



PREPARED FOR  
PALLIATIVE CARE AUSTRALIA

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# Background Report to the Paediatric Addendum to the Palliative Care Service Development Guidelines

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December 2018



## **Acknowledgements**

This Background Report (Report) has been produced independently by Aspex Consulting on the request of Palliative Care Australia. The information, statements, statistics and commentary (together the 'Information') contained in this Report have been prepared by Aspex Consulting from available material and from discussions held with stakeholders. The Report is attached to the Paediatric Addendum to Palliative Care Australia's Palliative Care Service Development Guidelines (2018) to provide background information. This Report has been developed based on Information received or obtained, on the basis that such Information is accurate and complete. The views expressed in this Report are not necessarily the views of Palliative Care Australia.

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## List of Abbreviations

AAP	American Academy of Paediatrics
ACGB	Australian Centre for Grief and Bereavement
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
CAT	Computerised Adaptive Tests
CDC	Centre for Disease Control
CPC	Centre for Palliative Care
CPCRE	Centre for Palliative Care Research and Education
ELNEC-PPC	End-of-Life Nursing Education Consortium Paediatric Palliative Care
EPEC	Education in Palliative and End-of-Life Care
FRACP	Fellowship of the Royal Australasian College of Physicians
FACHPM	Fellowship of the Australasian Chapter of Palliative Medicine
GP	General Practitioner
HRQOL	Health-related Quality of Life
IOM	Institute of Medicine
IPPC	Initiative for Paediatric Palliative Care
KKIND	Keeping Kids in No Distress
NICU	Neonatal Intensive Care Unit
NICE	National Institute for Health and Care Excellence
NSAP	National Standards Assessment Program
NSW	New South Wales
PaCSA	Palliative Care Self-Assessment
PCA	Palliative Care Australia
PCC4U	Palliative Care Curriculum for Undergraduates
PedsQL	Paediatric Quality of Life Inventory Generic Core Scale
PICU	Paediatric Intensive Care Unit
QuoCCA	Quality of Care Collaborative Australia
RACP	Royal Australasian College of Physicians
RCPCH	Royal College of Paediatrics and Child Health
SPPC	Specialist Paediatric Palliative Care
VPPCP	Victorian Paediatric Palliative Care Program
WHO	World Health Organisation
ZPD	Zone of Parental Discretion

# Introduction

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This Background Report is a supporting document to the *Paediatric Addendum to Palliative Care Australia's Service Development Guidelines* (December 2018). It provides evidence and analysis obtained from an appraisal of peer-reviewed and grey literature and discussions with stakeholders to underpin the expectations of Palliative Care Australia (PCA) for the paediatric palliative care service system.

This Background Report is organised as follows:

Chapter 1 provides background context to paediatric palliative care, including definitions of key terms, such as:

- ▶ Life-limiting illness/condition;
- ▶ Paediatric palliative care;
- ▶ Specialist paediatric palliative care;
- ▶ Perinatal palliative care;
- ▶ End-of-life care; and
- ▶ Family, carers, parents/guardians.

A brief overview of the history of the speciality in Australia is also provided.

Chapter 2 relates to the development of the paediatric palliative care service system, with a focus on:

- ▶ Planning for people who require paediatric palliative care;
- ▶ Early introduction of paediatric palliative care services;
- ▶ Providers of paediatric palliative care;
- ▶ Settings for paediatric palliative care;
- ▶ Providing a child and family-centred and effective continuum of paediatric palliative care services; and
- ▶ Recognising and supporting the contribution of families and carers to the paediatric palliative care system.

Chapter 3 provides information for planning the specialist paediatric palliative care workforce, including:

- ▶ Planning the specialist paediatric palliative care workforce;
- ▶ A capability framework for the paediatric palliative care workforce;
- ▶ Regional planning and networking of paediatric palliative care services;
- ▶ Professional education and training for all paediatric palliative care providers;
- ▶ Workforce support in paediatric palliative care; and
- ▶ Research, evaluation and benchmarking in paediatric palliative care.

# 1. Context – definitions and history

## Life-limiting illness or 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 paediatric resources, the term life-limiting illness also incorporates life-limiting conditions (for example: Cystic Fibrosis; Down syndrome).

## Paediatric palliative care

Palliative care for children represents a special, albeit closely related field to adult palliative care.<sup>1</sup> Paediatric palliative care is provided to children with life-limiting conditions who have an extremely wide range of diagnoses, often with overlapping disabilities and complex needs.<sup>2</sup>

The World Health Organisation's (WHO's) definition of palliative care for children, and their families, is as follows:<sup>3</sup>

- 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 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 even in children's homes.

*Together for Short Lives*, an umbrella charity for services and professionals working across paediatric palliative care in the UK, provides an alternative definition of paediatric palliative care:<sup>4</sup>

Palliative care for children and young people 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/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

## Specialist paediatric palliative care

Specialist paediatric palliative care (SPPC) covers services provided by medical practitioners, clinicians and others who have advanced training 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

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1. World Health Organisation, WHO Definition of Palliative Care for Children, 2018, available: <http://www.who.int/cancer/palliative/definition/en/>  
2. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, Arch Dis Child Educ Pract Ed. 2013 Dec;98(6):202-8.  
3. World Health Organisation, WHO Definition of Palliative Care for Children, 2018, available: <http://www.who.int/cancer/palliative/definition/en/>  
4. Together for Short Lives, Information – Children's palliative care definitions, available: [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

palliative care.<sup>5,6,7</sup> In Australia, advanced training in paediatric palliative care is relatively recent and for this reason, many clinicians working in SPPC care teams will have significant experience in, but not necessarily have advanced training in, paediatric palliative care. Over time, the number of practicing clinicians with advanced training is expected to increase.

## Perinatal palliative care

Within paediatric palliative care, neonates have distinct characteristics and unique needs. Firstly, a significant proportion of paediatric deaths, greater than 50%, occur in neonates and babies.<sup>8,9</sup> Causes of death in neonates often differ to that of older children, and are due largely to preterm birth and congenital disorders and syndromes. Palliative care may last from a few hours or days for neonates, to many years for children with complex chronic conditions. For neonates, palliative care often has the character of end-of-life care followed by bereavement care for the family, but for older children, palliative care can be quite clearly differentiated from end-of-life care.<sup>10</sup> Palliative care for neonates may also be initiated early and integrated into the antenatal care that the mother receives, leading to the broader term of perinatal, rather than neonatal palliative care.<sup>11</sup> Perinatal palliative care may be delivered by the obstetric management team, particularly for early pregnancy loss,<sup>12</sup> or provided concurrently with the obstetric management by the specialist paediatric palliative care team.

The perinatal period is considered by the Australian Institute of Health and Welfare (AIHW) to commence at 20 completed weeks of gestation (140 days) and end 28 completed days after birth,<sup>13</sup> which is different to the definition of the perinatal period provided by the WHO, which commences at 22 weeks of completed gestation (154 days) and ends seven completed days after birth.<sup>14</sup>

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.<sup>15</sup>

## End-of-life care

There is no clear-cut definition of the 'end-of-life'. In general, it refers to the last few days of life when a person is irreversibly dying, also known as the terminal phase. Whilst there are situations in which it is possible to identify the terminal phase with some accuracy, many diseases have an unpredictable disease trajectory and exacerbations which makes the transition to the terminal phase difficult to identify.<sup>16</sup> When it is possible to identify, the directions and goals of care change to focus on end-of-life.

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5. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care. Sydney: ACSQHC, 2016.
  6. Hain R, Heckford E, McCulloch R. Paediatric palliative medicine in the UK: past, present, future. *Arch Dis Child* 2012;97:381-4.
  7. NHPCO's paediatric standards: a key step in advancing care for America's children [press release]. National Hospice and Palliative Care Organization, 2009.
  8. Kiman, R., Doumic, L., Perinatal palliative care: a developing specialty, *Int. J Palliat Nurs.*, 2014 Mar;20(3):143-8.
  9. Bergstraesser E, Paediatric palliative care-when quality of life becomes the main focus of treatment, *Eur J Pediatr.* 2013 Feb;172(2):139-50.
  10. Bergstraesser E, Paediatric palliative care-when quality of life becomes the main focus of treatment, *Eur J Pediatr.* 2013 Feb;172(2):139-50.
  11. Balaguer A, Martín-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature, *BMC Pediatr.* 2012 Mar 12;12:25
  12. Queensland Government Department of Health, Queensland Clinical Guidelines – Translating evidence into best clinical practice, Maternity and Neonatal Clinical Guideline, Early Pregnancy Loss, 2018, available: [https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0033/139947/g-epl.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0033/139947/g-epl.pdf)
  13. Australian Government, Australian Institute of Health and Welfare, Perinatal Period, 2005, available: [www.aihw.gov.au/content/index.phtml/itemId/327314](http://www.aihw.gov.au/content/index.phtml/itemId/327314)
  14. World Health Organisation, Maternal and perinatal health, 2018, available: [http://www.who.int/maternal\\_child\\_adolescent/topics/maternal/maternal\\_perinatal/en/](http://www.who.int/maternal_child_adolescent/topics/maternal/maternal_perinatal/en/)
  15. Department of Health, Western Australia. Perinatal Palliative Care Model of Care. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.
  16. Caresearch – Palliative Care Knowledge Network, End-of-life Care, 2017, available: <https://www.caresearch.com.au/caresearch/ClinicalPractice/Physical/EndofLifeCare/tabid/738/Default.aspx>

*Together for Short Lives* describes end-of-life care as:

Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support, and support for the family into bereavement.<sup>17</sup>

## Family, carers, parents/guardians

The term 'family' includes people identified by the child as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets).<sup>18</sup> 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.<sup>19</sup> Parents/guardians are the person or persons identified by law as having parental responsibility for the child.<sup>20</sup>

## The history of paediatric palliative care

From an historical perspective, it is thought that paediatric palliative care evolved out of children's differing illness profiles and developmental needs, recognition of the importance of providing family-centred care,<sup>21</sup> and to meet gaps in the care of seriously ill and dying children.<sup>22</sup> From its outset, paediatric palliative care has shared the same philosophy of care as the adult specialty, while at the same time developing its own distinctive model.<sup>23</sup>

In 2000, the American Academy of Paediatrics (AAP) called for the development of clinical policies and minimum standards to promote the welfare of infants and children living with life-limiting or terminal conditions and their families, with the goal of providing equitable and effective support for curative, life-prolonging palliative care.<sup>24</sup> Paediatric palliative care was only formally recognised as a subspecialty in the United Kingdom in 2009. Within Australia, the first services commenced operating in New South Wales and South Australia in the 1990's.<sup>25</sup> In 2005, the Australian and New Zealand National Paediatric Palliative Care Reference Group was formed. In 2014, the Royal Australasian College of Physicians (RACP) ratified a formal training pathway for paediatricians specialising in palliative medicine.<sup>26</sup>

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17. Together for Short Lives, Information – Children's palliative care definitions, available: [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

18. Palliative Care Australia, 2018, Background Paper to the Palliative Care Service Development Guidelines, available: <http://palliativecare.org.au/quality>

19. Palliative Care Australia, 2018, Background Paper to the Palliative Care Service Development Guidelines, available: <http://palliativecare.org.au/quality>

20. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care. Sydney: ACSQHC, 2016.

21. Virdun C, Brown N, Phillips J, Luckett 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.

22. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

23. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

24. Committee on Bioethics. "Palliative care for children." *Paediatrics* 106.2 (2000): 351-357.

25. Knapp C, Madden V, Fowler S (Eds), 2012, *Paediatric Palliative Care: Global Perspectives*, Springer

26. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

## 2. Developing the paediatric palliative care service system

### 2.1. PLANNING FOR PEOPLE WHO REQUIRE PAEDIATRIC PALLIATIVE CARE SERVICES

#### Paediatric age ranges

The RACP defines 'paediatrics and child' as neonates (birth to four weeks) to children 17 years of age. However, it acknowledges an overlap with adolescent and young adults, who are regarded as 10 to 24 years of age.<sup>27</sup> This incorporates both the WHO definition of adolescents aged 10 to 19 years, and the Centre for Disease Control (CDC) definition of young adults aged 20 to 24 years.<sup>28</sup> In Australia, there are no universally accepted paediatric definitions within the health context. 'Child' is defined as a baby or infant, or as a young person determined by statute to be less than 17, or under 18 or 21 years in Australian law.<sup>29</sup>

Some of the broad definitions of (overlapping) paediatric age ranges include:<sup>30,31,32,33,34,35</sup>

- Neonate – 20 to 22 weeks of completed gestation to 7, 27- or 28-days following birth;
- Infant – 28 days to 364 days;
- Child – 28 days to 17 years;
- Adolescent – 10 years to 19 years; and
- Young adult – 20 years to 24 years.

There is a risk that confusion about eligibility requirements caused by ambiguous paediatric age ranges could restrict access and delivery of child health services, including palliative care. However, regardless of the presence or absence of age group definitions, health care access and eligibility may differ in children and young people based on biological, developmental, or psychosocial differences, and even by geographical location, rather than age alone.<sup>36</sup> Therefore, there may be a need for health services to broadly define paediatrics by age, but allow clinicians to exercise some discretion when assessing a child's eligibility for a paediatric palliative care service, particularly for those in the adolescent to young adult group.

Paediatric palliative care services are usually focused on supporting children and young people with life-limiting conditions who are considered not likely to survive to adulthood,<sup>37</sup> but this is not always the case. Patients typically transition to adult health care providers during the late teen years or early 20s, however, for paediatric patients with serious illness and life-limiting conditions, this

27. Royal Australasian College of Physicians, available: <https://www.racp.edu.au/about/racps-structure/paediatrics-child-health-division>

28. Linebarger JS, Ajayi TA, Jones BL., Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of paediatric palliative care, *Pediatr Clin North Am.* 2014 Aug;61(4):785-96

29. Clark, R., Locke, M., Bialocerkowski, A., Paediatric terminology in the Australian health and health education context: a systematic review, *Developmental Medicine and Child Neurology*, 2015;57:1011-1018

30. Australian Government, Australian Institute of Health and Welfare, Perinatal Period, 2005, available: [www.aihw.gov.au/content/index.phtml/itemId/327314](http://www.aihw.gov.au/content/index.phtml/itemId/327314)

31. World Health Organisation, Maternal and perinatal health, 2018, available: [http://www.who.int/maternal\\_child\\_adolescent/topics/maternal/maternal\\_perinatal/en/](http://www.who.int/maternal_child_adolescent/topics/maternal/maternal_perinatal/en/)

32. Australian Bureau of Statistics, Catalogue 4398.0 Causes of Infant and Child Deaths, Australia 1982 to 1996, 1998, available:

<http://www.abs.gov.au/ausstats/abs@.nsf/0/0A9D2467C7CA2AF8CA2568A900139375?OpenDocument>

33. World Health Organisation, Adolescent health, 2018, available: [http://www.who.int/topics/adolescent\\_health/en/](http://www.who.int/topics/adolescent_health/en/)

34. Royal Australasian College of Physicians, available: <https://www.racp.edu.au/about/racps-structure/paediatrics-child-health-division>

35. Linebarger JS, Ajayi TA, Jones BL., Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of paediatric palliative care, *Pediatr Clin North Am.* 2014 Aug;61(4):785-96

36. Clark, R., Locke, M., Bialocerkowski, A., Paediatric terminology in the Australian health and health education context: a systematic review, *Developmental Medicine and Child Neurology*, 2015;57:1011-1018

37. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed.* 2013 Dec;98(6):202-8

transition may be delayed or avoided entirely because of concerns regarding continuity of care, or the need for specialised knowledge about diseases that are predominantly treated by paediatricians in children's hospitals. Some services are adopting a lifetime approach to care, such as those specialising in metabolic diseases and cystic fibrosis. This reinforces the need for flexibility with age when determining paediatric palliative care service eligibility.

For the purposes of this document, 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.

## The differences between paediatric and adult palliative care

Unlike adult practice, paediatric palliative care is generally delivered over a longer time frame – on average, about 40% longer than for adults<sup>38</sup> – and for a wider range of conditions. Oncology comprises less than half of the workload for most specialist paediatric palliative care services, with neurological conditions, metabolic, genetic, cardiac and respiratory diseases, and severe acquired brain injury making up a significant proportion.<sup>39</sup>

Some of the key differences relating to paediatric palliative care include:<sup>40, 41</sup>

- 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, throughout even the most serious of illnesses;
- 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 sick child;

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38. Connor SR, Downing J, Marston J., Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis, *J Pain Symptom Manage*. 2017 Feb;53(2):171-177.

39. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed*. 2013 Dec;98(6):202-8.

40. Hill K, Coyne I., Palliative care nursing for children in the UK and Ireland, *Br J Nurs*, 2012 Mar 8-21;21(5):276-81.

41. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

- 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.

## Primary diagnosis

Life-limiting conditions in children have been categorised into four broad groups, as outlined in the table below. Categorisation of a life-limiting condition is not always easy. Some children can be classified by more than one group, particularly if they have a primary and a secondary diagnosis. Diagnosis is only part of the process – the spectrum and severity of the disease, subsequent complications, and the needs of, and impact on the child and family need to be considered.<sup>42</sup>

Group	Definition	Example
1	Life-limiting 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.	HIV, complex cardiac disease and Duchenne muscular dystrophy (DMD). Ongoing research and medical improvements have meant that some patients with Cystic Fibrosis are surviving into their 40’s and beyond. A similar trend is being seen with DMD.
3	Life-limiting, progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.	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.	Severe cerebral palsy or multiple disabilities (such as following brain or spinal cord injury).

