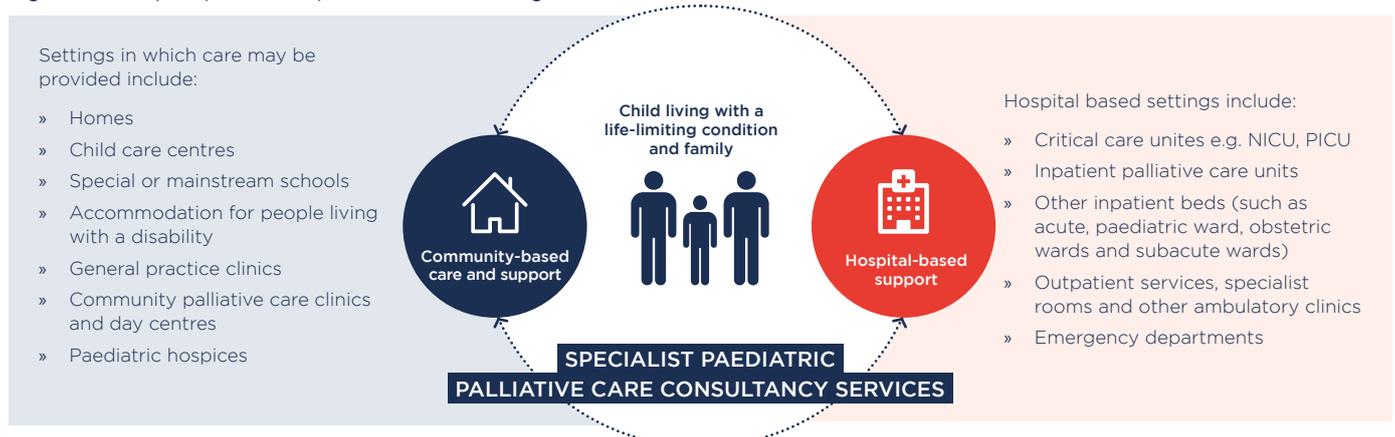
*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

Palliative Care Australia expects that critical care units, such as neonatal and paediatric intensive care units, will access and refer to paediatric palliative care programs. The optimal care model would include formal referral guidelines and established relationships between the critical care and specialist paediatric palliative care teams.

### Home

Most families choose for their child living with a life-limiting condition to spend as much time as possible at home, as parents commonly feel this is the most important thing they can do, and for many parents, palliative care represents an extension of care they would normally provide. Children generally also prefer to be at home among their own family members, friends, toys and pets. A child's life typically revolves around home.

Figure 2.3: Map of paediatric palliative care settings



Care in the home provides the child and family with many benefits, including:

- » The security of a familiar environment;
- » It is free from the disruption of hospital routines;
- » Privacy is enhanced;
- » Spiritual and cultural needs can be more easily met;
- » Siblings can be more involved in care; and
- » Parents typically feel more in control (when well supported by the specialist paediatric palliative care team).

However, a home care setting may also present disadvantages, including:

- » The physical and emotional burden of care;
- » Some symptoms can be difficult to manage in a home setting;
- » Access by health professionals is less immediate; and
- » There is a risk that parents may feel abandoned or insecure if there is a lack of ongoing contact with their child's regular hospital treating team.

Accordingly, home-based paediatric palliative care will often require multiple interventions and supports, including:

- » Close collaboration between primary paediatricians, community-based palliative care teams, other healthcare providers and the specialist paediatric palliative care team to ensure smooth transitions between settings, ongoing communication and continued care at home;
- » Continuous availability of palliative care support for the child and family, including emotional support and respite;
- » 24-hour access to suitably qualified and experienced practitioner support, including access to medication and advice for symptom control; and
- » Assistance for families who have complicated medical devices supporting the care of a child at home.

Palliative Care Australia expects that healthcare providers will strive to support the care location goal of the family, whether this be in their home, the hospital closest to their home with the capability to meet care needs, or a paediatric hospice. It will also be important that families have assurance that they have flexibility and choice in the preferred care setting and a recognition in care plans that families may change their preferred care setting at short notice and after-hours.

## Education

Even in the most serious of illnesses, a child continues to be a child and possess the developmental, social, emotional and spiritual needs of a child. To be effective, specialist paediatric palliative care should address the child's needs on a developmentally appropriate level in the place where the child lives, learns, grows and develops, and typically, that place is not a hospital. Child care centres, kindergartens and special or mainstream schools can be more than a place of learning, they can provide important relationships and a sense of normality for children living with life-limiting conditions and their families.

Effective collaboration between children and their families, healthcare providers, school professionals and governing bodies may benefit the child and their family through:

- » Effective symptom management;
- » Enhanced management of the child's psychosocial needs through collaboration between school social workers, counsellors or chaplains and the specialist paediatric palliative care team;
- » Online or tutor-led support to facilitate the child's learning, particularly if the child spends long periods of time at home;
- » A school liaison role to work as part of the specialist paediatric palliative care team;
- » Support to help the child to stay connected with their peers and socialise with their friends;
- » Opportunities for the child to participate in extra-curricular activities when activities when a condition may be considered to limit participation;
- » Respect for any wishes through a clear understanding of any advance care plans; and
- » The provision of grief and loss support to the school community.