42. Children’s Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

## Typical illness trajectories

As described in PCA's Palliative Care Service Development Guidelines,<sup>43</sup> the typical illness trajectories relevant to palliative care (descriptions provided below) may be applicable to children and adults alike.

Among people dying an expected death, three trajectories of illness are commonly described:

- *Short period of evident decline:* For people in this group, long maintenance of good function may be followed by a few weeks or months of rapid decline prior to death. Most reduction in function occurs in the person's last few months of life. Examples may include people with cancer.
- *Long-term limitations with intermittent serious episodes:* For people in this group, there is a gradual decline in function, interrupted by episodes of acute deterioration. There is a risk of dying during each of these acute episodes, but the person may survive many such acute episodes. The timing of death usually remains uncertain. Examples may include people living with chronic heart, lung or kidney failure.
- *Prolonged dwindling:* For people in this group, there is long-term, progressive disability and reduction in function. Death may follow other events such as infections, falls and fractures. Examples may include people living with neurodegenerative diseases.

These illness trajectories have historically distinguished between cancer and other chronic diseases. However, treatment gains for certain types of cancer have changed the 'typical' illness trajectory - some people live with cancer as a chronic disease, rather than experience a rapid decline.

Life-limiting conditions in paediatrics may follow an illness trajectory that can plausibly fit more than one primary diagnosis category.<sup>44</sup> The prognosis and trajectory of children's illnesses can often be difficult to predict.<sup>45</sup> Owing to the uncertain disease trajectory, children and their families often move back and forth between boundaries of critical illness and management of chronic illness before reaching the final stage, when death is deemed to be imminent.<sup>46</sup>

## Disparities in access

Access to specialist paediatric palliative care services can be limited, particularly in regional or rural locations.<sup>47,48</sup> Other barriers to programs include lack of services, difficulty identifying clinical deterioration and care during the end-of-life, discomfort in withholding or withdrawing treatments, communication problems, conflicts in care among providers and between parents and providers, and differences in cultural beliefs about care at the end of life.<sup>49</sup>

Within Australia, there is a wide spectrum of religious, spiritual and cultural beliefs about death and dying and health professionals are required to develop an understanding of a family's special or unique needs to ensure that genuine family-centred care is provided. There may be cultural barriers to providing the best care to a child and their family. This can be related to communication styles, language, a lack of specific support/resources or other concerns or fears that the family may have.<sup>50</sup> Effective communication is the key to gaining a better understanding of religious and cultural needs.

43. Palliative Care Australia, 2018, Background Paper to the Palliative Care Service Development Guidelines, available: <http://palliativecare.org.au/quality>

44. Wood F(1), Simpson S, Barnes E, Hain R., Disease trajectories and ACT/RCPC categories in paediatric palliative care., *Palliat Med.* 2010 Dec;24(8):796-806

45. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed.* 2013 Dec;98(6):202-8.

46. Hill K, Coyne I., Palliative care nursing for children in the UK and Ireland, *Br J Nurs.* 2012 Mar 8-21;21(5):276-81

47. Herbert A, Bradford N, Donovan L, Pedersen LA, Irving H., Development of a state-wide paediatric palliative care service in Australia: referral and outcomes over two years, *J Palliat Med.* 2014 Mar;17(3):288-95

48. Bradford NK, Armfield NR, Young J, Smith AC, Paediatric palliative care by video consultation at home: a cost minimization analysis, *BMC Health Serv Res.* 2014 Jul 28;14:328

49. Youngblut JM, Brooten D., Perinatal and paediatric issues in palliative and end-of-life care from the 2011 Summit on the Science of Compassion, *Nurs Outlook.* 2012 Nov-Dec;60(6):343-50

50. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

This communication can be either directly with the family or with representatives from the same cultural or religious group. Furthermore, being able to use a professional interpreter service has benefits such as translation of complex medical information and protection of privacy.<sup>51</sup>

## Potential demand

Estimating the need for paediatric palliative care is challenging. Many factors will influence the degree of expressed need for palliative care including:<sup>52</sup>

- Some illness trajectories will result in need for palliative care that may extend over several years. Children and adolescents are likely to have longer and more variable illness trajectories than those of adults, generating particular needs for palliative care.
- The extent of need for palliative care can vary by diagnosis. For example, the Worldwide Palliative Care Alliance and the WHO use estimates for the prevalence of symptoms including physical pain as an indicator of need for palliative care, citing high rates of pain prevalence for people dying with cancer and HIV/AIDs, but lower pain rates for people dying with renal failure. However, these indicators do not capture the need for palliative care arising from other symptoms including psychological distress.
- The complexity of needs (including physical symptoms, psychological distress, family and social support, information and practical needs) may also vary for people with the same diagnosis, so that diagnosis alone is not necessarily a good predictor of palliative care needs.

Accordingly, conceptually the population of people who are dying expected deaths fall within three broad groups based on the complexity of their needs for palliative care, comprising:

- *People with straightforward and predictable needs:* this group comprises people whose needs are generally able to be managed through their own resources (including with the support of family, friends and carers) and/or with the provision of palliative care by their existing health care providers (including General Practitioners, community nurses, geriatricians, oncologists and other health professionals). People in this group do not usually require care delivered by specialist palliative care providers.
- *People with intermediate and fluctuating needs:* this group includes people who experience intermittent onset of worsening symptoms (such as unmanaged pain, psychological distress and reduced functional independence) that might result in unplanned and emergency use of hospital and other health services. People in this group may require access to specialist palliative care services for consultation and advice. They will also continue to receive care from their existing health care providers.
- *People with complex and persistent needs:* this group comprises people with complex physical, psychological, social and/or spiritual needs that are not able to be effectively managed through established protocols of care. While people in this group will require more ongoing direct care by specialist palliative care providers, this should occur through partnerships and shared care models with existing health care providers.

## Population based planning

Based on work completed by Connor et al. using a population-based approach to planning, an estimate of the need for paediatric palliative care in Australia is thought to be 21 children per 10,000

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51. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

52. Palliative Care Australia, 2018, Background Paper to the Palliative Care Service Development Guidelines, available: <http://palliativecare.org.au/quality>

population, aged from 0-19 years of age.<sup>53</sup> This rate is based on the prevalence of 12 specific diagnoses identified by the WHO that are known to require palliative care.<sup>54</sup>

Connor et al. hypothesise that not all infants, children and adolescents with one of these diagnoses will require specialist paediatric palliative care. They argue that for many, the integration of palliative care with primary healthcare providers should be adequate to meet needs, but that children with more complex and persistent needs, estimated to be 37.5%, may require more specialised paediatric palliative care.<sup>55</sup> Based on Australia's population of 0-19 year-old children as at December 2017, the rates estimated by Connor et al. translate to a total of 6,595 children requiring palliative care, of whom 2,473 may require specialist paediatric palliative care.<sup>56</sup>

Based on work completed by Fraser in the UK, Bradford et al. reported a higher estimate of the prevalence of children aged 0-18 years living in Australia with a life-limiting condition, of 32 per 10,000 population.<sup>57</sup> Based on Australia's population of children aged 0-18 years as at December 2017, this equates to an estimated 9,535 children who may require palliative care.<sup>58</sup>

The prevalence of children with life-limiting conditions reported by Connor et al. and Bradford et al. appears conservative compared with an estimate provided by Children's Health Queensland, of approximately 14,000 Australian children aged less than 15 years old currently living with a life-limiting condition.<sup>59</sup> The variance in these estimates highlights the difficulty associated with population-based planning for paediatric palliative care.

The difficulty associated with using a population-based approach to planning was demonstrated in work recently undertaken in Scotland to identify the number of children and young people living with life-limiting conditions, and to describe their age, condition/diagnoses, geographic location and ethnicity.<sup>60</sup> This involved an extremely complex process of linking national administrative and health services datasets and analysing population level data. In total, 12 different data sources were used to develop their findings.

The estimated hospital-based prevalence of children and young people (ages 0-25 years) living with a life-limiting condition in Scotland in 2013-14 was 41.4 per 10,000 population. This was a marked increase from the hospital-based estimate of 27.3 per 10,000 population in 2003-04. The complete prevalence estimate, which includes children and young people with a life-limiting condition who were alive and residing in Scotland in 2013-14 but had not received inpatient care, was 95.7 per 10,000 population.<sup>61</sup> These results allowed for the development of very clear directions for future planning for paediatric palliative care in Scotland.

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53. Connor SR, Downing J, Marston J., Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis, *J Pain Symptom Manage.* 2017 Feb;53(2):171-177.

54. Connor SR, Downing J, Marston J., Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis, *J Pain Symptom Manage.* 2017 Feb;53(2):171-177

55. Connor SR, Downing J, Marston J., Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis, *J Pain Symptom Manage.* 2017 Feb;53(2):171-177

56. Australian Bureau of Statistics, 3101.0 Australian Demographic Statistics, Dec 2017, available: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3101.0Dec%202017?OpenDocument>

57. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med.* 2014 Nov;17(11):1206-13.

58. Australian Bureau of Statistics, 3101.0 Australian Demographic Statistics, Dec 2017, available: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3101.0Dec%202017?OpenDocument>

59. Queensland Government Children's Health Queensland Hospital and Health Service, Enhancing paediatric palliative care across Australia, 2018, available: <https://www.childrens.health.qld.gov.au/latest-news-enhancing-paediatric-care-across-australia/>

60. University of York Department of Health Sciences Social Policy Research Unit, Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study), 2015, available: [www.chas.org.uk](http://www.chas.org.uk)

61. University of York Department of Health Sciences Social Policy Research Unit, Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study), 2015, available: [www.chas.org.uk](http://www.chas.org.uk)

## Premature mortality

Due to the difficulties associated with population-based planning using the prevalence of life-limiting conditions, mortality statistics are often utilised to make inferences about how many children might require palliative care.<sup>62</sup>

In Australia in 2012, most deaths of children aged 0-14 years occurred in infants, in the first year of life (71%). Three-quarters (75%) of infant deaths in 2010–2012 were due to certain conditions originating in the perinatal period and congenital conditions. These include, for example, conditions related to short gestation and low birth weight, birth trauma and viral diseases acquired in utero. There were 1,031 infant deaths in Australia in 2012. The rate of infant deaths in 2012 was 338 deaths per 100,000 population aged less than 1 year of age (or about 1 death for every 296 infants).<sup>63</sup>

There were 472 deaths among children aged 1–14 in Australia in 2012. This age group experienced the lowest mortality rate of any age group in 2012 (12 deaths per 100,000 population aged 1-14; or 1 death for every 8,475 children aged 1–14). Perinatal and other congenital conditions accounted for 9% of the deaths, brain cancer 6% and cerebral palsy and related complications caused 4.6%.<sup>64</sup>

In 2012, there were 1,203 deaths among young people aged 15–24, or 39 per 100,000 population. Life-limiting conditions were not among the top five causes of death in this age group.<sup>65</sup>

## 2.2. EARLY INTRODUCTION OF PAEDIATRIC PALLIATIVE CARE SERVICES

Paediatric palliative care is not reserved for children when they are dying, rather it begins when a condition is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.<sup>66</sup> Palliative care is not in conflict for those receiving curative therapy. Consultations undertaken early in a child's illness trajectory allow the care team to travel on the journey of illness with the child and their family, establishing a long-term relationship built on trust and rapport.<sup>67</sup> This ultimately improves shared decision making,<sup>68</sup> enhances the quality of care provided,<sup>69</sup> maximises effective symptom management, initiates support for families and improves quality of life. An American study of palliative care consultation for children with advanced heart disease found that the initial consultation most commonly incorporated a discussion on the goals of care and provision of psychosocial support.<sup>70</sup>

In their 2014 report 'Dying in America', the Institute of Medicine (IOM) highlighted that, despite the publication of professional guidelines encouraging healthcare providers to incorporate paediatric palliative care as best practice in the management of children with life-limiting conditions, timely referrals were not at optimal levels.<sup>71</sup>

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62. Knapp C, Madden V, Fowler S (Eds), 2012, *Paediatric Palliative Care: Global Perspectives*, Springer Dordrecht Heidelberg London New York

63. Australian Government, Australian Institute of Health and Welfare, *Premature mortality in Australia – Deaths among infants (aged less than 1)*, 2017, available: <https://www.aihw.gov.au/reports/life-expectancy-death/premature-mortality-in-australia-1997-2012/contents/deaths-among-infants-aged-less-than-1>

64. Australian Government, Australian Institute of Health and Welfare, *Premature mortality in Australia – Deaths among children aged 1-14*, 2017, available: <https://www.aihw.gov.au/reports/life-expectancy-death/premature-mortality-in-australia-1997-2012/contents/deaths-among-children-aged-1-14>

65. Australian Government, Australian Institute of Health and Welfare, *Premature mortality in Australia – Deaths among young people aged 15-24*, 2017, available: <https://www.aihw.gov.au/reports/life-expectancy-death/premature-mortality-in-australia-1997-2012/contents/deaths-among-young-people-aged-15-24>

66. Brown A, Clark JD, *A Parent's Journey: Incorporating Principles of Palliative Care into Practice for Children with Chronic Neurologic Diseases*, *Semin Pediatr Neurol*. 2015 Sep;22(3):159-65

67. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed*. 2013 Dec;98(6):202-8.

68. Brown A, Clark JD, *A Parent's Journey: Incorporating Principles of Palliative Care into Practice for Children with Chronic Neurologic Diseases*, *Semin Pediatr Neurol*. 2015 Sep;22(3):159-65

69. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

70. Marcus, K, Balkin, E, Al-Sayegh, H, Guslits, E, Blume, E, Ma, C, Wolfe, J, Patterns and outcomes of care in children with advanced heart disease receiving palliative care consultation, *Journal of pain and symptom management*, 2018, Feb;55(2):351-358

71. Kaye EC, Friebert S, Baker JN., Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families, *Pediatr Blood Cancer*. 2016 Apr;63(4):593-7

The International Society of Paediatric Oncology advocates for timely implementation of palliative care for children globally.<sup>72</sup> Likewise, the AAP recommends that children with high-risk cancer and other life-limiting conditions should receive access to an integrated model of palliative care, in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome is cure or death.<sup>73</sup> Harrop and Edwards state that the most appropriate referrals to a paediatric palliative care service are for children not expected to live to adulthood.<sup>74</sup>

The integrated model of palliative care is widely supported in the literature,<sup>75,76,77,78,79</sup> with the introduction of healing and palliation (when indicated) alongside curative treatment as soon as any life-limiting diagnosis is given. Additionally, because loss can be experienced in many conditions, even in the absence of death, bereavement is represented as an ongoing, continual process throughout a disease process.<sup>80</sup> This applies to a variety of care settings, including the Paediatric Intensive Care Unit (PICU), with the integration of palliative care rapidly becoming the standard for high quality care of critically ill children.<sup>81</sup> Early palliative care integration for paediatric cancer patients is now considered optimal care.<sup>82</sup> The maternal benefits of perinatal palliative care were realised in a randomised trial involving infants with single-ventricle heart disease, which revealed that when palliative care is introduced prenatally, the early initiation decreased maternal anxiety, improved maternal positive reframing and improved communication and family relationships.<sup>83</sup>

Unfortunately, despite a growing body of data identifying paediatric palliative care as an integral component of high-quality care for all children with life-limiting conditions, timely integration of paediatric palliative care remains incomplete and inconsistent.<sup>84</sup>

Barriers to the uptake of palliative care identified in various studies include familial reluctance to acknowledge their child has an incurable condition,<sup>85</sup> and that parents are less likely to choose palliative care for children who lack a definitive diagnosis, or are early in their illness trajectory.<sup>86,87</sup> There is also a belief that palliative care for infants and children who are continuing to receive curative therapy is giving up hope for recovery or cure,<sup>88</sup> with a common misunderstanding among healthcare practitioners and families that palliative care services are reserved for terminally ill

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72. Kaye EC, Friebert S, Baker JN., Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families, *Pediatr Blood Cancer*. 2016 Apr;63(4):593-7
73. Kaye EC, Friebert S, Baker JN., Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families, *Pediatr Blood Cancer*. 2016 Apr;63(4):593-7
74. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed*. 2013 Dec;98(6):202-8
75. Kaye EC, Friebert S, Baker JN., Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families, *Pediatr Blood Cancer*. 2016 Apr;63(4):593-7
76. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature, *BMC Pediatr*. 2012 Mar 12;12:25.
77. Mahmood LA, Casey D, Dolan JG, Dozier AM, Korones DN., Feasibility of Early Palliative Care Consultation for Children With High-Risk Malignancies, *Pediatr Blood Cancer*. 2016 Aug;63(8):1419-22
78. Waldman E, Wolfe J, Palliative care for children with cancer, *Nat Rev Clin Oncol*. 2013 Feb;10(2):100-7
79. Levine DR, Mandrell BN, Sykes A, Pritchard M, Gibson D, Symons HJ, Wendler D, Baker JN., Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Paediatric Oncology, *JAMA Oncol*. 2017 Sep 1;3(9):1214-1220
80. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature, *BMC Pediatr*. 2012 Mar 12;12:25.
81. Boss R, Nelson J, Weissman D, Campbell M, Curtis R, Frontera J, Gabriel M, Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board, *Pediatr Crit Care Med*. 2014 Oct;15(8):762-7
82. Levine DR, Mandrell BN, Sykes A, Pritchard M, Gibson D, Symons HJ, Wendler D, Baker JN., Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Paediatric Oncology, *JAMA Oncol*. 2017 Sep 1;3(9):1214-1220
83. Hancock H, Pituch K, Uzark K, Bhat P, Fifer C, Silveira M, Yu S, Welch S, Donohue J, Lowery R, Aiyagari R, A randomized trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease, *Cardiology in the young*, 2018, 28:561-570
84. Kaye EC, Friebert S, Baker JN., Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families, *Pediatr Blood Cancer*. 2016 Apr;63(4):593-7
85. Knapp C, Thompson L, Factors associated with perceived barriers to paediatric palliative care: a survey of paediatricians in Florida and California, *Palliat Med*. 2012 Apr;26(3):268-74
86. Hoell, J., Warfsmann, J., Gagnon, G, Trocan, L., Balzer S., Oommen, P., Borkhardt, A, Janßen, G., Kühlen, M., Palliative care for children with a yet undiagnosed syndrome, *Eur J Pediatr* (2017) 176:1319–1327
87. Levine DR, Mandrell BN, Sykes A, Pritchard M, Gibson D, Symons HJ, Wendler D, Baker JN., Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Paediatric Oncology, *JAMA Oncol*. 2017 Sep 1;3(9):1214-1220
88. Hill K, Coyne I., Palliative care nursing for children in the UK and Ireland, *Br J Nurs*, 2012 Mar 8-21;21(5):276-81.

children.<sup>89</sup> One Canadian study also discovered that the term 'palliative care' itself is an obstacle, due to the negative connotations associated with the service.<sup>90</sup> One health service in New York changed the name of their palliative care team to the Paediatric Supportive Care Team, acknowledging that the term 'palliative care' can be difficult for referring teams to mention to their patients.<sup>91</sup>

An Australian study identified the components and principles that are desirable in an early paediatric palliative care consultation and which, through education of clinicians, may help to standardise practices and assist non-specialist clinicians and families to understand the goals of palliative care,<sup>92</sup> thereby improving early integration. The authors developed a flow-chart (refer Appendix 1), which includes the following components and principles:<sup>93</sup>

- Establish goals/expectations of referring practitioner;
- Establish rapport with family;
- Establish family's understanding of palliative care;
- Discussion of current issues and symptoms for child, including psychosocial;
- Clinician-initiated discussions;
- Family-initiated discussions; and
- Management plan communicated to family.

## 2.3. PROVIDERS OF PAEDIATRIC PALLIATIVE CARE

### Specialist paediatric palliative care

SPPC services are defined as those supported by a medical specialist with advanced training in paediatric palliative medicine.<sup>94,95</sup> Most tertiary paediatric hospitals in Australia have at least some SPPC services, but the actual composition at each site is unique. The holistic nature of palliative care necessitates a multidisciplinary team approach to ensure attention to planning, coordination and communication within the care team.<sup>96</sup> Teams may consist of various disciplines including, but not limited to:<sup>97</sup>

- Medical;
- Nursing;
- Social work;
- Occupational therapy;
- Speech therapy;
- Dietetics;
- Physiotherapy;

89. Mahmood LA, Casey D, Dolan JG, Dozier AM, Korones DN., Feasibility of Early Palliative Care Consultation for Children With High-Risk Malignancies, *Pediatr Blood Cancer*. 2016 Aug;63(8):1419-22

90. Mahmood LA, Casey D, Dolan JG, Dozier AM, Korones DN., Feasibility of Early Palliative Care Consultation for Children With High-Risk Malignancies, *Pediatr Blood Cancer*. 2016 Aug;63(8):1419-22

91. Mahmood LA, Casey D, Dolan JG, Dozier AM, Korones DN., Feasibility of Early Palliative Care Consultation for Children With High-Risk Malignancies, *Pediatr Blood Cancer*. 2016 Aug;63(8):1419-22

92. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

93. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med*. 2014 Nov;17(11):1206-13.

94. Hain R, Heckford E, McCulloch R. Paediatric palliative medicine in the UK: past, present, future. *Arch Dis Child* 2012;97:381-4.

95. NHPCO's paediatric standards: a key step in advancing care for America's children [press release]. National Hospice and Palliative Care Organization, 2009.

96. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, *MJA* Vol 179 15 September 2003; 179: S20-S2

97. Feudtner C, Womer J, Augustin R, et al. Paediatric palliative care programs in children's hospitals: a cross-sectional national survey. *Paediatrics* 2013;132:1063-70.

- Pharmacy
- Play therapy;
- Psychology;
- Bereavement coordination;
- Volunteer coordination;
- Chaplain/Pastoral Care; and
- Music/art therapy.

The common reluctance of families to engage paediatric palliative care emphasises the importance of having access to multidisciplinary team members whose areas of expertise are family dynamics, including psychologists and social workers.<sup>98</sup>

Services which may be provided by SPPC providers include:<sup>99</sup>

- Medically supported respite, or short breaks, for children living with a life-limiting condition;
- Acute admissions for the management of poorly controlled symptoms;
- Stepped discharge from hospital;
- Compassionate withdrawal of life-sustaining treatment (e.g. ventilation);
- Specific support for sibling/s;
- End-of-life care; or
- Specific child bereavement services.

## The paediatric palliative care workforce

It is well recognised that families caring for a child living with a life-limiting condition face intense challenges, extreme suffering, and tremendous grief.<sup>100</sup> As most health professionals are not experienced with the conditions and palliative care needs of a child, the child's primary specialist team often leads care, with a specialist paediatric palliative care service providing a supportive layer for primary and community-based services, or for other hospital-based teams, via consultation.<sup>101</sup> When there are relatively few specialised paediatric palliative care professionals available, the consultative model maximises their availability.<sup>102</sup>

One model of paediatric palliative care that has been implemented in New South Wales to enhance access to SPPC when needed during a child's illness is the Pop-Up Model of Care.<sup>103</sup> 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 is provided by the SPPC. This team can be quickly mobilised around the child and family to provide support for the duration of the child's illness and for the family in bereavement.<sup>104</sup> These specialist teams also

98. Knapp C, Thompson L, Factors associated with perceived barriers to paediatric palliative care: a survey of paediatricians in Florida and California, *Palliat Med.* 2012 Apr;26(3):268-74

99. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed.* 2013 Dec;98(6):202-8.

100. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med.* 2014 Nov;17(11):1206-13.

101. Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, *J Palliat Med.* 2014 Nov;17(11):1206-13.

102. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, *MJA* Vol 179 15 September 2003; 179: S20-S2

103. CareSearch, NSW Paediatric Palliative Care Programme, Supporting families to care for a child with a life-limiting illness, available: <https://www.caresearch.com.au/caresearch/tabid/3149/Default.aspx>

104. NSW Ministry of Health, The NSW Government plan to increase access to palliative care 2012-2016, available: <http://www.health.nsw.gov.au/palliativecare/Publications/palliative-care-plan-2012-2016.pdf>

provide hospital-based consultancy services and consultation to General Practitioners (GPs), community palliative care services and community nursing services.

The aim of a pop-up intervention is to facilitate responsive and well-coordinated palliative care by providing in-time training and education to local health providers. A comprehensive care plan is made during a pop-up intervention to outline the child's care needs and guide local providers. The multidisciplinary SPPC team will assess when a pop-up consultation is needed. This is guided by:<sup>105</sup>

- The clinical needs of the child;
- Psychosocial care of the family;
- Education needs of local clinicians;
- Geographic location (e.g. rural/remote locations); and
- Bereavement follow-up.

Ongoing pop-up interventions may be necessary throughout a child's illness to address the changing care needs requiring support by the specialist services.<sup>106</sup>

In many parts of Australia, geography and workforce limitations make it impossible for SPPC services to take on direct care aspects for children and families in their local community.<sup>107</sup> They do, however, take on an important role in facilitating communication between specialist/tertiary paediatric services and primary care providers, including GPs, to ensure all relevant medical information and documentation is available for smooth transitions between hospital and community care.

Given the growing desire for many families to care for their child at home as much as possible,<sup>108,109</sup> including end-of-life care, the GP can play an important role in the management of the paediatric palliative care patient. Armitage and Trethewie described a GP's role as including clinical reviews, symptom management, support for community palliative care teams and, if needed, certification after death.<sup>110</sup> The GP's role can extend to family support, identifying parent and sibling needs, and bereavement support.

Palliative care depends on a multidisciplinary team approach.<sup>111</sup> Using a team approach enables SPPC services to provide the GP with relevant information, specific education, advice and ongoing support to fulfil their important role for the child and family. The GP and other local services are critical components of the team supporting the child.

Keele et al. defines palliative care teams as a group that provides centralised access to services that are offered to children with complex chronic conditions and their families concurrently with curative therapies throughout the course of the illness.<sup>112</sup> Palliative care teams may consist of many different types and numbers of members depending on the program age, resources available, and population base served.<sup>113</sup>

105. CareSearch, NSW Paediatric Palliative Care Programme, Supporting families to care for a child with a life-limiting illness, available: <https://www.caresearch.com.au/caresearch/tabid/3149/Default.aspx>

106. CareSearch, NSW Paediatric Palliative Care Programme, Supporting families to care for a child with a life-limiting illness, available: <https://www.caresearch.com.au/caresearch/tabid/3149/Default.aspx>

107. Armitage & Trethewie. "Paediatric palliative care-the role of the GP." Australian family physician 43.4 (2014): 176.

108. Monterosso L, Kristjanson LJ. Supportive and palliative care needs of families of children who die from cancer: an Australian study. Palliat Med 2008;22:59-69.

109. Vickers J, Thompson A, Collins GS, Childs M, Hain R. Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. J Clin Oncol 2007;25:4472-76.

110. Armitage, Nicole, and Susan Trethewie. "Paediatric palliative care-the role of the GP." Australian family physician 43.4 (2014): 176.

111. Waldman E, Wolfe J, Palliative care for children with cancer, Nat Rev Clin Oncol. 2013 Feb;10(2):100-7

112. Keele, et al. "The effect of palliative care team design on referrals to paediatric palliative care." Journal of palliative medicine 19.3 (2016): 286-291.

113. Knapp C, Thompson L, Factors associated with perceived barriers to paediatric palliative care: a survey of paediatricians in Florida and California, Palliat Med. 2012 Apr;26(3):268-74

Little is known about the ideal size and team composition for children. The composition of the palliative care team may change depending on the setting (inpatient or outpatient) and circumstances. For example, a patient and family's initial need for palliative care may change with time, as more support may be needed at home, or to help with meaningful outpatient activities such as school, hobbies, and seeing friends.<sup>114</sup>

Specialised settings may have specialised team requirements. For example, in the Neonatal Intensive Care Unit (NICU), a neonatal palliative care team may include (but not be limited to):

- Palliative care physician;
- Neonatologists (including specialists in paediatric palliative care);
- Paediatricians;
- Psychologists;
- Midwives;
- Lactation consultants;
- Neonatal nurses;
- Pharmacists;
- Social Workers;
- Speech therapists;
- Physiotherapists;
- Occupational therapists; and
- Bereavement counsellors.

The designation of a key worker, sometimes known as a care coordinator, to coordinate care is considered by Hynson et al. to be an essential part of the SPPC team, as many care providers and agencies may be involved across a range of care settings.<sup>115</sup>

An example of a care coordinator is the Nurse Navigator role in Queensland's public health system.<sup>116</sup> Nurse navigators aims 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. Nurse Navigators will link with GP's who identify and refer their frequently presenting, most complex patients (adult or children), who require a coordinated approach to improve their health outcomes.

Children and their families may also benefit from accessing community palliative care services; however, many of the conditions that affect children are encountered only in paediatric practice. Paediatricians bring specialist knowledge of such conditions and a broader understanding of the developmental and physiological aspects of care, often having been involved in caring for the child over many years. They generally wish to maintain this involvement. In Australia, community palliative care teams can provide support to families who wish to care for their child at home. This comprises at least nursing support, and many services also offer medical advice, allied health services, pastoral care and complementary therapies.<sup>117</sup>

Other important members of the SPPC team include volunteers. In a study of volunteers in hospices, Burbeck et al. found that volunteers were involved with all client groups, including families referred

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114. Knapp C, Thompson L, Factors associated with perceived barriers to paediatric palliative care: a survey of paediatricians in Florida and California, *Palliat Med.* 2012 Apr;26(3):268-74

115. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, *MJA* Vol 179 15 September 2003; 179: S20-S2

116. Queensland Government, Queensland Health, 2018, Nurse Navigator Service Referral, available: <https://www.health.qld.gov.au/sunshinecoast/html/services/nurse-nav>

117. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, *MJA* Vol 179 15 September 2003; 179: S20-S2

in the antenatal period and bereaved families, and in a range of activities, most commonly greeting people at the hospice, and providing recreational activities with children and siblings, or potentially sitting with children in the last hours of life.<sup>118</sup> It was also found that smaller hospices and those providing solely home-based care involve fewer volunteers with direct contact with children and young people, and their families, than larger hospices. However, it was reported that the widest range of activities were undertaken by volunteers in families' homes compared with larger hospices.<sup>119</sup>

Clinical ethicists may also play a necessary role in the paediatric palliative care team. For the past several decades, the fields of paediatric palliative care and clinical ethics have to a large degree overlapped, with common ethical issues covering autonomy, truth-telling, futility, value-based decision making and professional boundaries. These struggles are difficult when the patient is a competent adult and considered exponentially more difficult when concerning children.<sup>120</sup> End-of-life decision-making for babies with an adverse prognosis is also ethically challenging.<sup>121</sup>

Ultimately, the paediatric palliative care team must pursue a path of care that is in the child's best interest. Issues can arise when care involves a child who has the capacity to make reasonable decisions, that are contrary to the decisions of the parents,<sup>122</sup> or when family interests outweigh the best interests of a baby or child with no competency or mental capacity to make decisions.<sup>123</sup>

One framework for use in situations when there are entrenched disagreements between clinicians and parents about clinical treatment decisions is the Zone of Parental Discretion (ZPD).<sup>124</sup> This approach helps doctors decide whether a parental choice should be overridden. It is readily assumed that parents are the default medical decision-makers for their children<sup>125</sup>, however, their right to make medical decisions is not unlimited. The ZPD presents the parents' moral authority as a zone or space between boundaries of probable harm and best interests and is designed to focus attention on the moral weight of parents as the decision makers for the child, in addition to focusing on the wellbeing of the child.<sup>126</sup>

McDougall, Gillam and Gold explain that when the parents' decision is within the ZPD, understanding their reasons will assist the clinician in advocating effectively for the best treatment option. When the parents' decision is outside the ZPD, understanding their reasons will be necessary in finding the least intrusive or damaging way to intervene.<sup>127</sup> Clinical ethics input into these challenging situations may provide invaluable assistance not only to the paediatric palliative care team, but most importantly to the child and their family.

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118. Burbeck, Rachel, et al. "Volunteer activity in specialist paediatric palliative care: a national survey." *BMJ supportive & palliative care* (2013): bmjspcare-2012.

119. Burbeck, Rachel, et al. "Volunteer activity in specialist paediatric palliative care: a national survey." *BMJ supportive & palliative care* (2013): bmjspcare-2012.

120. Feudtner, Nathanson PG., Paediatric palliative care and paediatric medical ethics: opportunities and challenges, *Paediatrics*. 2014 Feb;133 Suppl 1:S1-7

121. Kiman, R., Doumic, L., Perinatal palliative care: a developing specialty, *Int. J Palliat Nurs.*, 2014 Mar;20(3):143-8.

122. Feudtner, Nathanson PG., Paediatric palliative care and paediatric medical ethics: opportunities and challenges, *Paediatrics*. 2014 Feb;133 Suppl 1:S1-7

123. Kiman, R., Doumic, L., Perinatal palliative care: a developing specialty, *Int. J Palliat Nurs.*, 2014 Mar;20(3):143-8.

124. McDougall R, Delany C, Gillam L, The value of open deliberation in clinical ethics, and the role of parents' reasons in zone of parental discretion, *Am. J Bioeth.* 2018, Aug;18(8):47-49

125. Salter E, Deciding for a child: a comprehensive analysis of the best interest standard, *Theor Med Bioeth* (2012) 33:179–198

126. McDougall R, Delany C, Gillam L, The value of open deliberation in clinical ethics, and the role of parents' reasons in zone of parental discretion, *Am. J Bioeth.* 2018, Aug;18(8):47-49

127. McDougall, R., L. Gillam, and H. Gold. 2016. The zone of parental discretion, In *When doctors and parents disagree: Ethics, paediatrics and the zone of parental discretion*, eds. R. McDougall, C. Delany, and L. Gillam, 14–24. Sydney: Federation Press.

Despite the limited quality of the evidence, various studies suggest that a SPPC team may improve quality of life for children and parents, improve symptom control, favourably impact the place of care and increase the likelihood of a preferred place of death.<sup>128,129,130</sup>

Verberne et al. found that parents feel supported by the SPPC team and increasingly valued the SPPC team. Parents highly appreciated the process-related aspects, the practical support and the SPPC team's sensitive and reliable attitude.<sup>131</sup> These three elements probably underlie the achievement of reported outcomes, such as improved quality of life of the child and family.