Palliative Care Australia expects that education providers will be recognised as integral to the paediatric palliative care team and will be supported in this role by specialist palliative care services.

## Emergency services

When urgent healthcare needs arise, children living with life-limiting conditions may require the use of emergency services, such as ambulances or emergency departments. Such settings may present challenges in relation to child and family-centred care, particularly if clinical decisions need to be made in isolation of established management plans or advance care plans. Submission of authorised care plans to emergency services can assist treating clinicians to understand the wishes of the child and family in relation to life-sustaining medical treatment, and if care at home becomes too difficult, the preferred location for end-of-life care.

Palliative Care Australia expects that care planning for children living with life-limiting conditions includes the anticipation of intermittent use of emergency services, use of referral pathways, and sharing of care plans between key providers.

## Telehealth

Telehealth consultations can be just as effective as face-to-face consultations and are a feasible and acceptable means of facilitating a palliative care consultation. Telehealth can be used to link the specialist paediatric palliative care team with families caring for a child receiving palliative care, or with a child and family's local health care providers, regardless of their geographic distance from the specialist paediatric palliative care team. Telehealth also enables the specialist paediatric palliative care team to provide collegial support and education to other healthcare providers and deliver bereavement support.

Notwithstanding the advantages of telehealth, potential barriers to use include:

- » Financial – the cost of technological devices and in-home installation may be prohibitively high for some families, and funding models may not support provider participation; and
- » Connectivity – there may be issues around information system connectivity in some geographic areas.

Palliative Care Australia expects telehealth to be a core modality to promote cost-effective delivery of child and family-centred paediatric palliative care, and to support team-based service models and education. Specialist paediatric palliative care services should seek to address the barriers to telehealth as part of their planning priorities.

## 2.5 Providing a child and family-centred and effective continuum of paediatric palliative care services

Palliative Care Australia expects that children with a life-limiting condition and families will have access to an effective continuum of palliative care services.

This is based on key elements including:

- » Timely assessment and referral to the services that best meet the needs of children with a life-limiting condition and families;
- » Collaborative decision-making and informed communication on values and priorities for care through mechanisms such as advance care plans;
- » Effective provision of care by multidisciplinary teams with the required workforce competencies; and
- » Continuity and coordination of care as a child's needs change and they transition between different types of care.

Each of these elements is discussed below.

### 2.5.1 Child and family-centred care

A central component of the holistic nature of specialist paediatric palliative care is support for both the child and the child's family. The care of a child living with a life-limiting condition can prove an emotional, social, physical and financial strain on the family that provides care for their child. Aspects of a child and family-centred approach include:

- » The focus of support includes the whole family;
- » Open and honest communication by the health care team with children and families underscored by active listening to children and families to understand their needs;
- » Promoting the role of families as competent and leading partners in their child's palliative care including by:
  - Supporting parents to collaborate with specialists;
  - Enabling parents to understand options for care, setting goals and making decisions; and
  - Recognising and respecting that different cultures may have different decision-making processes.
- » Goals of care that recognise and that are appropriate to the developmental phases of childhood and adolescence; and
- » Bereavement support is anticipated, planned and available to address the layers of trauma that families may experience with the condition and death of a child.

## 2.5.2 Referral and assessment services

To facilitate early introduction of palliative care, referrals should be made to the specialist paediatric palliative care team by the primary treating team at the time of, or soon after, a child's initial diagnosis of a life-limiting condition.

As with adult palliative care, key barriers to timely referral include uncertainties around prognosis for many conditions and a belief that palliative care is only beneficial after curative treatment has been exhausted. To this end, a key concept that is relevant across child and adult palliative care is that palliative care can be integrated with ongoing efforts to cure or modify disease.

### Background evidence and analysis\*

There is evidence that timeliness of referral can be enhanced through the use of palliative care consultation criteria (referral triggers or screening criteria), with referrals encouraged for patients who meet the criteria. The use of consultation criteria in neonatal and paediatric intensive care units offers the potential to promote greater mutual accountability between the specialist paediatric palliative care team and the intensive care unit and in turn, enhance timely and appropriate access to palliative care.

*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

Early referral, good communication, and comprehensive care planning enables other health professionals to provide child and family-centred palliative care with more confidence and competence.

Palliative Care Australia expects that children with life-limiting conditions and families will receive timely referral to paediatric palliative care and comprehensive assessments of their care needs.

A comprehensive paediatric palliative care assessment should include:

- » A medical evaluation (medical and psychosocial history, physical examination);
- » Management of physical symptoms;
- » Assessment of psychological, psychiatric, and cognitive symptoms;
- » Condition understanding and care preferences (i.e. personal goals, expectations, understanding of illness trajectory and risks versus benefits of therapies);
- » Existential and spiritual concerns;

- » Social and economic resources and needs of the child living with a life-limiting condition and their families, including for care in the home;
- » Continuity of and coordination of care across settings; and
- » Bereavement planning.

Palliative care assessments are essential in ensuring that the preferences of the child living with a life-limiting condition and their family, are met. This should include a review of existing advance care plans to ensure that they are contemporaneous.