Keele et al. discovered that team composition and availability may not be critical to SPPC team utilisation and should not be viewed as deterrents to team development.<sup>132</sup> Hospitals with some of the needed personnel but not all team members should consider creating formal teams. As these teams grow, they will need increasing support to meet patient and family needs and mitigate the risk of provider burnout.<sup>133</sup>

## 2.4. SETTINGS FOR PROVIDING PAEDIATRIC PALLIATIVE CARE

Specialist palliative care services for children may be delivered in a variety of settings. SPPC teams may be found in tertiary children's hospitals, in paediatric wards or critical care units in acute hospitals, and occasionally within community-based services.<sup>134</sup> If local demand is sufficient, children's hospices may exist that offer a specialist service.

Additionally, specialist paediatric palliative care teams will often 'in-reach' to local hospitals, as well as support palliative care in community services, including schools, churches and athletics clubs, and at home.<sup>135</sup> The specialists support the core palliative care skills of those providing the primary health care, such as children's community nurses, general paediatricians and GPs.<sup>136</sup>

Some families feel more comfortable with their child receiving care in a hospital setting. For families with children who have spent long periods in hospital, the ward community may become more familiar than the local community, because staff and fellow families understand their predicament in a way that friends and extended family cannot.<sup>137</sup>

### Home

Most families choose to spend as much time at home as possible, as parents commonly feel this is the last thing they can do for their child, and for many parents, palliative care represents an extension of the care they would normally provide. The home environment provides families with the security of a familiar environment, free from the disruption of hospital routines, and helps maintain some family normality.<sup>138</sup> Privacy is enhanced, siblings can be included, and parents feel more in control. Children generally prefer to be at home among their own toys, pets, family members and friends.<sup>139</sup>

128. Niswander LM, Cromwell P, Chirico J, et al. End-of-life care for children enrolled in a community-based paediatric palliative care program. *J Palliat Med* 2014;17:589–91.

129. Herbert A, Bradford N, Donovan L, et al. Development of a state-wide paediatric palliative care service in Australia: referral and outcomes over two years. *J Palliat Med* 2014;17:288–95.

130. Kassam A, Skiadaresis J, Alexander S, et al. Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. *Pediatr Blood Canc* 2015;62:1409–13.

131. Verberne, et al. "Parental experiences with a paediatric palliative care team: A qualitative study." *Palliative medicine* 31.10 (2017): 956-963.

132. Keele, et al. "The effect of palliative care team design on referrals to paediatric palliative care." *Journal of palliative medicine* 19.3 (2016): 286-291.

133. Keele, et al. "The effect of palliative care team design on referrals to paediatric palliative care." *Journal of palliative medicine* 19.3 (2016): 286-291

134. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed.* 2013 Dec;98(6):202-8

135. Davis KG, Integrating Paediatric Palliative Care into the School and Community, *Pediatr Clin North Am.* 2016 Oct;63(5):899-911.

136. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed.* 2013 Dec;98(6):202-8

137. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, *MJA* Vol 179 15 September 2003; 179: S20–S2

138. Mherekumombe M, From inpatient to clinic to home to hospice and back: Using the 'pop-up' paediatric palliative model of care, *Children* 2018, 5, 55.

139. Harrop E, Edwards C., How and when to refer a child for specialist paediatric palliative care, *Arch Dis Child Educ Pract Ed.* 2013 Dec;98(6):202-8

Palliative care is complex, and multiple interventions and supports are required if care is to be managed at home.<sup>140</sup> Home care requires close collaboration between primary paediatricians, service providers and the SPPC to ensure a smooth transition and continued care at home.<sup>141</sup> The continuous availability of palliative care support for children and families is an essential component of a home care service, to enable 24-hour access to symptom control, including access to medication and suitably qualified and experienced practitioners, as well as emotional support, among other things.<sup>142,143</sup> Assistance must also be available for families who have complicated, technological medical devices supporting the care of a child at home. Sufficient access to these elements of a home care service may help to reduce the number of presentations to acute facilities.<sup>144</sup>

When clinical encounters occur in the home setting, there is an increased chance that professional 'boundary-crossing' may occur, and clinicians must pay special attention to approach professional boundaries with careful judgement.<sup>145</sup> The goal of holistic family-centred care, and efforts to maintain collaboration with parents to reach optimal outcomes for the child, may lead to clinicians becoming deeply and personally involved. An example of this is sharing meals with families, as the family is likely acting out of politeness and perhaps with gratitude for the medical services being provided. The ethical dilemma here relates to the balance required between providing comprehensive palliative care services and ensuring enough distance to maintain the neutrality of the professional relationship. This requires the boundaries of the palliative care relationship to be defined to maintain a clear, therapeutic clinical focus.<sup>146</sup>

## School

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, SPPC 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.<sup>147</sup> School can be more than a place of learning, providing important relationships for children, their parents and siblings. School may also provide a reassuring rhythm to life and a sense of normality amid chaos and upheaval.<sup>148</sup>

An effective collaboration between the child, healthcare providers and the school professionals may ensure the best possible opportunity for the child and family to manage successfully. Some of the specific needs of the child that might be met at school through an effective collaboration include:<sup>149</sup>

- Effective pain and symptom management that supports continued school participation. This may include medication provision through a school nurse, or non-pharmacological interventions that can be provided by teachers;
- Anticipating needs and establishing plans to address symptoms before they arise;
- School social workers, counsellors or chaplains can help the child to understand their diagnosis, and that it is not their fault that they are sick;
- Facilitating the child's learning through online support or through a tutor, particularly if the child spends long periods of time at home;
- Assisting the child to stay connected with their peers and socialise with their friends;

140. Bradford N, Young J, Armfield NR, Bensink ME, Pedersen LA, Herbert A, Smith AC, A pilot study of the effectiveness of home teleconsultations in paediatric palliative care, *J Telemed Telecare*. 2012 Dec;18(8):438-42

141. Chong LA, Khalid F., Paediatric palliative care at home: a single centre's experience, *Singapore Med J*. 2016 Feb;57(2):77-80

142. Maynard L, Lynn D., Innovative approach to providing 24/7 palliative care for children, *Nurs Child Young People*. 2014 Jul;26(6):27-34

143. Chong LA, Khalid F., Paediatric palliative care at home: a single centre's experience, *Singapore Med J*. 2016 Feb;57(2):77-80

144. Chong LA, Khalid F., Paediatric palliative care at home: a single centre's experience, *Singapore Med J*. 2016 Feb;57(2):77-80

145. Jankowski JB, Professional boundary issues in paediatric palliative care, *Am J Hosp Palliat Care*. 2014 Mar;31(2):161-5

146. Jankowski JB, Professional boundary issues in paediatric palliative care, *Am J Hosp Palliat Care*. 2014 Mar;31(2):161-5

147. Davis KG, Integrating Paediatric Palliative Care into the School and Community, *Pediatr Clin North Am*. 2016 Oct;63(5):899-911

148. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, *MJA* Vol 179 15 September 2003; 179: S20-S2

149. Davis KG, Integrating Paediatric Palliative Care into the School and Community, *Pediatr Clin North Am*. 2016 Oct;63(5):899-911

- Providing opportunities for the child to participate in extra-curricular activities when an illness may normally be considered to limit participation; and
- Helping the child to live the life they want to the greatest extent possible.

Whatever the setting, ensuring the active and ongoing involvement of the child's GP or local paediatrician with the palliative care providers is important to allow trust to be established early and maintained, so that families can move between the various places of care according to the child's condition and the family's needs.<sup>150</sup>

## NICU and PICU

International findings indicate that of the children who die in hospital, somewhere in the range of 80% to 91% die within a NICU or a PICU.<sup>151,152</sup> In 2014, the IOM recommended primary palliative care as integral to all neonates and their families in the intensive care setting.<sup>153</sup>

With the initiation of palliative care perinatally, obstetric units and NICUs may require the establishment of an active and effective SPPC to cater for neonates with lethal congenital anomalies, neonates that are pre-viable or at the limits of viability, and neonates who do not respond to aggressive medical management.<sup>154</sup> Within a PICU, the integration of SPPC can ensure that there is a focus on pain and symptom management, enhancing quality of life, communication and decision-making, advance care planning and grief and bereavement, as well as specialist input into the complex situations, ensuring treatment plans and clinical interventions follow agreed goals of care objectives.<sup>155,156</sup>

End-of-life care is part of the scope of practice in all critical care units, however, palliative care principles have not been embraced in neonatology as rapidly as in other areas of medicine.<sup>157</sup> An Australian study that characterised the end-of-life care provided in a single tertiary neonatal unit, where paediatric palliative care was accessible via a consultative service, found that the unit was not meeting all of the end-of-life care needs of infants and their families, and that care was generally more comprehensive when the palliative care service was consulted.<sup>158</sup> It concluded that neonatal staff have significant scope to improve end-of-life care, by providing psychosocial, emotional and spiritual supports, additional to the meticulous medical care that already occurs.<sup>159</sup>

It is important to recognise that when the goals of care transition from curative to palliative, many life-limiting conditions can be managed outside the intensive 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 put in place.<sup>160</sup>

150. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, MJA Vol 179 15 September 2003; 179: S20–S2

151. Madden K, Wolfe J, Collura C., Paediatric Palliative Care in the Intensive Care, Crit Care Nurs Clin North Am. 2015 Sep;27(3):341-54

152. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, Palliat Med. 2015 Apr;29(4):371-9

153. Leong Marc-Aurele K, Nelesen R., A five-year review of referrals for perinatal palliative care. J Palliat Med. 2013 Oct;16(10):1232-6.

154. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escibano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature, BMC Pediatr. 2012 Mar 12;12:25.

155. Boss R, Nelson J, Weissman D, Campbell M, Curtis R, Frontera J, Gabriel M, Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board, Pediatr Crit Care Med. 2014 Oct;15(8):762-7

156. Madden K, Wolfe J, Collura C., Paediatric Palliative Care in the Intensive Care, Crit Care Nurs Clin North Am. 2015 Sep;27(3):341-54

157. Gilmour D, Davies M, Herbert A, Adequacy of palliative care in a single tertiary neonatal unit, J Paediatr Child Health, 2017 Feb;53(2):136-144

158. Gilmour D, Davies M, Herbert A, Adequacy of palliative care in a single tertiary neonatal unit, J Paediatr Child Health, 2017 Feb;53(2):136-144

159. Gilmour D, Davies M, Herbert A, Adequacy of palliative care in a single tertiary neonatal unit, J Paediatr Child Health, 2017 Feb;53(2):136-144

160. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

## Telehealth

Although not technically a setting for healthcare, telehealth is a mode of communication that can support the provision of healthcare in many settings. Clinical encounters in the home need not all be face-to-face, with studies undertaken in Queensland finding that telehealth is a feasible and acceptable means of facilitating a palliative care consultation at home. Telehealth can be effectively used to link the SPPC team into the home of families caring for a child receiving palliative care, regardless of their physical distance from the SPPC, which may reduce the burden on families at a distressing time. Furthermore, telehealth consultations were found to be as effective as face-to-face consultations, according to 14 established principles and components of a paediatric palliative care consultation.<sup>161</sup> Telehealth also enables the SPPC team to provide collegial support and education to other healthcare providers and deliver bereavement support, particularly in rural and remote areas.

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.

## Inter-setting transfers

The hallmark of providing paediatric palliative care is providing holistic care. This can be achieved wherever a patient is located. Children are transferred between care facilities for various reasons and it is important to consider the child, their family's wishes, and their preferences during a transfer from an acute care facility to ensure that their quality of life is maintained. Consideration must also be given to the complexity of care, technology and equipment support required, as well as functional and social aspects of the child and family, including psychosocial and spiritual domains.<sup>162</sup>

Risks of transfer include discontinuity of care or changes to treatment, including medication regimes and therapies, which often arise due to poor communication, inadequate preparation, limited finance, and limited or inexperienced staff.<sup>163</sup>

Involving key healthcare providers in coordinating the discharge ensures that the child has the required supports in place, the necessary paperwork, and an acute management plan for deterioration along with an advanced care directive.<sup>164</sup> A pop-up model of care can facilitate a transfer or discharge, by supporting the accepting provider through in-time training and education for the specific needs of the child and family. The pop-up support can be provided face-to-face or by telehealth, or a combination of both.<sup>165</sup>

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161. Bradford NK, Armfield NR, Young J, Herbert A, Mott C, Smith AC, Principles of a paediatric palliative care consultation can be achieved with home Telemedicine, J Telemed Telecare. 2014 Oct;20(7):360-4.

162. Mherekumombe M, From inpatient to clinic to home to hospice and back: Using the "pop-up" paediatric palliative model of care, Children 2018, 5, 55.

163. Mherekumombe M, From inpatient to clinic to home to hospice and back: Using the "pop-up" paediatric palliative model of care, Children 2018, 5, 55.

164. Mherekumombe M, From inpatient to clinic to home to hospice and back: Using the "pop-up" paediatric palliative model of care, Children 2018, 5, 55.

165. Mherekumombe M, From inpatient to clinic to home to hospice and back: Using the "pop-up" paediatric palliative model of care, Children 2018, 5, 55.

## 2.5. PROVIDING A CHILD AND FAMILY CENTRED AND EFFECTIVE CONTINUUM OF PAEDIATRIC PALLIATIVE CARE SERVICES

### Referral and assessment

To facilitate the goal of early introduction of paediatric palliative care, regardless of whether the child's condition is incurable or not, referrals should be made by primary care providers or subspecialty medical practitioners soon after initial diagnosis.<sup>166</sup>

A recent survey of more than 40 US children's hospitals examining palliative care referral patterns found that:<sup>167</sup>

- Less than 25% of referrals were made at the time of diagnosis of a life-limiting condition;
- Most referrals came from hospital-based specialists rather than primary care physicians, specifically paediatric intensivists;
- Referrals from neonatologists, gastroenterologists, endocrinologists, nephrologists and cardiologists could have been higher, given the AAP recommends that all children with life-limiting conditions be offered palliative care;
- Increased referrals occurred when a SPPC team consisted of all members recommended by the AAP;
- The addition of certain team members in particular, including advanced nurse practitioners or pain consultants, increased referrals;
- Referral rates were similar regardless of whether 24/7 SPPC coverage was available or not; and
- Barriers to referral included uncertain prognosis and a belief that palliative care is only beneficial after curative treatment has been exhausted.

A study of referrals to a perinatal palliative care service in San Diego over a five-year period found that there was an average lag time of two months between diagnosis and referral to the palliative care service. The authors found that earlier referral could provide the opportunity to care for those who wished to terminate the pregnancy, and for those who chose to continue with the pregnancy, the perinatal palliative care team could help the family to create memories of the pregnancy and provide or refer to appropriate counselling. Furthermore, the authors concluded that more palliative care service time would allow parents to better prepare for the precious and potentially brief moments with their babies in delivery.<sup>168</sup>

With the aim of improving paediatric palliative care referrals in the PICU in one of the largest and most comprehensive paediatric hospitals in the US, the PICU and palliative care teams developed palliative care consultation criteria (screening criteria) and referral was encouraged for all patients meeting the criteria. The result was a five-fold increase in the number of referrals to palliative care, likely due to the screening criteria being embedded in the consciousness and routine of the PICU clinicians, a process potentially driven by a new sense of mutual accountability between the PICU and palliative care providers. Screening criteria were thereby considered to be an effective tool for improving access to palliative care in the PICU.<sup>169</sup>

166. Keele, et al. "The effect of palliative care team design on referrals to paediatric palliative care." *Journal of palliative medicine* 19.3 (2016): 286-291.

167. Keele, et al. "The effect of palliative care team design on referrals to paediatric palliative care." *Journal of palliative medicine* 19.3 (2016): 286-291.

168. Leong Marc-Aurele K, Nelesen R., A five-year review of referrals for perinatal palliative care. *J Palliat Med.* 2013 Oct;16(10):1232-6

169. Lutmer JE, Humphrey L, Kempton TM, Moore-Clingenpeel M, Ayad O., Screening Criteria Improve Access to Palliative Care in the PICU, *Pediatr Crit Care Med.* 2016 Aug;17(8):e335-42

## Advance care planning

International guidelines and medical societies strongly recommend advance care planning for children and adolescents.<sup>170</sup> The UK's *Together for Short Lives* Standards recommend the development of both a child and family care plan and an end-of-life care plan.<sup>171</sup>

Advance care planning for children and young people with life-limiting conditions has the potential to improve care for children and their families, provide the opportunity to make decisions based on clear information at an appropriate time (before acute deterioration) and avoid potentially harmful intensive clinical interventions at the end-of-life.<sup>172</sup>

Advance care planning is a multidisciplinary, dynamic process between an individual, their care providers and those close to them, which enables the recognition of preferences for care, and therefore allows children and families to achieve some sense of control in their situation.<sup>173</sup>

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,<sup>174</sup> which provides a guide to advance care planning, 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 2 and 3 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.

Suggested elements of paediatric advance care planning include:<sup>175</sup>

1. Timely and repeated discussions about future treatment preferences, adjusted to the family;
2. Coordination by one person/service;
3. Shared decision-making in line with the principles of informed consent;
4. Valid documentation of the decisions;
5. Circulation of advance care plans to all relevant providers;
6. Regular review of decisions;
7. Involvement and education of all relevant healthcare providers (including psychosocial professionals); and
8. Inclusion of daily life issues.