## 2.5.3 Collaborative decision-making

Decision making requires a collaborative approach that encompasses the wishes of the child, family and the clinicians involved in care. A collaborative approach requires the specialist paediatric palliative care team to recognise and be responsive to the individual preferences and needs of the child and their family. Additionally, clinicians need to:

- » Recognise the primary role of the parents in decision-making and take into account their wishes regarding the extent to which their child is involved in decision-making; and
- » Involve children as much as possible in discussions about their own care, even when they are not able to make decisions on their own. When communicating information to children about their care it is important to use words and other communication methods that are understandable to the child.

To support collaborative decision-making, information provided to families should be:

- » Specific to the child's individual circumstances;
- » Clearly explained and understandable;
- » Consistent;
- » Up-to-date; and
- » Provided verbally and in writing.

This should assist families to:

- » Understand options for care;
- » Collaborate with the multidisciplinary clinicians involved in care to set goals;
- » Discuss and regularly review with children how they want to be involved in making decisions about their care, because this varies between individuals, at different times, and depending on what decisions are being made; and
- » Explain to children that their contribution to decisions about their care is very important, but that they do not have to make decisions alone.

## 2.5.4 Advance care planning

Advance care planning is a process of discussions between families and health care providers about preferences for care, treatments and goals in the context of the child's current and anticipated future health. The objective is to determine the overall goal of medical care, and the interventions that should and should not be provided. This will guide current treatment, as well as future treatment in the event of a deterioration in the child's condition. It also helps families to prepare for the future, consider priorities and plan where they would hope to be (home, hospital or hospice) when their child reaches the end of their life.

Advance care planning is a multidisciplinary, dynamic process between a child and their family, their care providers and those close to them. In most cases these are discussions that evolve and progress over time.

Advance care planning is a process in which:

- » The clinical team shares with the family knowledge about the child's condition, prognosis and the potential efficacy and benefit versus the burden of various interventions; and
- » The child and family shares with the clinical team their values, goals and hopes, and what they believe the child might experience as a benefit or a burden.

The most important element of advance care planning is the process of reflection and information sharing. This will help families and clinicians to make the best possible decisions if an urgent medical situation arises.

### Background evidence and analysis\*

Advance care planning should begin by talking about what the family understands about the situation, what is important to them, what their hopes and goals are, and what their fears are. The Thinking Ahead framework, which provides a guide to advance care planning and is available through the Royal Children's Hospital Melbourne website, provides a four-step approach to conversations:

1. Living with a life-limiting condition: these discussions should take place soon after diagnosis of a life-limiting condition, or during a stable phase.
2. Current or future potential deterioration: this builds on Step 1 and should occur where there is deterioration or significant risk of sudden, acute deterioration.
3. The goals of care: this builds on Steps 1 and 2 and should occur where there is significant risk of sudden, acute deterioration.
4. End-of-life care: this discussion should occur if the child is clearly dying and the primary goal of care is comfort.

*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

Palliative Care Australia expects that specialist paediatric palliative care teams will support children and families in relation to advance care planning, and in consultation with children and families, enable advance care plans to be shared appropriately with other treating teams, emergency services and relevant community groups, such as schools.

## 2.5.5 A team-based approach to service provision

Teamwork has long been an integral part of the philosophy and practice of palliative care in Australia. Paediatric palliative care lends itself particularly well to this approach because of the multiple dimensions involved in caring for children living with a life-limiting condition: physical, social psychological, and spiritual, as well as meeting the needs of family.

Palliative Care Australia expects that specialist paediatric palliative care services will be provided through multidisciplinary teams.

A team approach to the provision of specialist paediatric palliative care services requires a broad mix of health professionals including specialist paediatric palliative care physicians, nurses and allied health professionals with qualifications, experience or skills in paediatric palliative care. Meeting palliative needs requires a diverse range of health and other professionals. (The workforce profiles required to deliver team-based specialist paediatric palliative care are specified in more detail in the workforce Capability Framework in Chapter 3.)

## 2.5.6 Continuity and coordination of care

Ensuring continuity and coordination of care for children and families using paediatric palliative care services is essential. Coordination of family-centred paediatric palliative care involves the transfer of information between many health providers and community services, with the actual variety of people and organisations involved varying with each individual patient.

Palliative Care Australia expects that hospitals, health services and all health professionals will implement systems to ensure continuity and coordination of care including:

- » Timely referral to a paediatric palliative care service (at or close to the time of initial diagnosis);
- » Speedy and straightforward admission to suitable inpatient care, when this is needed;
- » Speedy and straightforward transfer from hospital-based paediatric palliative care to community-based paediatric palliative care, and vice versa as required;
- » Continuity of clinical and allied care across various settings and/or continuity of records to ensure the effective transfer of care between different teams of health professionals;
- » Coordination of care with other health professionals (medical, nursing and community health services) that may be involved in providing other health care or social support requirements, separate to the services provided by the paediatric palliative care workforce; and
- » Discharge planning that ensures relevant information and advice is provided to the child living with a life-limiting condition and family, as well as the health professionals with ongoing responsibility for their care.

## 2.5.7 Transition

Transition from paediatric to adult palliative care can be complex and fraught with difficulties and occurs in tandem with the transition of multiple other treating teams. Effective transition support should:

- » Be developmentally appropriate;
- » Identify the support available to the child, which includes but is not limited to their family;
- » Identify a single practitioner – who should act as a ‘named worker’ – to coordinate their transition of care and support; and
- » Be person-centred in a way that:
  - Treats the child as an equal partner in the process and includes their views and needs;
  - Involves the child and their family, primary care practitioners and colleagues in education, as appropriate;
  - Supports the child to make decisions and builds their confidence to direct their own care and support over time; and
  - Fully involves the child in terms of the way it is planned, implemented and reviewed.

Palliative Care Australia expects that families and, most importantly, children must be actively involved in the transition process, with effective transition support approaches planned and implemented.

### Background evidence and analysis\*

To ensure that a child and their family is not overwhelmed by the number of health providers and community services involved with their care, and to promote coordination and continuity of care, it is important that a member of the specialist paediatric palliative care team takes on the role of a named worker, or care coordinator. The care coordinator needs to be someone who will have ongoing involvement with the family during the palliative care phase, or during transition from paediatric to adult services, and needs to be easily accessible to the family as a first point of contact as new problems or concerns arise.

Some of the expectations of a care coordinator include:

- » Providing a link between the child and various healthcare teams involved in their care and support;
- » Helping the child navigate services;
- » Acting as a representative for the child, to support and advocate as needed;

- » Ensuring the child has support for education and employment, community inclusion, health and wellbeing and independent living and housing options;
- » Supporting the child for a minimum of six months following transition to adult services, or as negotiated with the child; and
- » Handing over their responsibilities to a named worker or care coordinator in adult services.

An example of a named worker / care coordinator is the introduction of Nurse Navigator positions into Queensland's public health system. They aim to reduce fragmentation, mitigate barriers, educate and empower patients and assist in the coordination of care. There are two components to the nurse-led model: Nurse Navigators working as generalists in the community and Nurse Navigators who work across community and acute sectors in speciality areas, such as palliative care.

\*For additional information and referencing, please refer to the companion document *Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

## 2.6 Recognising and supporting the contribution of families to the paediatric palliative care service system

Section 2.6 outlines what services and support should be accessible to the families of people living with a life-limiting condition. The type and range of support services include:

- » Information, education and support for families;
- » After-hours access;
- » Equipment and medical supplies for home-based care;
- » Respite care; and
- » Grief and bereavement support.

### 2.6.1 Information, education and support for families

Palliative Care Australia expects that an essential component of high-quality paediatric palliative care is effective communication between children living with a life-limiting condition, family members, and health professionals, underpinned by access to educational and informational resources.

Families need information and training on practical aspects of home-based care including symptom management, medication administration and nursing care. Also critical are discussions about the child's clinical condition, their prognosis and the goals of care. Family meetings are an essential tool in paediatric palliative care to inform, deliberate, clarify, make decisions and set goals for future care. Counselling and psychological support may be required to help family members cope with anticipatory grief, loss of hope, and other concerns that may arise.

#### Background evidence and analysis\*

Siblings of children with life-limiting conditions have been found to experience poor quality of life in emotional, family, academic, and social domains, and a loss of attention and status within their family. Siblings have reported feeling 'left in the dark' or confused about their sibling's symptoms without having them explained, with some even feeling misled at the end of their sibling's life.

Suggestions to help siblings adjust to having a sibling with a life-limiting condition and cope with the changes in life this brings include:

- » Engaging siblings in care discussions throughout the treatment process;
- » Providing a role for siblings in caregiving tasks as desired;
- » Assigning a social worker to specifically work with the sibling;

\*For additional information and referencing, please refer to the companion document *Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

The intensity and longevity often associated with paediatric palliative care often contributes to major psychosocial challenges for parents including:

- » Physical and social isolation from the community, often exacerbated by withdrawal from the workforce;
- » The enormity of their caregiving role and ownership of the responsibility associated with caring duties; and
- » Taking on their child's caregiving role and the change in their life path.

Parents report clinical levels of distress, fatigue and below-average quality of life. Such impacts may also persist into bereavement, leading to an increased overall mortality rate of parents after the death of their child.

The range of challenges often experienced by families reinforces the importance of the specialist paediatric palliative care team providing an advocacy and support role for families so that they may gain access to support across the care continuum, including:

- » Access to in-home psychological counselling;
- » Access to short breaks from caring through respite;
- » Access to trained volunteers to provide support in the home;
- » Enabling time and activities for other children;
- » Access to advocacy and support around non-health care issues including transport, finance, enabling school attendance and/or visiting teacher arrangements, and other practical issues related to family life; and
- » Peer support for parents to help reduce the feelings of isolation.

#### Sibling and grandparents support

The wellbeing of siblings and grandparents may be adversely affected and give rise to short and longer-term risks to health outcomes.

- » Referring to local and national resources, such as support groups;
- » Providing education to the family about the needs of siblings;
- » Encouraging siblings to remain engaged in activities that are important to them;
- » Helping the family identify a 'safe adult' in the siblings' world who they can talk to about their feelings;
- » Making referrals to mental health professionals, such as social workers or psychologists for assessment and counselling, when needed; and
- » Asking siblings directly about their experience.

Other types of sibling support include: arranged activities; opportunities for networking with other siblings within the care environments; and respite care for the child living with a life-limiting condition, allowing siblings more time to spend with their parents.