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170. Lotz JD, Jox RJ, Borasio GD, Führer M, Paediatric advance care planning from the perspective of health care professionals: a qualitative interview study, . Palliat Med. 2015 Mar;29(3):212-22

171. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, Palliat Med. 2015 Apr;29(4):371-9

172. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, Palliat Med. 2015 Apr;29(4):371-9

173. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, Palliat Med. 2015 Apr;29(4):371-9

174. The Royal Children's Hospital Melbourne, The Thinking Ahead Framework, 2014, available: <https://www.rch.org.au/thinkingahead/framework/>

175. Lotz JD, Jox RJ, Borasio GD, Führer M, Paediatric advance care planning from the perspective of health care professionals: a qualitative interview study, . Palliat Med. 2015 Mar;29(3):212-22

Decision making at the end-of-life requires a collaborative approach that encompasses the wishes of the child and family with clinicians involved in care, which may be a multidisciplinary team consisting of a GP, general paediatrician or paediatric palliative care provider. PICU staff can also make useful contributions to these discussions by explaining the implications of a PICU admission and the potential burden of intensive therapies, even though the child may not be at a point that requires intensive care treatment.<sup>176</sup>

It is important for parents to retain control over decisions relating to their child's life and death and to consent to interventions. Even quite young children will have a view on treatments offered and their wishes should be part of the decision-making process.<sup>177</sup> These discussions can be challenging, particularly at times when the child or young person's condition is stable and initiating decision making about end-of-life care may appear premature.<sup>178</sup>

Many barriers to paediatric advance care planning have been described in the literature, including:<sup>179,180,181</sup>

- Time constraints;
- Conflicting clinical demands;
- Lack of formal training in communication skills;
- Lack of established rapport with the family (especially in the PICU);
- Failure to recognise or acknowledge the child's illness trajectory;
- Lack of consensus among the multidisciplinary health care providers involved, stemming from differing clinical judgement, differing ethical and moral attitudes, differing tolerance for risk and differing expectations of medical intervention; and
- Clinicians may be afraid of taking away hope, forcing and overburdening both the parents and the child as well as potentially destroying the trusting relationship with the family.

Advance care planning for children with complex chronic medical conditions has been found to increase when palliative care is introduced early in an outpatient primary care setting.<sup>182</sup> Advance care planning is considered to be a valuable process which supports decisions being made in partnership with patients and families, towards the delivery of continuous holistic care in a preferred place.<sup>183</sup> There are also benefits of the advance care planning process for healthcare professionals, particularly around ethical dilemmas that professionals experience with the delivery of invasive and intensive therapies at the end-of-life.<sup>184</sup>

When the patient is a child with a life-limiting condition, the best interests of the child and minimisation of harm intertwines with the needs for both the child and the family.<sup>185</sup> A child's inability to act autonomously and their necessary reliance on parents as surrogate decision makers complicates the resolution of ethical questions in paediatric practice. There are occasions when

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176. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, *Palliat Med.* 2015 Apr;29(4):371-9

177. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, *A practical guide to Palliative Care in Paediatrics*, 2014.

178. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, *Palliat Med.* 2015 Apr;29(4):371-9

179. Liberman DB, Song E, Radbill LM, Pham PK, Derrington SF., Early introduction of palliative care and advanced care planning for children with complex chronic medical conditions: a pilot study, *Child Care Health Dev.* 2016 May;42(3):439-49

180. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, *Palliat Med.* 2015 Apr;29(4):371-9

181. Lotz JD, Jox RJ, Borasio GD, Führer M, Paediatric advance care planning from the perspective of health care professionals: a qualitative interview study, *Palliat Med.* 2015 Mar;29(3):212-22

182. Liberman DB, Song E, Radbill LM, Pham PK, Derrington SF., Early introduction of palliative care and advanced care planning for children with complex chronic medical conditions: a pilot study, *Child Care Health Dev.* 2016 May;42(3):439-49

183. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, *Palliat Med.* 2015 Apr;29(4):371-9

184. Mitchell S., Dale J., Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff, *Palliat Med.* 2015 Apr;29(4):371-9

185. Jankowski JB, Professional boundary issues in paediatric palliative care, *Am J Hosp Palliat Care.* 2014 Mar;31(2):161-5

parents insist on treatment that health professionals view as inappropriate. Conversely, parents may refuse treatment of potential benefit to the child. A child's inability to communicate or participate must not mean that the child's suffering is excluded from considerations of benefits or burdens. Decision making should involve the child (where possible), the family, and all the health professionals providing care. A child's ability to make informed choices depends on their life experience and developmental level. A child's preferences and insights may guide decision making by others, even if a child is not deemed sufficiently competent to act autonomously. The RACP, the Royal College of Paediatrics and Child Health (UK) and the AAP all strongly advocate the participation of children in decision making to the extent that their ability allows.<sup>186,187,188</sup>

Advance care planning becomes even more important for children who transition to adult palliative care services. For children, two types of advance care plans can be distinguished ethically and legally: an advanced directive completed by a legally competent minor; and an advanced directive issued by a person having legal custody of an incompetent child (usually the parents). The type of plan in place may change with transition from a paediatric to adult palliative care service, reinforcing the need for repeated discussions about future treatment preferences and advance care plans to be regularly reviewed.<sup>189</sup>

## Continuity and coordination of care

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. The Children's Health Queensland Hospital and Health Service provides a model illustrating how numerous the members involved in a child's care may be, including key differences between regional and tertiary centres (refer to Appendix 2).<sup>190</sup>

Transition from paediatric to adult palliative care is complex and fraught with difficulties, and in some cases, can lead to increased mortality during the transition period.<sup>191,192</sup> Owing to the parent/family and patient attachment to paediatric providers, there may be feelings of reluctance and fear to leave behind health care providers who may have provided care for years<sup>193</sup> and this may represent a loss for families.<sup>194</sup> Young people may also struggle to form a relationship with members of their new medical team, and care plans and routine surveillance may be disrupted due to a lack of communication.<sup>195</sup> The more individual approach of adult services may be threatening to young people and their families who have grown used to the family-centred model of paediatric palliative care services, and having spent years protecting their child, parents may find it difficult to watch him/her become more independent. Parents are generally more involved as direct caregivers and decision makers than in the adult setting, which they may find hard to relinquish.<sup>196</sup> Families and,

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186. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, MJA Vol 179 15 September 2003; 179: S20–S2

187. Linebarger JS, Ajayi TA, Jones BL., Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of paediatric palliative care, *Pediatr Clin North Am.* 2014 Aug;61(4):785-96

188. The Royal Australasian College of Physicians Paediatrics and Child Health Division, Decision-making at the end of life in infants, children and adolescents, 2008, available: <https://www.racp.edu.au/docs/default-source/advocacy-library/decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf>

189. Lotz JD, Jox RJ, Borasio GD, Führer M, Paediatric advance care planning from the perspective of health care professionals: a qualitative interview study, *Palliat Med.* 2015 Mar;29(3):212-22

190. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

191. Linebarger JS, Ajayi TA, Jones BL., Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of paediatric palliative care, *Pediatr Clin North Am.* 2014 Aug;61(4):785-96

192. Toluwalase A, Edmonds, K, Palliative Care Answers the Challenges of Transitioning Serious Illness of Childhood to Adult Medicine, *J Pall Med*, 2014, 17(4):469-471

193. Linebarger JS, Ajayi TA, Jones BL., Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of paediatric palliative care, *Pediatr Clin North Am.* 2014 Aug;61(4):785-96

194. Paediatric Palliative Medicine, Department of Paediatric Palliative Medicine, Cardiff, Paediatric palliative care: not so different from adult palliative care?, *Br J Hosp Med (Lond).* 2010 Jan;71(1):36-9

195. Linebarger JS, Ajayi TA, Jones BL., Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of paediatric palliative care, *Pediatr Clin North Am.* 2014 Aug;61(4):785-96

196. Hynson, J., Gillis, J., Collins, J., Irving, H. and Trethewie, S., The dying child: how is care different?, MJA Vol 179 15 September 2003; 179: S20–S2

most importantly, young people must be actively involved in the transition process, with their desires acknowledged and met wherever possible.<sup>197</sup>

To ensure that the family is not overwhelmed by the number of health providers and community services involved with care, it is important that a member of the team takes on the role of coordinator.<sup>198</sup> Continuity and coordination of care throughout both a child's illness and the bereavement period through one reliable point of contact means that children and their families are not required to navigate uncharted territory alone. If a parent knows they can be directly in contact with the right person, who is well-informed about their child and family, they can save valuable time by not having to repeatedly tell their story. Furthermore, the contact is likely to be able to answer their question or directly support them.<sup>199</sup> The coordinator needs to be someone who will have ongoing involvement with the family during the palliative care phase and into bereavement, 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.<sup>200</sup>

The National Institute for Health and Care Excellence (NICE) has developed a comprehensive guideline for transition from child to adult services.<sup>201</sup> It includes:

- Overarching principles;
- Transition planning, including:
  - ▶ Timing and review;
  - ▶ A named worker;
  - ▶ Involving young people;
  - ▶ Building independence; and
  - ▶ Involving parents and carers.
- Support before transfer;
- Support after transfer; and
- Supporting infrastructure.

## 2.6. RECOGNISING AND SUPPORTING THE CONTRIBUTION OF FAMILIES AND CARERS TO THE PAEDIATRIC PALLIATIVE CARE SERVICE SYSTEM

### Support for families and carers

A central component of the holistic nature of SPPC is support for the child's family. The care of a child with a life-limiting condition can be an emotional, physical and financial strain on the family that provides care for their child. The significant psychosocial challenges faced by these caregivers are well recognised. Parents report clinical levels of distress, moderate fatigue and below-average quality of life.<sup>202</sup> Such impacts may also persist into bereavement, leading to the increased overall

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197. Paediatric Palliative Medicine, Department of Paediatric Palliative Medicine, Cardiff, Paediatric palliative care: not so different from adult palliative care?, . Br J Hosp Med (Lond). 2010 Jan;71(1):36-9

198. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

199. Verberne, et al. "Parental experiences with a paediatric palliative care team: A qualitative study." Palliative medicine 31.10 (2017): 956-963

200. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

201. National Institute for Health and Care Excellence, Transition from children's to adults' services for young people using health or social care services, 2016, available:<https://www.nice.org.uk/guidance/ng43/chapter/Recommendations>

202. Collins A, Hennessy-Anderson N, Hosking S, Hynson J, Remedios C, Thomas K, Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study, Palliat Med. 2016 Dec;30(10):950-959

mortality rate of parents after the death of their child.<sup>203,204</sup> Parents often need support collaborating with specialists, understanding options for care, setting goals and making decisions.<sup>205</sup>

The Perth Children's Hospital operates a Keeping Kids in No Distress (KKIND) service which aims to help children cope with trauma, anxiety and distress caused by illness or hospitalisation.<sup>206</sup> Staff, including an acute pain service nurse practitioner, a clinical psychologist, occupational therapists, a clinical nurse and allied health assistants, work with children and their families to help them cope with normal stress and anxiety while they are in hospital or having medical procedures.

Children and their families are assessed for three levels of KKIND service:

- Universal – when a child is experiencing some distress about being in hospital but is coping well, general support will be provided for the family as well as information about common issues children experience in hospital. Distress levels will be monitored, and the family can be referred for more help if necessary.
- Targeted – when a child is showing increasing signs of distress and persistent signs of not coping, staff will provide extra support and guidance. Distress levels will be monitored, and the family can be referred for more help if necessary.
- Clinical – if a child is showing severe distress, a referral for psychological, social and mental health support may be provided.

A study of the lived experience of parents caring for a child with a life-limiting condition in Australia identified some of the psychosocial challenges parents were found to endure:<sup>207</sup>

- The experience of feeling 'trapped inside the house' describes parents' physical and social isolation from community, their exclusion from the workforce and the associated impacts on their health and well-being that resulted from being the primary caregiver. Few of the parents had remained in their current employment since becoming a caregiver. The majority had stopped work, reduced their working hours and/or changed career path to accommodate more flexible work options;
- Parents described the enormity of their caregiving role, conceptualised as being the protector of their child. This role as protector entailed holding all knowledge of the child's unique and specific care needs and also all ownership of the responsibility associated with caring duties;
- The pervasiveness of living with the probability of the child's death. For all parents, the idea of death was mostly unspeakable. Uncertainty and grief for the life that could have been were common, both for themselves and for their child and family; and
- Parents accepted that taking on the caregiving role meant embarking on a new life path. Their life as a caregiver was described to be different to the one they had imagined or expected, but the finality of their circumstances was conceptualised as part of life's new course for them.

Suggestions to alleviate or lessen some of these challenges included: increasing the availability of in-home psychological counselling, respite or short-breaks and grief and bereavement counselling; use of trained volunteers to provide support in the home; and establishment of a peer mentoring system to help reduce the feelings of isolation.<sup>208</sup>

203. Collins A, Hennessy-Anderson N, Hosking S, Hynson J, Remedios C, Thomas K, Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study, *Palliat Med.* 2016 Dec;30(10):950-959

204. Ling J, Payne S, Connaire K, McCarron M., Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model, *Child Care Health Dev.* 2016 Jan;42(1):51-9

205. Davis KG, Integrating Paediatric Palliative Care into the School and Community, *Pediatr Clin North Am.* 2016 Oct;63(5):899-911.

206. Government of Western Australia Child and Adolescent Health Service, Keeping Kids in No Distress (KKIND), available: <https://pch.health.wa.gov.au/our-services/keeping-kids-in-no-distress>

207. Collins A, Hennessy-Anderson N, Hosking S, Hynson J, Remedios C, Thomas K, Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study, *Palliat Med.* 2016 Dec;30(10):950-959

208. Collins A, Hennessy-Anderson N, Hosking S, Hynson J, Remedios C, Thomas K, Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study, *Palliat Med.* 2016 Dec;30(10):950-959

Optimal elements of a SPPC would see a parent supported by:<sup>209</sup>

- A break from caring through respite, or short breaks;
- Enabling parental time with other children;
- Access to trusted staff;
- Bereavement support; and
- Planned activities for other children.

Having access to support and advice around the clock is important for continuity of care, and parents report feeling less abandoned and more reassured when after-hours access to paediatric palliative care is available.<sup>210</sup> However, the provision of after-hours support for patients receiving palliative care has been well documented as a challenge from the perspective of both the patients and the health professionals who care for them.<sup>211</sup> In Queensland, an after-hours phone service, operated by oncology clinical nurse consultants who are experienced in paediatric palliative care, provides support for families and primary care teams caring for a child with a life-limiting condition. The main reasons for calls to the service relate to communication, practical issues, symptom management and emotional support. A review of the service found it to be well-accessed by families and primary care providers, suggesting it is a simple, effective, and valuable after-hours support service.<sup>212</sup>

## NICU parents

One sub-group of parents, those with a child with a life-limiting condition in a NICU, were found to have another specific challenge relevant to the NICU environment; they wanted to understand the facts and expressed a desire to understand the system.<sup>213</sup> The NICU is an unfamiliar environment for most people and an admission is often unexpected, leaving parents unprepared for the enormity of a NICU.

As NICU parents often experience a range of emotions and often have difficulty processing information and making decisions when their newborn is critically ill, it is imperative that the SPPC team supports parents not only emotionally, but cognitively too, to help them understand the environment, the various staff roles and the therapies being provided.<sup>214</sup> Falck et al. found that mothers of children in the NICU value transparent communication that provides information in a personalised and sensitive manner. Family meetings are also considered a valued forum for communication, shared decision making and for parents to advocate for their child.<sup>215</sup>

## Sibling and grandparent support

Ideally the role of the paediatric palliative care clinician 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.<sup>216</sup>

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

209. 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.

210. Verberne, et al. "Parental experiences with a paediatric palliative care team: A qualitative study." *Palliative medicine* 31.10 (2017): 956-963.

211. Bradford N, Irving H, Smith A, Pedersen L, Herbert A, Palliative Care After-Hours: A review of a phone support service, *J Pediatr Oncol Nurs*. 2012, May-Jun;29(3):141-50.

212. Bradford N, Irving H, Smith A, Pedersen L, Herbert A, Palliative Care After-Hours: A review of a phone support service, *J Pediatr Oncol Nurs*. 2012, May-Jun;29(3):141-50.

213. Falck AJ, Moorthy S, Hussey-Gardner B., Perceptions of Palliative Care in the NICU, *Adv Neonatal Care*. 2016 Jun;16(3):191-200

214. Falck AJ, Moorthy S, Hussey-Gardner B., Perceptions of Palliative Care in the NICU, *Adv Neonatal Care*. 2016 Jun;16(3):191-200

215. Falck AJ, Moorthy S, Hussey-Gardner B., Perceptions of Palliative Care in the NICU, *Adv Neonatal Care*. 2016 Jun;16(3):191-200

216. Jones BL, Contro N, Koch KD., The duty of the physician to care for the family in paediatric palliative care: context, communication, and caring., *Paediatrics*. 2014 Feb;133 Suppl 1:S8-15

family.<sup>217</sup> 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.<sup>218</sup>

Suggestions to help siblings adjust to having an ill sibling and to cope with the changes in life this may bring include:<sup>219</sup>

- 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;
- 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 considered helpful included: arranged activities; opportunities for networking with other siblings within the care environments; and respite or short breaks for the child living with a life-limiting condition, allowing siblings more time to spend with their parents.<sup>220</sup> 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. This can provide parents with a great deal of comfort and peace of mind in what may frequently be chaotic situations.<sup>221</sup>

Grandparents represent an important source of informal support for families managing childhood illness, often providing emotional and practical support to the child and parents, as well as any healthy siblings. Like siblings, grandparents can also experience reduced psychological wellbeing. Grandparents may experience 'double worry': worry about the well-being of their grandchild as well as their own child (the child's parent).<sup>222</sup>

Recent Australian studies reported that grandparents of children with cancer experienced clinically significant anxiety and clinically significant depression.<sup>223,224</sup> Grandparents described feeling helplessness, guilty and isolated during their grandchild's cancer treatment. Grandparents also reported physical symptoms, a decline in health, eating poorly, exercising less, sleeping less and experiencing more 'aches and pains'. Yet, fewer than 5% of grandparents had accessed psychosocial support.<sup>225</sup>

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217. Gaab, E., Owens, G., MacLeod, R., Siblings caring for and about paediatric palliative care patients, *J of Pall Med*, 2014, 17(1): 62-67

218. Jones BL, Contro N, Koch KD., The duty of the physician to care for the family in paediatric palliative care: context, communication, and caring., *Paediatrics*. 2014 Feb;133 Suppl 1:S8-15

219. Jones BL, Contro N, Koch KD., The duty of the physician to care for the family in paediatric palliative care: context, communication, and caring., *Paediatrics*. 2014 Feb;133 Suppl 1:S8-15

220. Virdun C, Brown N, Phillips J, Luckett 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.

221. Davis KG, Integrating Paediatric Palliative Care into the School and Community, *Pediatr Clin North Am*. 2016 Oct;63(5):899-911.