Parents and their children benefit considerably when teachers, coaches and other adult caregivers take an interest in, and provide extra care and support to their other children.

Palliative Care Australia expects that the role of the specialist paediatric palliative care team includes promoting the wellbeing of siblings and grandparents through education, monitoring of mental and physical health, and ensuring referrals to appropriate resources on the team and in the community.

### 2.6.2 After-hours access

After-hours access to support is essential for families.

Palliative Care Australia expects that specialist paediatric palliative care services should include after-hours access to provide advice and/or direct clinical support including responding to acute situations such as unmanaged pain.

After-hours access arrangements need to support continuity of care and should avoid the situation where families seek emergency assistance from ambulances, hospital emergency departments or telephone support services (such as HealthDirect) that are not involved in the provision of ongoing care for the child living with a life-limiting condition. Specialist paediatric palliative care services should ensure that there are protocols in place with general practitioners, emergency health and other relevant services to assist in providing after-hours services that are responsive to the needs of children living with a life-limiting condition and their families.

It is recognised that arrangements for the provision of after-hours access will vary according to whether the child living with a life-limiting condition is under the care of specialist palliative care services or other health professionals (such as General Practitioners) who are providing generalist palliative care.

Palliative Care Australia expects that after-hours access should be available as follows:

- » For all children who are under the care of specialist palliative care services, there should be tiered systems of access including telephone support and home visits by nurses and/or medical practitioners, as required; and
- » For children receiving palliative care from other health professionals, the minimum requirement is to have after-hours access to telephone support organised through their treatment team.

The provision of after-hours access should be built into the resourcing of specialist paediatric palliative care services, in recognition that it is an essential element of service delivery. After-hours access through specialist paediatric palliative care services can be organised through a tiered or stepped access framework to increasingly higher levels

of support and direct care, beginning with telephone advice and progressing to nursing and/or medical support based on needs assessment. Telehealth services are one approach to providing after-hours access, in both metropolitan and rural locations. However, telehealth services must be supported by systems that ensure direct access to medical and/or nursing support, when required.

### 2.6.3 Equipment and medical supplies for home-based care

Families may access equipment to support care at home through a range of different programs that are funded in each of the health, and disability sectors, with some equipment also funded by private health insurers and non-government organisations.

Palliative Care Australia expects that all providers of paediatric palliative care will advise families about mechanisms to access necessary equipment appropriate to paediatric requirements, including equipment via prescription. Specialist paediatric palliative care clinicians should ensure children and their families have access to necessary equipment.

### 2.6.4 Respite

To sustain the energy required to meet their child's care needs, many carers, be they parents, foster-parents, guardians, grandparents or siblings, require respite or short breaks. Short breaks may be formally structured and can be an essential component of children's palliative care, providing a break from the routine of caring for both the child and family.

The medical, nursing, emotional and behavioural needs of a child are dynamic, which means the need for short breaks may vary and occur unexpectedly. Thus, respite needs to respond to these varied requirements and preferences in a culturally, socially and spiritually appropriate way for each family. The option for emergency respite is important to accommodate unanticipated changes in a child's condition or unforeseen events within a family as a whole.

#### Background evidence and analysis\*

Benefits of respite or short breaks have been acknowledged as being multi-dimensional: it allows parents to rest, spend time with a partner/spouse, be with their other children, or carry out everyday tasks. Factors that influence a parent's decision to use respite include: the child's age, diagnosis and the family's capacity to meet their child's care needs. Notwithstanding the need for respite, there are also barriers to access that mean families may not be able to benefit from respite even when this has been an expressed preference.

*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

Home respite is often the location of choice for parents, particularly if time left with their child is perceived to be limited. Furthermore, hospital admissions can be more stressful than providing care at home. However, there are potential issues regarding the impact of care provision in the home on family life, siblings and the concept of home.

For respite or short breaks to be acceptable to parents they require assurance that their child is safe and being well-cared for, which can be particularly challenging for parents when respite is provided out-of-home in locations such as a hospital, hospice or a designated respite centre. Parents may be concerned about the competency and experience of staff and want consistency in staffing and the development of trust before they are able to handover their caring responsibilities to others. To enable skilled and optimal care for children and young people with rare and complex conditions, staff are required to understand the child's care needs prior to the period of respite.

Palliative Care Australia expects that paediatric palliative care providers should, at a minimum, provide information to families about options to access respite care.

Specialist paediatric palliative care services should organise or facilitate access to respite care, as required by families. This may include home-based respite, inpatient hospital respite or hospice respite. The need for respite or short breaks, should be a trigger to reassess the ongoing viability of caring for the child at home.

### 2.6.5 Grief and bereavement support

Grief and bereavement services for families are an essential element of support when a child has a life-limiting condition. Support for those experiencing grief can be obtained from many professional and informal sources. Specialist paediatric palliative care services are one of many resources that may be involved in organising and/or providing grief and bereavement support. The specialist paediatric palliative care team should ensure that there is a bereavement care plan in place that is tailored to the individual needs of each family.

Families may experience anticipatory grief, when they find out that a loved one is dying, they often begin grieving for them, even though they are still alive. They may grieve the impending loss, not just of them physically, but also the loss of their presence in life, the loss of their dreams and their future. Accordingly, grief and bereavement support should commence from diagnosis. Grief and bereavement counsellors may also be able to help parents talk to their child and their siblings about death and prepare them with clear and honest explanations.

In response to differing levels of need, grief and bereavement services should be organised along a continuum comprising:

- » Universal services – these services should be available to support all bereaved people; and
- » Targeted services – these specialist services should be available to support people at risk of, or experiencing, complicated grief.

Some of the key risk factors of complicated grief that are present in paediatric palliative care include:

- » Close kinship to the dying child;
- » Religious and spiritual beliefs and practices (for some, religious/spiritual beliefs result in lower levels of grief and, for others, a stronger faith can lead to more severe experiences of grief);
- » Aggressive treatment interventions that were experienced by the child (for example, intensive care, ventilation, resuscitation);
- » Family conflict regarding treatment;
- » Economic hardship created by treatment;
- » Caregiver burden;
- » Low acceptance of impending death; and
- » Death in the hospital (rather than home).

Screening and assessing for psychosocial and spiritual distress and risk of complicated grief is a continuous process undertaken from the time a child enters the paediatric palliative care service to many months after the child's death (where pertinent). These assessments are a multidisciplinary undertaking because children and their families may disclose different information to different staff at different times.

All providers of paediatric palliative care services (whether generalist or specialist) need to have the capacity to assess where family members sit along a continuum of need for grief and bereavement support services and refer accordingly. Staff should be aware of the range of inpatient and community support services available and provide information on how to access them. Interagency collaboration should ensure effective and coordinated support.

Palliative Care Australia expects that specialist paediatric palliative care services should operate as part of a continuum of services to provide grief and bereavement support that is aligned with people's needs.

# 3. Planning the workforce and system capabilities to deliver paediatric palliative care services

# 3

This chapter identifies Palliative Care Australia’s expectations for the workforce and system capabilities required to deliver high-quality paediatric palliative care services.

It covers:

- » Planning of the specialist paediatric palliative care workforce (Section 3.1);
- » Specifying the workforce capabilities required to provide a continuum of paediatric palliative care services across both specialist paediatric palliative care services and paediatric palliative care provided by other health professionals (Section 3.2);
- » Identifying an approach to regional planning of paediatric palliative care services and networking arrangements to support effective referral and consultative support services (Section 3.3);
- » Promoting the acquisition of paediatric palliative care skills through professional education and training (Section 3.4);
- » Identifying the requirements to support the paediatric palliative care workforce (Section 3.5); and
- » Promoting continuous learning and quality improvement through research, evaluation and benchmarking in paediatric palliative care (Section 3.6).

## 3.1 Planning the specialist paediatric palliative care workforce

Access to paediatric palliative care is dependent on a robust approach to the planning of the specialist paediatric palliative care workforce encompassing the three main workforce components – medical practitioners, nurses, and other professionals.

Palliative Care Australia expects that the specialist paediatric palliative care workforce will have expertise and specialist training in paediatric palliative care.

It is acknowledged that this workforce is a scarce resource and that there are no benchmarks on the ‘optimal’ specialist paediatric palliative care workforce requirements that can be applied for population planning purposes.

Palliative Care Australia expects that governments and specialist paediatric palliative care services will collaborate to improve workforce data to support enhanced workforce modelling and the development of planning benchmarks.

In addition to tackling data gaps, the development of workforce planning benchmarks should be an important research priority for specialist paediatric palliative care services.

### Medical practitioners

The Royal Australasian College of Physicians (RACP) offers Advanced Training in Palliative Medicine, for adults or paediatrics, for medical practitioners who have either completed RACP Basic Training, or who have Fellowship with another designated Specialty College. The Advanced Training requires three years of full-

time equivalent training, undertaken at an accredited training site. Trainees entering the program through RACP Basic Training will be awarded Fellowship of the Royal Australasian College of Physicians (FRACP) and Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM). Trainees entering the program through Fellowship of another Specialty College will be awarded Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM).

The size of the medical specialist workforce providing specialist paediatric palliative care is not clearly quantifiable. As at June 2018, the Australian Health Practitioner Regulation Agency database identified 5 specialists in paediatrics and child health with a specialty field of paediatric palliative care medicine. However, the number of practicing specialist paediatric palliative care physicians is likely to be higher, as some of the specialists have alternative speciality fields listed in the database, such as general paediatrics or medical oncology.

A pragmatic approach to the provision of specialist paediatric palliative care services is required, one which leverages, integrates and complements existing resources. Specialist paediatric palliative care physicians can add value by providing expertise on palliative care issues in the paediatric and intensive care settings, and on paediatric issues in palliative care settings.

An aspirational workforce goal for paediatric palliative care would be an increase in the number of trained specialist paediatric palliative care physicians across Australia to achieve a critical mass in each jurisdiction. A complementary strategy would include the addition of components of paediatric palliative medicine training into other medical speciality training programs, such as those completed by neonatologists, paediatric intensive care physicians, obstetricians or general practitioners. This would ensure that physicians operating in settings in which paediatric palliative care is more commonly required would have a minimum level of proficiency in paediatric palliative care.

### **Nursing professionals**

The value of nurses in palliative care should be acknowledged in both direct care and consultative services. Ensuring an adequate supply of palliative care nurses who are competent and confident with paediatrics is particularly important in expanding access to community-based palliative care, including in people's homes.