222. Wakefield C, Fardell J, Doolan E, Drew D, De Abreu Lourenco R, Young A, Cohn R, Grandparents of children with cancer: Quality of life, medication and hospitalisations, *Paediatric Blood and Cancer*, 2016; 00:1-9

223. Wakefield C, Fardell J, Doolan E, Drew D, De Abreu Lourenco R, Young A, Cohn R, Grandparents of children with cancer: Quality of life, medication and hospitalisations, *Paediatric Blood and Cancer*, 2016; 00:1-9

224. Wakefield C, Drew D, Ellis S, Doolan E, McLoone J, Cohn R, Grandparents of children with cancer: a controlled study of distress, support and barriers to care, *Psychooncology*, 2014 Aug;23(8):855-61.

225. Wakefield C, Fardell J, Doolan E, Drew D, De Abreu Lourenco R, Young A, Cohn R, Grandparents of children with cancer: Quality of life, medication and hospitalisations, *Paediatric Blood and Cancer*, 2016; 00:1-9

## 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. Respite, which is also referred to as short breaks or specialist short breaks, may be formally or informally structured and is often cited as an essential component of children's palliative care, providing a break for both the child and family from the routine of care.<sup>226,227</sup>

The medical, nursing, emotional and behavioural needs of a child living with a life-limiting condition are dynamic, which means the need for respite 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.<sup>228</sup> The option for emergency respite, or short breaks, is important to accommodate unanticipated changes in a child's condition or unforeseen events within a family as a whole.<sup>229</sup>

Home respite is often the location of choice for parents, particularly if their child is unwell and if time left with their child is perceived to be limited. Furthermore, hospital admissions can be more stressful than providing care at home.<sup>230</sup> However, there are potential issues regarding the impact of care provision in the home on family life, siblings and the concept of home.<sup>231</sup>

Benefits of respite 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 respite 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.<sup>232</sup> Ling et al. found that parents are 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.<sup>233</sup> 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, or short break.<sup>234</sup>

Other reported barriers to accessing adequate respite include a paucity of appropriately trained respite providers, complexity of care of their child, lack of financial support or the family being geographically isolated.<sup>235</sup>

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226. Ling J, Payne S, Connaire K, McCarron M., Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model, *Child Care Health Dev.* 2016 Jan;42(1):51-9

227. Smith CH, Graham CA, Herbert AR., Respite needs of families receiving palliative care, *J Paediatr Child Health.* 2017 Feb;53(2):173-179

228. Smith CH, Graham CA, Herbert AR., Respite needs of families receiving palliative care, *J Paediatr Child Health.* 2017 Feb;53(2):173-179

229. Smith CH, Graham CA, Herbert AR., Respite needs of families receiving palliative care, *J Paediatr Child Health.* 2017 Feb;53(2):173-179

230. Ling J, Payne S, Connaire K, McCarron M., Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model, *Child Care Health Dev.* 2016 Jan;42(1):51-9

231. Ling J, Payne S, Connaire K, McCarron M., Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model, *Child Care Health Dev.* 2016 Jan;42(1):51-9

232. Ling J, Payne S, Connaire K, McCarron M., Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model, *Child Care Health Dev.* 2016 Jan;42(1):51-9

233. Ling J, Payne S, Connaire K, McCarron M., Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model, *Child Care Health Dev.* 2016 Jan;42(1):51-9

234. Viridun C, Brown N, Phillips J, Luckett 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.

235. Smith CH, Graham CA, Herbert AR., Respite needs of families receiving palliative care, *J Paediatr Child Health.* 2017 Feb;53(2):173-179

## Grief and bereavement support

Grief and bereavement services for families are another important element of support when a child has a life-limiting condition. This support may commence before the child dies, as grief and bereavement counsellors may be able to help parents talk to their child and their siblings about death and prepare them with clear and honest explanations.<sup>236</sup> Sometimes parents and siblings may also 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.<sup>237</sup>

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:<sup>238</sup>

- Close kinship to the child who is dying;
- 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 medical intervention (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.<sup>239</sup>

Paediatric palliative care clinicians have an ethical duty to care for the families of children with life-limiting conditions through their bereavement. This is predicated on the principle of non-abandonment. The principle of non-abandonment is an important one in paediatric palliative care, as many families report being well cared for during their child's treatment but feel as if the team members suddenly disappear after the death of the child.<sup>240</sup> Family-centred care requires assistance to the family in bereavement after death. Medical specialists can support and be supported by their

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236. Australian Center for Grief and Bereavement, After the loss of a child – a resource for parents of children in palliative care, 2015, available:[https://www.grief.org.au/ACGB/ACGB\\_Publications/Resources\\_for\\_the\\_Bereaved/Paediatric\\_Palliative\\_Care.aspx](https://www.grief.org.au/ACGB/ACGB_Publications/Resources_for_the_Bereaved/Paediatric_Palliative_Care.aspx)

237. Australian Center for Grief and Bereavement, After the loss of a child – a resource for parents of children in palliative care, 2015, available:[https://www.grief.org.au/ACGB/ACGB\\_Publications/Resources\\_for\\_the\\_Bereaved/Paediatric\\_Palliative\\_Care.aspx](https://www.grief.org.au/ACGB/ACGB_Publications/Resources_for_the_Bereaved/Paediatric_Palliative_Care.aspx)

238. Victoria State Government, Bereavement support standards for palliative care services, 2012, available: <https://www2.health.vic.gov.au/about/publications/researchandreports/Bereavement-support-standards-for-palliative-care-services>

239. Victoria State Government, Bereavement support standards for palliative care services, 2012, available: <https://www2.health.vic.gov.au/about/publications/researchandreports/Bereavement-support-standards-for-palliative-care-services>

240. Jones BL, Contro N, Koch KD., The duty of the physician to care for the family in paediatric palliative care: context, communication, and caring., *Paediatrics*. 2014 Feb;133 Suppl 1:S8-15

multidisciplinary palliative care team members in providing compassionate, ethical, and holistic bereavement care to the entire family.<sup>241</sup>

Hospitals play a role in providing transitional bereavement support for the whole family, specifically in the perinatal, neonatal and paediatric settings. Hospital-based interventions may include phone calls at key intervals, the provision of resource materials, group programs, particularly for siblings, and remembrance programs.<sup>242</sup>

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241. Jones BL, Contro N, Koch KD., The duty of the physician to care for the family in paediatric palliative care: context, communication, and caring., *Paediatrics*. 2014 Feb;133 Suppl 1:S8-15

242. Donovan L, Wakefield C, Russell V, Cohn R, Hospital-based bereavement services following the death of a child: a mixed study review, *Palliat Med*. 2015 Mar;29(3):193-210.

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

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### 3.1. PLANNING THE SPECIALIST PAEDIATRIC PALLIATIVE CARE WORKFORCE

*For information pertaining to the composition of the paediatric palliative care workforce, refer to Chapter 2.3 of this document.*

### 3.2. A CAPABILITY FRAMEWORK FOR THE PAEDIATRIC PALLIATIVE CARE WORKFORCE

Each Australian state has a clinical capability framework for palliative care. PCA expects States and Territories to use the national palliative care workforce capability framework as a broad template to update their existing role delineation and clinical services capability frameworks. A review of each of these current frameworks was undertaken to identify specific references to paediatrics, with the results for each state outlined below.

#### **New South Wales**

The New South Wales (NSW) Framework for the Statewide Model for Palliative and End-of-Life Care Service Provision is a high-level framework designed to inform the development of a comprehensive model of care for equitable palliative and end-of-life care service provision in NSW. It acknowledges the unique needs of paediatrics.<sup>243</sup>

Specifically, the Framework highlights that “there are some groups in the community who have special needs in relation to palliative and end-of-life care. These include people [living] with dementia, *children and adolescents*, [Indigenous] Australians and those from different cultural or linguistic backgrounds. The needs of these specific groups are often particularly difficult to meet within the current service models and arrangements” (emphasis added).<sup>244</sup>

No further reference is made to children or paediatrics within the NSW Framework for the Statewide Model for Palliative and End-of-Life Care Service Provision.

#### **Queensland and South Australia**

Queensland Health’s Clinical Services Capability Framework (CSCF) has been designed to guide a coordinated and integrated approach to health service planning and delivery in Queensland.<sup>245</sup> Service networking by health facilities is fundamental to providing essential service links across a range of sites and settings, ensuring continuity of care and integrated levels of care for safe and sustainable services to meet community need. This is particularly important in parts of Queensland

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243. NSW Agency for Clinical Innovation, Framework for the Statewide Model for Palliative and End of Life Care Service Provision, 2013, available: [https://www.aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0019/184600/ACI-Framework-for-Statewide-Model-of-PEoLC-Service-Provision.pdf](https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0019/184600/ACI-Framework-for-Statewide-Model-of-PEoLC-Service-Provision.pdf)

244. NSW Agency for Clinical Innovation, Framework for the Statewide Model for Palliative and End of Life Care Service Provision, 2013, available: [https://www.aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0019/184600/ACI-Framework-for-Statewide-Model-of-PEoLC-Service-Provision.pdf](https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0019/184600/ACI-Framework-for-Statewide-Model-of-PEoLC-Service-Provision.pdf)

245. Queensland Government Department of Health, Clinical Services Capability Framework Fact Sheet 6 Service Networks, available: [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0033/444489/cscf-fs5-service-networks.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0033/444489/cscf-fs5-service-networks.pdf)

where health service provision is complicated by geographical distance, low population size and density, and limited health service options.<sup>246</sup>

The CSCF for palliative care comprises six levels, with Level 6 applying to the most complex and comprehensive services. The CSCF for palliative states that:

Although the general principles and basic approach of palliative care apply to children, adolescents and adults, there are important differences between these age groups, which must be addressed when providing children's palliative care.<sup>247</sup>

The differences associated with children's palliative care include:<sup>248</sup>

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

Children's palliative care recognises children have complex clinical and support needs, while their family and/or carers have an increased emotional burden and the risk of complicated grief. In addition to the requirements outlined in the Fundamentals of the Framework, specific workforce requirements include:<sup>249</sup>

- All health professionals involved in the care of palliative patients are educated about the psychosocial impact of life-limiting condition for the patient and family, and in the management of issues associated with dying, death and bereavement; and
- Where children's palliative care is provided, a range of professional healthcare providers have experience in paediatrics and have undertaken, or are working towards, a children's palliative care qualification.

The South Australia Health Clinical Services Capability Framework has been reproduced with the permission of the Queensland Department of Health and it contains the same information in relation to paediatric palliative care.<sup>250</sup>

## Victoria

The Palliative Care Service Capability Framework for Victoria does not refer to children or paediatrics.<sup>251</sup>

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246. Queensland Government Department of Health, Clinical Services Capability Framework Fact Sheet 6 Service Networks, available:

[https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0033/444489/cscf-fs5-service-networks.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0033/444489/cscf-fs5-service-networks.pdf)

247. Queensland Government Department of Health, Palliative Care Services CFCSv3.2 Module Overview, available:

[https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0022/444361/cscf-palliative-care.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0022/444361/cscf-palliative-care.pdf)

248. Queensland Government Department of Health, Palliative Care Services CFCSv3.2 Module Overview, available:

[https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0022/444361/cscf-palliative-care.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0022/444361/cscf-palliative-care.pdf)

249. Queensland Government Department of Health, Palliative Care Services CFCSv3.2 Module Overview, available:

[https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0022/444361/cscf-palliative-care.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0022/444361/cscf-palliative-care.pdf)

250. South Australian Government SA Health, Clinical Services Capability Framework Palliative Care, 2016, available:

<http://www.sahealth.sa.gov.au/wps/wcm/connect/29469e804e49f7e991aed9c09343dd7f/15137.3-22+Palliative+Care-WebSec.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-29469e804e49f7e991aed9c09343dd7f-m08cvse>

251. Victorian State Government Health and Human Services, Palliative Care Service Capability Framework, 2016, available:

<https://www2.health.vic.gov.au/about/publications/policiesandguidelines/palliative-care-service-capability-framework>

## Western Australia

The Western Australia Health Clinical Services Framework does not make specific reference to children or paediatrics in relation to palliative care.<sup>252</sup>

## Tasmania

The Tasmania Palliative Care Service Delivery Model does not make specific reference to children or paediatrics.<sup>253</sup>

### 3.3. REGIONAL PLANNING AND NETWORKING OF PAEDIATRIC PALLIATIVE CARE SERVICES

A summary of current paediatric palliative care services within each state and territory of Australia is provided below.<sup>254</sup>

## New South Wales

The paediatric palliative care services currently provided within NSW include:

### **Sydney Children's Hospital Network**

The Sydney Children's Hospital Network Department of Palliative Care incorporates The Children's Hospital at Westmead, The Sydney Children's Hospital at Randwick and Bear Cottage, a children's hospice in Manly.

The Children's Hospital at Westmead and the Sydney Children's Hospital at Randwick have a team of specialist doctors, nurses and allied health professionals providing consultative services and working alongside the primary medical team caring for a child and family throughout an illness. Bear Cottage is the only children's hospice in NSW and provides paediatric palliative care 24 hours a day with support from specialist medical resources at the Sydney Children's Hospital.

### **John Hunter Children's Hospital**

The paediatric palliative care service at the John Hunter Children's Hospital in Newcastle provides support to children with life limiting conditions from the Hunter, New England and North Coast regions of NSW.

## Queensland

The paediatric palliative care services currently provided within Queensland include:

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252. Government of Western Australia Department of Health, WA Health Clinical Services Framework 2014-2024, available: [http://www.health.wa.gov.au/hrit/docs/publications/Clinical\\_Framework\\_2014-2024.pdf](http://www.health.wa.gov.au/hrit/docs/publications/Clinical_Framework_2014-2024.pdf)

253. [https://www.dhhs.tas.gov.au/palliativecare/better\\_access\\_to\\_palliative\\_care\\_project\\_outcomes\\_2012\\_-\\_2017/project\\_activities/tasmanian\\_model\\_of\\_service\\_delivery\\_for\\_palliative\\_care](https://www.dhhs.tas.gov.au/palliativecare/better_access_to_palliative_care_project_outcomes_2012_-_2017/project_activities/tasmanian_model_of_service_delivery_for_palliative_care)

254. Palliative Care Australia, Paediatric Palliative Care Planning – Find a Service, 2018, available: <http://palliativecare.org.au/children>

## **Children's Hospital Queensland Hospital and Health Service**

The Children's Hospital Queensland in Brisbane provide support to children with a life-limiting condition and their families in several places, including home, the Children's hospital, local hospitals and hospice.

## **Hummingbird House**

Hummingbird House in Brisbane delivers medically supported, best practice paediatric palliative care for children with life-limiting conditions, and their families. It provides access to short break stays, family support services, creative therapies, and end-of-life care.

## **South Australia**

The paediatric palliative care services currently provided within South Australia include:

### **Women's and Children's Hospital**

The Women's and Children's Hospital Paediatric Palliative Care Service covers South Australia and the Northern Territory and provides:

- Clinical and consultative services;
- Coordination of GPs and health care agencies in the community;
- Support for staff in hospital medical units, metropolitan and regional health service centres;
- Coordination of services and case management; and
- Education in the specialty of paediatric palliative care.

Referrals are accepted from health care professionals across the care spectrum and families may also self-refer.

## **Victoria**

The paediatric palliative care services currently provided within Victoria include:

### **The Royal Children's Hospital Melbourne**

The Royal Children's Hospital Melbourne runs a consultation-liaison team responsible for the care of children with palliative care needs and their families called the Victorian Paediatric Palliative Care Program. This is a partnership between the Royal Children's Hospital Melbourne, Monash Children's Hospital and Very Special Kids. The team does not provide direct patient care, rather, team members facilitate better communication between tertiary institutions and care providers in the community allowing more children to be cared for at home by palliative care agencies and other services. Phone advice is available to clinicians 24/7.

### **Very Special Kids**

Very Special Kids is the only children's hospice in Victoria and it offers families access to planned and emergency respite, as well as end-of-life care. The hospice provides 24-hour medical and nursing care.