Nurses working in advanced practice roles, including as nurse practitioners, has gained increasing recognition and has allowed the development of more nurse-led models for the provision of specialist palliative care. In addition to providing direct care, nurse practitioners (and other advanced practice nurses) have an important role in providing consultative support to other health professionals (such as general practitioners) who provide palliative care to people living with a life-limiting condition.

Palliative Care Australia expects that nurse-led models of care be expanded to include the provision of specialist paediatric palliative care.

### **Other professionals**

Palliative Care Australia expects that specialist paediatric palliative care services will have access to a wide range of professionals appropriate to paediatric palliative care, including:

- » Social work;
- » Occupational therapy;
- » Speech therapy;
- » Dietetics;
- » Physiotherapy;
- » Pharmacy;
- » Psychology;
- » Music/art therapy;
- » Accredited interpreters;
- » Grief and bereavement counsellors; and
- » Pastoral care through multifaith chaplains and spiritual advisors.

Grief and bereavement counsellors are considered to be a core part of a paediatric palliative care team and to provide an essential component of paediatric palliative care.

### 3.2 A capability framework for the paediatric palliative care workforce

The Palliative Care Service Development Guidelines (2018) incorporate a national palliative care workforce capability framework, consisting of three levels, which outlines the expected scope of services, and workforce profile to deliver those services.

Whilst there are many principles of palliative care that are common across child and adult age groups, there are important differences that must be recognised:

- » Variations in diagnoses;
- » Developmental, psychological and social needs of children;
- » The unique place of children as dependent members of families;
- » Particular ethical issues where minors are concerned;
- » Physiological factors relating specifically to children and their illnesses; and
- » Bereavement issues for families.

Accordingly, specific workforce requirements apply to the provision of paediatric palliative care, whichever level of service is involved:

- » All health professionals involved in paediatric palliative care are educated about the psychosocial impact of a life-limiting condition for the child and family, and in the management of issues associated with dying, death and bereavement; and
- » In the provision of paediatric palliative care, the treating team comprises a range of clinicians with experience in paediatrics and who either have, or are working towards, a paediatric palliative care qualification.

Palliative Care Australia expects that specialist paediatric palliative care services align with the national palliative care workforce capability framework (2018).

### 3.3 Regional planning and networking of paediatric palliative care services

Access to specialist paediatric palliative care services can be limited, particularly in regional, rural or remote locations. The consultative paediatric palliative care model of care is configured to provide specialist advice and support to a child's primary treating team. In this model, the child or young person and their family are cared for by their local treating team, ensuring continuity of care, and specialist paediatric palliative care advice is provided on a consultative basis. This model allows the specialist paediatric palliative care clinician to see more patients than they would otherwise be able to accommodate, whilst also building palliative care capability in primary healthcare providers.

A variation on networked arrangements involving consultative support is the 'pop-up' model of care. Under this model, a specialist palliative care team supports a local team of health professionals using just-in-time education, with the objective of building the capability and capacity required to deliver high quality paediatric palliative care, irrespective of geographical location. The intervention may require that the specialist service travel from a city location to a rural or remote location, or alternatively, if travel is not possible, telehealth services are utilised to ensure timely support. The pop-up model allows the team to be quickly mobilised around the child and family to provide support for the child and the family, including in bereavement, whether they are at home or in hospital. Pop-up teams can help coordinate care across the hospital and community, provide advice and support for complex symptom management and psychosocial support for all members of the family.

The Quality of Care Collaborative Australia (QuoCCA) project, is an example of a pop-up education model, which works with health professionals in urban, rural, regional and remote areas who may care for children with palliative care needs. The project seeks to improve the quality of palliative care provided to children in close proximity to their home.

Palliative Care Australia expects that planning of specialist paediatric palliative care services by States and Territories will ensure that:

- » Every child with a life-limiting condition and their family will have access to at least one specialist paediatric palliative care team, recognising that networked arrangements supported by telehealth and outreach support will be necessary for less populous jurisdictions;
- » Specialist paediatric palliative care teams provide networking and palliative care consultative support to other health professionals to enable children and families to have timely and responsive access to paediatric palliative care services; and
- » The right care is provided to the right people in the right setting with the right mix of health professionals at the right time.

### 3.4 Professional education and training for all paediatric palliative care providers

The Palliative Care Service Development Guidelines promote the acquisition of palliative care skills through professional education and training, with the following skills identified as important:

- » Communication skills, especially when conveying potentially distressing information regarding prognosis and care options for people close to death;
- » Effective management of symptoms;
- » Critical appraisal skills, including the ability to assess a person's palliative care requirements, whether medical, functional, psychological, financial, emotional or spiritual;
- » Skills in providing advice and assisting with advance care planning;
- » Ethical decision making; and
- » Skills related to care provided when people are close to death that aims to preserve the dignity of the person and their family.

The above skills are relevant to paediatric palliative care. In addition, specific attention is required to the following elements of *paediatric* palliative care:

- » Child and family-centred palliative care;
- » Developmental, psychological and social needs of children;
- » The role of the health care team in the perinatal and neonatal context;
- » Team collaboration and care planning; and
- » Transition to young adult services.