## Western Australia

The paediatric palliative care services currently provided within Western Australia include:

### Perth Children's Hospital

The Perth Children's Hospital runs the Western Australia Paediatric Palliative Care Service, which consists of a team comprising a doctor, nurses, social workers and a secretary, who work alongside the child's clinical team/s to provide support to children, parents and carers, as well as clinical staff and community-based services.

## Northern Territory and Tasmania

While the Northern Territory does not have a dedicated paediatric palliative care service, their palliative care services provide care and support for people of all ages. Children and families requiring specialist paediatric palliative care services may be referred to the Women's and Children's Hospital in Adelaide, South Australia.

While Tasmania does not have a dedicated paediatric palliative care service, their palliative care services provide care and support for people of all ages. Children and families requiring specialist paediatric palliative care services may be referred to The Royal Children's Hospital Melbourne.

## Australian Capital Territory

The Australian Capital Territory (ACT) recognised the need for a specialist paediatric palliative care service in the ACT Health Directorate's Palliative Care Services Plan 2013-2017,<sup>255</sup> and subsequent Paediatric Palliative Care Model of Care. The Paediatric Palliative Care Service is currently under development, with a specialist advanced nurse role providing a consultative service in collaboration with the existing palliative care, and other clinical and non-government services in the ACT. Care is provided to children residing in the ACT, and also regional NSW when their primary teams are based at The Canberra Hospital and the Centenary Hospital for Women and Children. A new ACT Health Directorate's Palliative Care Service Plan is in the consultation phase and will provide the framework for the ongoing development of the Paediatric Palliative Care Service. Children living in the ACT and families requiring specialist paediatric palliative care services may also be referred to the Sydney Children's Hospital Network if required.

## Models of care

There are varying models of SPPC in Australia that utilise available resources to provide holistic palliative care to the child and their family to support the provision of palliative care in the home, or as close to home as possible. These models are dependent on location, resources and historical factors.<sup>256</sup>

Access to specialist paediatric palliative care services can be limited, particularly in regional or rural locations.<sup>257,258</sup> The consultative paediatric palliative care model of care is configured to provide specialist advice and support to a child's primary healthcare team. In this model, the child or young

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255. ACT Government Health, Palliative care Services Plan 2013-2017, available: <https://www.pallcareact.org.au/act-palliative-care-strategy/>

256. Mherekumombe M, Frost J, Hanson S, Shepard E, Collins J, Pop up: A new model of paediatric palliative care, 2016, Journal of Paediatrics and Child Health 52 (2016) 979-982

257. Herbert A, Bradford N, Donovan L, Pedersen LA, Irving H., Development of a state-wide paediatric palliative care service in Australia: referral and outcomes over two years, J Palliat Med. 2014 Mar;17(3):288-95

258. Bradford NK, Armfield NR, Young J, Smith AC, Paediatric palliative care by video consultation at home: a cost minimization analysis, BMC Health Serv Res. 2014 Jul 28;14:328

person and their family are cared for by their usual healthcare team, ensuring continuity of care throughout the child's illness trajectory, and specialist paediatric palliative care advice is provided on a consultative basis.<sup>259</sup> This model allows the specialist paediatric palliative care physician to see more patients than they would otherwise be able to accommodate, whilst also building palliative care capability in primary healthcare providers.

A similar model of paediatric palliative care services for children/young people and their families has been established in New South Wales. However, rather than just a sole paediatric palliative care medical specialist providing the consultative service, an entire SPPC team provides the care via a Pop-Up model of care. A pop-up intervention aims to build capacity and enable local health services to feel confident to care for patients and their families at home, or as close to home as possible. It aims to establish a network of care around a child and family supported by the specialist service.<sup>260</sup>

These teams provide support to children and their families in a responsive manner, whether they are at home or in hospital. They support the primary treating team of a child referred to the service to enhance the coordination of care across the hospital and community. The teams can provide advice and support for complex symptom management and psychosocial support for all members of the family.<sup>261</sup>

The service also provides: support to clinicians caring for children at home, including GPs, nurses and care workers; targeted training to support professionals; and ongoing access to paediatric palliative care expertise for families and clinicians by telephone, telehealth or other communication modes.<sup>262</sup> The pop-up model of care is one way of delivering SPPC to a relatively small, but geographical dispersed population. It can be adapted in any setting, as it uses locally available resources to enhance the care of children requiring palliative care.<sup>263</sup>

A different model operates in Victoria. The Victorian Paediatric Palliative Care Program (VPPCP) consultation-liaison team is responsible for the facilitation of care of children with palliative care needs and their families. The VPPCP team, comprising specialist medical, case management/social work, occupational therapy and nursing staff, works closely with each of the member organisations to identify children, coordinate care and provide appropriate advice regarding various aspects of patient management. Educational activities for staff from both hospital and community agencies are also offered. The team members do not provide direct patient care. Rather, they facilitate communication between tertiary institutions and care providers in the community and aim to support more children to be cared for at home by palliative care agencies and other services.<sup>264</sup>

## Designing a paediatric palliative care service

If a health service is considering the establishment of a paediatric palliative care service, there are several practical considerations that may help guide program planning and implementation, including:<sup>265</sup>

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259. 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.

260. NSW Ministry of Health, Support services for dying children and their families, available: <http://www.health.nsw.gov.au/palliativecare/Pages/support-services-for-dying-children-and-their-families.aspx>

261. NSW Ministry of Health, Support services for dying children and their families, available: <http://www.health.nsw.gov.au/palliativecare/Pages/support-services-for-dying-children-and-their-families.aspx>

262. NSW Ministry of Health, Support services for dying children and their families, available: <http://www.health.nsw.gov.au/palliativecare/Pages/support-services-for-dying-children-and-their-families.aspx>

263. Mherekumombe M, Frost J, Hanson S, Shepard E, Collins J, Pop up: A new model of paediatric palliative care, 2016, *Journal of Paediatrics and Child Health* 52 (2016) 979–982

264. The Royal Children's Hospital, The Victorian Paediatric Palliative Care Program, Available: [https://www.rch.org.au/rch\\_palliative/home/The\\_Victorian\\_Paediatric\\_Palliative\\_Care\\_Program/](https://www.rch.org.au/rch_palliative/home/The_Victorian_Paediatric_Palliative_Care_Program/)

265. Schmidt, K., Paediatric palliative care: starting a hospital-based program, *Pediatr Nurs.*, 2011 Sep-Oct;37(5):268-74.

- Which clinical services are offered within the organisation that would likely require paediatric palliative care? Examples may include:
  - ▶ Oncology;
  - ▶ Neurology;
  - ▶ PICU; or
  - ▶ NICU.
- How many children die annually within the organisation?
  - ▶ Is there a tracking system in place?
  - ▶ Does tracking include deaths outside the hospital?
- What complementary services are already offered within the organisation? Are there other organisations that they may partner with to provide a service? Examples may include:
  - ▶ Social work;
  - ▶ Pastoral care;
  - ▶ Bereavement follow-up programs;
  - ▶ Mental health;
  - ▶ Pain management;
  - ▶ Physiotherapy; or
  - ▶ Community programs.
- What type of clinical model of care would fit within the organisation? Examples include:
  - ▶ An inpatient unit;
  - ▶ Designated palliative care beds within a paediatric or diagnostically based unit; or
  - ▶ A paediatric palliative care service by consultation only.
- How will patients enter the service – what referral pathways would need to be established?
- Do the IT systems support care across multiple settings and transition of services?
- Will the organisation be able to support the educational and research requirements of a service?
- What debriefing and support mechanisms will be available for staff?
- What metrics will need to be established to continually monitor the service?
- What are the expected resource implications for the organisation?

## Perinatal palliative care service

For a hospital with an obstetric service, a NICU or paediatric palliative care service, the 'Framework for clinical practice in perinatal medicine' provides guidance for the establishment of a perinatal palliative care service.<sup>266</sup> Generally, there are three circumstances where perinatal palliative care may be considered:<sup>267</sup>

- Prenatally diagnosed fetal anomalies or life-limiting conditions;
- Pre-viable pre-term fetus where birth is imminent; and
- Newborn with postnatally diagnosed life-limiting condition.

The 'Framework for clinical practice in perinatal medicine' divides palliative care planning into eight stages.<sup>268</sup>

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266. Balaguer A, Martín-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature, BMC Pediatr. 2012 Mar 12;12:25.

267. Department of Health, Western Australia. Perinatal Palliative Care Model of Care. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.

268. Balaguer A, Martín-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature,

- Eligibility of fetus or baby for palliative care;
- Family care (including psychological support, creating memories, support of spiritual/personal belief and social support);
- Communication and documentation; and
- Flexible parallel care planning.

The next four stages represent points of care transition:<sup>269</sup>

- Pre-birth care;
- Transition from active postnatal care to supportive care;
- End-of-life care; and
- Post end-of-life care.

The Western Australia Department of Health 'Perinatal Palliative Care Model of Care' suggests three planning stages reflect best-practice perinatal palliative care:<sup>270</sup>

- Entry into a palliative care pathway;
- Living with the condition; and
- End-of-life and bereavement care.

Goals of care for the fetus/newborn and their families include to:<sup>271,272</sup>

- Receive best practice perinatal palliative care according to their needs;
- Participate in decision making and care planning throughout their care with the focus being on the best interests of the baby;
- Institute a thoughtful approach to controlling pain and other symptoms that affect quality of life;
- Receive coordinated care across all sectors of health and community agencies;
- Receive care and support in their chosen place of care; and
- Be supported in their bereavement.

Maternal health and wellbeing during pregnancy, childbirth and the postnatal period remain a component of maternity care, including when there is a palliative approach to the care of the baby.<sup>273</sup>

### 3.4. PROFESSIONAL EDUCATION AND TRAINING FOR ALL PAEDIATRIC PALLIATIVE CARE PROVIDERS

According to Peng et al., a lack of knowledge of paediatric palliative care, and consequently a lack of confidence in oneself, can result in hesitation in providing paediatric palliative care.<sup>274</sup> This is supported by Widger et al. who found that clinicians considered they had gaps in the care they were providing to children with cancer, due to a self-identified lack of education for health professionals in

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BMC Pediatr. 2012 Mar 12;12:25.

269. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J., The model of Palliative Care in the perinatal setting: a review of the literature, BMC Pediatr. 2012 Mar 12;12:25.

270. Department of Health, Western Australia. Perinatal Palliative Care Model of Care. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.

271. Marc-Aurele, & English. "Primary palliative care in neonatal intensive care." Seminars in perinatology. Vol. 41. No. 2. WB Saunders, 2017.

272. Department of Health, Western Australia. Perinatal Palliative Care Model of Care. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.

273. Department of Health, Western Australia. Perinatal Palliative Care Model of Care. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.

274. Peng NH, Lee CH, Lee MC, Huang LC, Chang YC, DeSwarte-Wallace J, Effectiveness of Paediatric Palliative Care Education on Paediatric Clinicians, West J Nurs Res. 2017 Dec;39(12):1624-1638

paediatric palliative care.<sup>275</sup> Specifically, oncologists and other health professionals reported that a lack of training contributed to children with cancer experiencing a great deal of suffering from pain and other symptoms left inadequately treated, some parents feeling abandoned both before and after their child's death, family-centred care not being uniformly practiced, and siblings' needs not always being adequately addressed.<sup>276</sup>

Peng et al. propose that education is the key to giving paediatricians and paediatric nurses the knowledge, skills, and confidence they need to provide quality end-of-life care for children and their families.<sup>277</sup> A search for specific paediatric palliative care educational courses, both in Australia and internationally, was conducted and the results are provided below.

## Australian education courses

In Australia, the 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 College will be awarded Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM).<sup>278</sup> Alternatively, the RACP also offers a 6-month Clinical Diploma of Palliative Medicine that is available to registered medical practitioners. It involves supervised, work-place based training to prepare graduates to practice independently.<sup>279</sup>

The Centre for Palliative Care (CPC) at the University of Melbourne has a state-wide role in palliative care education, with a focus on ensuring education is multidisciplinary and delivered by experts in their field who may be drawn from multiple institutions around Victoria, as appropriate. The goals for CPC regarding palliative care education are to:<sup>280</sup>

- Increase general understanding and skill in palliative care through education and training of the general health workforce; and
- Develop future leaders in palliative care through programs designed to increase the number of palliative care physicians, and through facilitating opportunities for networking, peer support and leadership development.

For paediatric palliative care, the CPC offers two one-day non-award courses: Psychosocial and Spiritual Aspects and Ethics. These short courses also form part of the award courses: Specialist Certificate in Palliative Care or the Graduate Certificate in Palliative Care. These courses are designed for doctors, nurses and allied health professionals.<sup>281</sup>

The Centre for Palliative Care Research and Education (CPCRE) in Queensland offers a variety of educational resources for GP's, nurses, allied health professionals and residential aged care

275. Widger K, Friedrichsdorf S, Wolfe J, Liben S, Pole JD, Bouffet E, Greenberg M, Husain A, Siden H, Whitlock JA, Rapoport A., Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer, BMC Palliat Care. 2016 Jan 27;15:12

276. Widger K, Friedrichsdorf S, Wolfe J, Liben S, Pole JD, Bouffet E, Greenberg M, Husain A, Siden H, Whitlock JA, Rapoport A., Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer, BMC Palliat Care. 2016 Jan 27;15:12

277. Peng NH, Lee CH, Lee MC, Huang LC, Chang YC, DeSwarte-Wallace J, Effectiveness of Paediatric Palliative Care Education on Paediatric Clinicians, West J Nurs Res. 2017 Dec;39(12):1624-1638

278. The Royal Australasian College of Physicians, Palliative Medicine, available: <https://www.racp.edu.au/trainees/advanced-training/advanced-training-programs/palliative-medicine>

279. The Royal Australasian College of Physicians, Clinical Diploma in Palliative Medicine, available: <https://www.racp.edu.au/trainees/advanced-training/advanced-training-programs/clinical-diploma-of-palliative-medicine>

280. The University of Melbourne, Professional Development in Paediatric Palliative Care, available: <https://commercial.unimelb.edu.au/custom-education/search-courses/palliative-care/pcppc>

281. The University of Melbourne, Professional Development in Paediatric Palliative Care, available: <https://commercial.unimelb.edu.au/custom-education/search-courses/palliative-care/pcppc>

facilities. CPCRE has a state-wide role in developing, providing, promoting and supporting palliative care education. In collaboration with other education providers, clinical services, Primary Health Networks and aged care organisations, the CPCRE develops evidence based educational resources and provides a range of educational activities to enhance palliative care services in Queensland.<sup>282</sup>

The Palliative Care Curriculum for Undergraduates (PCC4U) project is led by Queensland University of Technology in collaboration with the Queensland Government, Flinders University in South Australia, and Curtin University of Technology in Western Australia and is funded by the Australian Government Department of Health. The PCC4U aims to promote and sustain the inclusion of the principles and practice of palliative care in all health care training. Four learning modules incorporate:<sup>283</sup>

- Principles of palliative care;
- Communicating with people with life-limiting illnesses;
- Clinical assessment and intervention in palliative care; and
- Optimising function in palliative care.

Flinders University in South Australia offers postgraduate training in palliative care via a graduate Certificate, Graduate Diploma or Masters in Palliative Care for people with a health professional background who are working in or interested in palliative care.<sup>284</sup>

The Australian Centre for Grief and Bereavement (ACGB) offer a webinar titled Family Bereavement After the Loss of a Child, with the following learning outcomes:<sup>285</sup>

- Understand the different types of child loss;
- Distinguish the similarities and differences between the different types of child loss;
- Respond to a family after child loss;
- Have strategies for supporting a family after child loss; and
- Have the resources available for families after child loss.

The Quality of Care Collaborative Australia (QuoCCA) for Paediatric Palliative Care project, delivered in partnership with children's hospitals across the country since 2014, aims to improve the quality of palliative care provided to children through research and educational initiatives.<sup>286</sup> A major focus of QuoCCA is educating staff in regional, rural and remote hospitals and clinics. This includes nurse educators employed throughout Australia, an allied health education team, and employment of medical fellows to allow more paediatricians to receive training in children's palliative care.<sup>287</sup>

The QuoCCA includes the following tertiary children's hospitals:<sup>288</sup>

- Children's Hospital Queensland, Brisbane, Queensland;
- John Hunter Children's Hospital, Newcastle, New South Wales;
- Sydney Children's Hospital, Randwick, New South Wales;
- Royal Children's Hospital Melbourne, Victoria;
- Women's and Children's Hospital, Adelaide, South Australia; and

282. Queensland Health, Centre for Palliative Care Research and Education – Education, 2018, available: [www.health.qld.gov.au/cpre/education](http://www.health.qld.gov.au/cpre/education)

283. Australian Government Department of Health, Palliative Care Curriculum for Undergraduates (PCC4U) Project, available: <http://media.pcc4u.org/Documents/FactSheet.pdf>

284. Flinders University, Palliative Care, available: <https://www.flinders.edu.au/study/courses/postgraduate-palliative-care>

285. The Australian Centre for Grief and Bereavement, Family Bereavement After the Loss of a Child [https://www.grief.org.au/Shared\\_Content/Events/Event\\_Display.aspx?EventKey=GTW080818](https://www.grief.org.au/Shared_Content/Events/Event_Display.aspx?EventKey=GTW080818)

286. Queensland Government Children's Health Queensland Hospital and Health Service, Enhancing paediatric palliative care across Australia, 2018, available: <https://www.childrens.health.qld.gov.au/latest-news-enhancing-paediatric-care-across-australia/>

287. Queensland Government Children's Health Queensland Hospital and Health Service, Enhancing paediatric palliative care across Australia, 2018, available: <https://www.childrens.health.qld.gov.au/latest-news-enhancing-paediatric-care-across-australia/>

288. <https://www.caresearch.com.au/quocca/tabid/4509/Default.aspx>

- Perth Children's Hospital, Perth, Western Australia.