Palliative Care Australia expects that governments, the academic sector and professional associations will ensure that suitable courses and programs are available, accessible and delivered by a suitably trained workforce, such as educators, to develop specialist paediatric palliative care skills across the disciplines of medicine, nursing and allied health.

Palliative Care Australia expects that funders and providers will strengthen existing efforts to ensure that an increasing share of the health workforce receives education and training to improve their skills to provide paediatric palliative care.

This should be measured by increased provision of paediatric palliative care services by other health professionals. It will be important for paediatric/neonatologist training to incorporate palliative care training, ideally with a placement in a specialist paediatric palliative care unit.

### 3.5 Workforce support in paediatric palliative care

Another important system capability is workforce support to assist health professionals in managing the challenges of working in paediatric palliative care. Paediatric palliative care is a complex and demanding area of work for health professionals. Some of the demands and stressors specific to paediatric palliative care include:

- » Difficult conversations about diagnosis and/or prognosis with a child living with a life-limiting condition and their family;
- » The sadness and distress that follows the death of a child. Staff caring for children living with a life-limiting condition often develop therapeutic relationships with the child and family over a long period;
- » Recognising and knowing the right thing to do, then not being able to carry it out, may cause a distress called moral distress;
- » Multidisciplinary decision-making; reaching a consensus on the best management for children living with a life-limiting condition and their families, with other healthcare teams;
- » Absorption of the emotions expressed by children living with a life-limiting condition and their families;
- » The burden of supporting entire families, not only the child with a life-limiting condition; and
- » Challenges to one's personal belief system about the medical network, teamwork, death, and dying.

There is an urgent need for more rigorous research to identify how best to support all health professionals providing paediatric palliative care.

### Background evidence and analysis\*

Staff distress can lead to emotional distress, unsafe or poor quality of patient care, job dissatisfaction or burnout. Burnout can be described as the accumulated experience of working in an environment that has an impact upon emotional wellbeing, the personalisation of work and any sense of accomplishment in the work environment.

It is imperative that strategies be developed and incorporated into the standard support for staff caring for children with life-limiting conditions. Potential strategies which may be useful in managing the common emotional, cognitive and behavioural responses to stressful situations can be organised into personal and workplace strategies.

Personal strategies include the development of self-care into daily life, such as ensuring adequate sleep, diet and exercise, and finding a balance between work and non-work activities.

Workplace strategies include peer support, operational debriefings and psychological debriefings. For organisations creating a culture of strong ethical standards, structures that support staff to make ethical decisions in the best interests of the child and family are crucial. A transparent and accessible Clinical Ethics Committee is one example of a structure that supports a moral culture.

*\*For additional information and referencing, please refer to the companion document Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines*

Palliative Care Australia expects that the provision of workforce support should be factored into the capability and resourcing of specialist paediatric palliative care services.

This includes specialist paediatric palliative care providers giving support to other health professionals who may provide paediatric palliative care only intermittently and without the benefits of a supportive multidisciplinary team environment.

## 3.6 Research, evaluation and benchmarking in paediatric palliative care

Australia is relatively well-served in relation to palliative care research, evaluation and benchmarking capabilities, although unsurprisingly, given the lower prevalence of paediatric patients compared to adults, there is less research available on paediatric palliative care.

CareSearch (the Australian palliative care knowledge network) includes paediatric palliative care as part of its collection of systematic reviews on evidence related to palliative care. CareSearch also maintains a register of Australian research projects and studies in palliative care to increase awareness of current research activities. It also provides access to a research data management system tool that supports data collection and reporting.

Palliative Care Australia's National Palliative Care Standards articulate a vision for the provision of holistic, individualised, sensitive and best practice palliative care for the person receiving care, their family and carers. Palliative Care Australia's Palliative Care Self-Assessment (PaCSA) portal will provide all specialist palliative care services across Australia, support for quality improvement from 2019.

The Palliative Care Outcomes Collaboration (PCOC) is a national program that uses standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in the PCOC is voluntary and open to all palliative care service providers across Australia. Currently, a paediatric-specific, validated outcome measure is not available through the program.

A number of quality indicators and associated measures for palliative care and care at the end-of-life for children exist, although further work is required to validate the indicators. These include outcome, process and structure indicators, such as:

Outcome indicators:

- » Health Related Quality of Life (Child, Parents, Siblings);
- » Distressing symptoms during treatment;
- » Management of symptoms at end-of-life; and
- » Location of death.

Process indicators:

- » Timing of palliative care service introduction;
- » Information resources provided to the family;
- » Health professionals aware of the child/family goals of care;
- » Care plan created;
- » Sibling support offered;
- » Equipment needs assessed; and
- » Preferences for location of care at the end-of-life discussed with family.

Structure indicators:

- » Access to care in the right location, at the right time;
- » Availability of a multi-disciplinary team;
- » Care coordinator or named worker identified;
- » Psychosocial support available for the family;
- » Psychosocial support available for the child; and
- » Availability of palliative care services in the community.

Palliative Care Australia notes the paucity of research, evaluation and benchmarking of paediatric palliative care services.

Palliative Care Australia expects the resource commitment for this sector to be strengthened to drive continuous learning and quality improvement in the organisation and delivery of paediatric palliative care services.





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