The resources provided by QuoCCA for health professionals align with PCA's National Standards Assessment Program (NSAP), or Palliative Care Self-Assessment (PaCSA) as redesigned in 2018-19, and include:<sup>289</sup>

- Foundations of Paediatric Palliative Care;
  - ▶ Resources to Inform Clinical Practice;
  - ▶ Family Related Resources;
- Psychosocial Foundations of Palliative Care;
- Symptom Management;
- Advance Care Planning;
- Bereavement;
- Quality Improvement; and
- Education Resources:
  - ▶ On-line communication module;
  - ▶ Introduction to Paediatric Palliative Care (Western Australia);
  - ▶ Paediatric and Adolescent Palliative Care Model (Western Australia);
  - ▶ International Children's Palliative Care Network e-learning; and
  - ▶ SickKids Online Paediatric Pain Curriculum.

## International education courses

The End-of-Life Nursing Education Consortium – Paediatric Palliative Care Program (ELNEC-PPC) is a 10-module course developed by the American Association of Colleges of Nursing and City of Hope National Medical Centre. The course is designed for health care professionals to provide a more thorough understanding of how the end of a child's life affects families, friends, and care givers. The ten modules of the course address different aspects of coping with a terminal illness and provide insights into the bereavement process. The course aims to enhance the provision of care for patients, as well as emotional and spiritual support for survivors.<sup>290</sup>

The Education in Palliative and End-of-Life Care for Paediatrics (EPEC-Paediatrics) curriculum was developed by Friedrichsdorf et al. in collaboration with 35 national and international leaders in the field of paediatric pain medicine, haematology/oncology and palliative care, as well as parent advisors, through funding provided by the National Institutes of Health and National Cancer Institute in the United States of America.<sup>291</sup> The EPEC-Paediatrics curriculum consists of 24 modules designed for various modes of delivery. The modules include communication, team collaboration, family-centred care, grief and bereavement, ethics, pain management and self-care for professionals, among others.<sup>292</sup>

The Combined Curriculum in Paediatric Palliative Medicine was prepared by the Education Subgroup of the British Society for Paediatric Palliative Medicine and Association of Children's Hospice Doctors. It aims to inform the training and assessment of both specialist paediatric palliative care physicians and other doctors, such as paediatricians, adult palliative care physicians and GPs,

289. Quality of Care Collaborative Australia, Resources for Health Professionals, 2018, available: <https://www.caresearch.com.au/caresearch/tabid/4176/Default.aspx>

290. St Jude Children's Hospital Research Hospital, ELNEC Paediatric Palliative Care Seminars, 2018, available:[https://www.cure4kids.org/ums/home/public\\_area/pubcourse/?courses\\_id=41](https://www.cure4kids.org/ums/home/public_area/pubcourse/?courses_id=41)

291. Widger K, Friedrichsdorf S, Wolfe J, Liben S, Pole JD, Bouffet E, Greenberg M, Husain A, Siden H, Whitlock JA, Rapoport A., Protocol: Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer., BMC Palliat Care. 2016 Jan 27;15:12

292. Widger K, Friedrichsdorf S, Wolfe J, Liben S, Pole JD, Bouffet E, Greenberg M, Husain A, Siden H, Whitlock JA, Rapoport A., Protocol: Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer., BMC Palliat Care. 2016 Jan 27;15:12

who care for children with a life-limiting condition. The curriculum is divided into three sections; technical, interpersonal and intrapersonal.<sup>293</sup>

There are many common themes in the different educational resources identified and they have been designed to be delivered in a variety of ways, including didactic sessions, video presentations, interactive discussions, practice exercises, online modules, webinars and face-to-face sessions. Educational opportunities for professionals working with children requiring palliative care are central to future development within the specialty.<sup>294</sup> The range of international educational initiatives available provide an opportunity to learn with and from others working within the field.

### 3.5. WORKFORCE SUPPORT IN PAEDIATRIC PALLIATIVE CARE

The death of a child has an impact on staff at both a professional and personal level, with the full extent of the impact of these intense care experiences not really known,<sup>295,296</sup> but assumed to be high. To maintain the health and wellbeing of staff, as well as sustaining the quality of the service provided, staff support is an important consideration.<sup>297</sup>

Staff distress describes the emotional and psychological sensitivity that arises during complex care experiences, particularly those that staff perceive to be a negative experience.<sup>298</sup> Staff caring for children with a life-limiting condition often develop strong relationships over a prolonged period and can become very involved with the entire family. When the child dies, it can be a particularly intense and stressful time for all staff involved.

Staff distress can lead to emotional distress, unsafe or poor quality of patient care, job dissatisfaction or burnout.<sup>299,300</sup> Burnout can be described as the accumulated experience of working in an environment that impacts upon your emotional wellbeing, the personalisation of your work and any sense of accomplishment in the work environment.<sup>301</sup>

Staff may also experience moral distress, when they recognise and know the right thing to do but are then not able to carry it out.<sup>302</sup> Strong feelings of frustration, anger and anxiety can be experienced by doctors, nurses and allied health professionals when their own values and beliefs are impacted.

Despite these negative consequences, there often is a lack of support in place for providers who are experiencing these issues. It is imperative that deliberate strategies be developed and incorporated into the standard support for providers caring for children with life-limiting conditions,<sup>303</sup> particularly in relation to building staff resilience and promoting staff wellbeing.

A model for supporting staff might include the following elements:<sup>304</sup>

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293. Association of Paediatric Palliative Medicine, Combined Curriculum in Paediatric Palliative Care, 2015, available: <http://www.appm.org.uk/14.html>

294. Peng NH, Lee CH, Lee MC, Huang LC, Chang YC, DeSwarte-Wallace J, Effectiveness of Paediatric Palliative Care Education on Paediatric Clinicians, West J Nurs Res. 2017 Dec;39(12):1624-1638

295. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

296. Jonas DF, Bogetz JF, Identifying the Deliberate Prevention and Intervention Strategies of Paediatric Palliative Care Teams Supporting Providers during Times of Staff Distress, J Palliat Med. 2016 Jun;19(6):679-83

297. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

298. Jonas DF, Bogetz JF, Identifying the Deliberate Prevention and Intervention Strategies of Paediatric Palliative Care Teams Supporting Providers during Times of Staff Distress, J Palliat Med. 2016 Jun;19(6):679-83

299. Jonas DF, Bogetz JF, Identifying the Deliberate Prevention and Intervention Strategies of Paediatric Palliative Care Teams Supporting Providers during Times of Staff Distress, J Palliat Med. 2016 Jun;19(6):679-83

300. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

301. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

302. Austin W, Kelecevic J, Goble E, Mekechuk J, An overview of Moral Distress and the Paediatric Intensive Care Team, Nursing Ethics, 20019, 16 (1), 57-68

303. Jonas DF, Bogetz JF, Identifying the Deliberate Prevention and Intervention Strategies of Paediatric Palliative Care Teams Supporting Providers during Times of Staff Distress, J Palliat Med. 2016 Jun;19(6):679-83

304. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

- Psycho-education: the provision of information on the impact of stress and trauma;
- Training in coping skills and strategies; and
- Structured systems of workplace support, including opportunities to reflect on specific events and the potential for their personal impact.

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.<sup>305</sup>

Personal strategies include the development of self-care into daily life, such as ensuring adequate sleep, diet and exercise, which are all important for general fitness and building resilience. Finding a balance in life between work and non-work activities is also very important and is an effective strategy for health professionals' self-care in the longer term.<sup>306</sup> Learning specific strategies for managing stress can also give staff a greater sense of control. These specific skills include identifying and challenging negative thinking, time management skills, problem solving techniques and relaxation training.<sup>307</sup>

Workplace strategies include peer support, operational debriefings and psychological debriefings. Peer support involves training staff to manage the effects of the traumatic events to which they are exposed. This may involve developing skills to more effectively support each other and, where appropriate, refer to outside supports.<sup>308</sup> For organisations creating a culture of strong ethical standards, support structures for ethical decision making are crucial. A transparent and accessible Clinical Ethics Committee for example, is a structure that supports moral culture. Allowing teams time for discussion and debrief during complex cases, or after a child's death, strengthens a robust ethical approach. Allowing a safe workplace and team culture is essential, where staff feel safe to speak up and raise concerns.<sup>309</sup>

Operational debriefings focus more directly on the specifics of the care provided, particularly what was done, by whom, and with what resources. This type of debrief is generally undertaken by appropriately trained line managers and considers what additional learning can be gained from reflecting on the type of care provided. Psychological debriefs may involve follow-up of the group and/or individuals with a more supportive reflection of the experience.<sup>310</sup>

## 3.6. RESEARCH, EVALUATION AND BENCHMARKING IN PAEDIATRIC PALLIATIVE CARE

### Research and Evaluation

Outcome measurement of health service performance is necessary to make benchmark comparisons, develop clinical guidelines, and determine clinical effectiveness. Determining effectiveness is driven by the need to ensure the most efficient and appropriate use of resources relative to clinical outcomes. In an environment of fiscal constraint, particularly as it relates to health expenditure, it is incumbent upon policy makers, health care organisations, and researchers to ensure best use of public monies through implementation of the most effective intervention.

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305. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

306. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

307. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

308. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

309. Cherny N, Werman B, Kearney M, Burnout compassion fatigue and moral distress in palliative care, in Oxford Textbook of Palliative Medicine, 5th edition, Edited by Cherny N, Fallon M, Kaasa S, Portenoy R, and Currow D, Oxford University Press, 2015.

310. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

When determining the effectiveness of an intervention, one must assess and quantify the costs and the benefits. Although there are arguably many benefits gained from paediatric palliative care, health-related quality of life (HRQOL) is the primary outcome that is used to demonstrate intervention benefits. However, before selecting an instrument to measure HRQOL, the status of the children receiving services must be considered. For instance, in traditional paediatric palliative care programs, where services are mainly offered at the end-of-life, decline in HRQOL may be more rapid than in programs where children are receiving palliative care from the point of diagnosis, referred to as integrated programs. The stage of disease progression clearly has an impact on assessment of HRQOL.

There are numerous HRQOL instruments that have been used in paediatric populations. In a prior review of the literature, Knapp et al.<sup>311</sup> found more than 130 HRQOL studies conducted with children who had life-limiting conditions. Most of the instruments were found to be used for cancer, cystic fibrosis, and cerebral palsy. Among these more than 130 studies, the most widely used instrument was shown to be the Paediatric Quality of Life Inventory Generic Core Scale (PedsQL),<sup>312</sup> which has been validated in a variety of conditions such as asthma, cancer, heart disease, rheumatology, and diabetes.<sup>313,314,315</sup>

Difficulties in measuring HRQOL in palliative care have been previously cited in the literature.<sup>316,317</sup> HRQOL instruments are limited by the fact that patients in palliative care programs may be immobile and/or have diminished cognitive skills.

Beyond developing new instruments, there are other potential solutions for measuring HRQOL in paediatric palliative care. Item response theory and computerised adaptive tests (CAT) present novel opportunities for measuring HRQOL within this population.<sup>318,319</sup> Taenzer et al. found particularly encouraging results given the clinicians did not receive any specialised training in the use of the instrument or computer report, however, there were improvements in patients' HRQOL scores.<sup>320</sup> They noted that interventions with proven efficacy are available at the centre for the treatment of HRQOL problems, such as anxiety, mood disturbance and pain and symptom control.

Based on the existing evidence, it is clear that more research is needed in this area. Rigorous qualitative research is needed to understand what factors affect the HRQOL of children with life-limiting conditions.

Notwithstanding the difficulties in measuring HRQOL, there are several quality indicators and associated measures for palliative and end-of-life care for children for potential use by health

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311. Knapp, Caprice, and Vanessa Madden. "Conducting outcomes research in paediatric palliative care." *American Journal of Hospice and Palliative Medicine* 27.4 (2010): 277-281.
  312. Vami, James W., et al. "The PedsQL™ 4.0 as a paediatric population health measure: feasibility, reliability, and validity." *Ambulatory paediatrics* 3.6 (2003): 329-341.
  313. Vami JW, Burwinkle TM, Rapoff MA, Kamps JL, Olson N. The PedsQL in paediatric asthma: reliability and validity of the Paediatric Quality of Life Inventory generic core scales and asthma module. *J Behav Med.* 2004;27(3):297-318.
  314. Vami, James W., Michael Seid, and Paul S. Kurtin. "PedsQL™ 4.0: Reliability and validity of the Paediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations." *Medical care* (2001): 800-812.
  315. Vami JW, Burwinkle TM, Szer IS. The PedsQL Multidimensional Fatigue Scale in paediatric rheumatology: reliability and validity. *J Rheumatol.* 2004;31(12):2494-2500.
  316. Jordhoy MS, Inger Ringdal G, Helbostad JL, Oldervoll L, Loge JH, Kaasa S. Assessing physical functioning: a systematic review of quality of life measures developed for use in palliative care. *Palliat Med.* 2007;21(8):673-682.
  317. Mularski RA, Dy SM, Shugartman LR, et al. A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res.* 2007;42(5):1848-1870.
  318. Hays R, Morales L, Reise S. Item response theory and health outcomes measurement in the 21st century. *Med Care.* 2000;38(9S): I128-I142.
  319. Taenzer, Paul, et al. "Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients." *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 9.3 (2000): 203-213.
  320. Taenzer, Paul, et al. "Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients." *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 9.3 (2000): 203-213.

providers, although further work is required to validate the indicators.<sup>321</sup> These include outcome, process and structure indicators, such as:<sup>322,323</sup>

#### **Outcome indicators:**

- Child and parent HRQOL;
- 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 end-of-life care discussed with family.

#### **Structure indicators:**

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

## **Benchmarking**

The purpose of benchmarking in paediatric palliative care is to provide participating services with the opportunity to compare their service to other services, which ultimately drives better care and outcomes for children and their families.<sup>324</sup>

Most paediatric palliative care services and hospices are involved in quality improvement activities. This involves changes in practice that lead to better care and outcomes for patients and families. The National Palliative Care Standards (5<sup>th</sup> edn)<sup>325</sup> have been established to articulate a vision for the provision of holistic, individualised, sensitive and best practice palliative care for the person receiving care, their family and carers.

PCA's PaCSA is a quality improvement program available for all specialist palliative care services across Australia and will be released in 2019. It will seek to:

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321. Duc J, Widger K, Bouffet E, Friedrichsdorf S, Greenberg M, Husain A, Liben S, Pole J, Siden H, Whitlock J, Wolfe J, Rapoport A, Identifying indicators of quality palliative and end-of-life care for children with cancer, Presentation at the 21<sup>st</sup> International Congress on Palliative Care, Montreal Canada, Oct 2016, University of Toronto

322. Duc J, Widger K, Bouffet E, Friedrichsdorf S, Greenberg M, Husain A, Liben S, Pole J, Siden H, Whitlock J, Wolfe J, Rapoport A, Identifying indicators of quality palliative and end-of-life care for children with cancer, Presentation at the 21<sup>st</sup> International Congress on Palliative Care, Montreal Canada, Oct 2016, University of Toronto

323. Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

324. Queensland Government., Children's Health Queensland Hospital and Health Service, A practical guide to palliative care in paediatrics, 2014.

325. Palliative Care Australia, National Palliative Care Standards 5<sup>th</sup> Edition, available: <http://palliativecare.org.au/standards>

- Enable services to engage in continuous quality improvement through self-assessment against the PaCSA every two years;<sup>326</sup> and
- Allow palliative care services to prioritise key improvement quality areas and implement a quality improvement action plan.<sup>327</sup>

In the USA, the Initiative for Paediatric Palliative Care (IPPC) is a large project aimed at enhancing the capacity of children's hospitals to:<sup>328</sup>

- Maximise family involvement in decision making and care planning;
- Involve children in decisions regarding their care and care planning as fully as possible;
- Reduce pain and distressful symptoms for children with life-limiting conditions;
- Provide emotional and spiritual support to children and families;
- Facilitate the resolution of families' practical needs, such as the need for respite or short breaks;
- Facilitate continuity of care across care settings, both within and outside the hospital, by providing each family with a designated care coordinator; and
- Offer grief and bereavement support to the child and the family before and after death.

The IPPC encourages hospitals to:<sup>329</sup>

- Develop explicit policies and practices to advance the vision of family-centred care;
- Integrate palliative care with cure-oriented care from the beginning of the diagnosis;
- Develop strategies for enhancing the palliative care clinical competence of staff;
- Develop specific, routine mechanisms for meeting each of the child and family goals; and
- Commit to measuring the institution's progress toward these goals through routine, periodic data collection.

Although only currently being tested in seven hospitals, the aim of the IPPC is to inspire a national effort to improve palliative care for children and their families.

Workforce productivity is poorly defined in paediatric palliative care and little consensus exists regarding the optimal ways to define, measure and analyse productivity, due to difficulties with identification, measurement and interpretation of metrics applicable to a multidisciplinary care model.<sup>330</sup> The absence of consensus impedes aggregation and analysis of data to benchmark workforce efficiency and effectiveness.<sup>331</sup> Future research into this area will be required as the speciality develops within Australia.

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326. Palliative Care Australia, National Standards Assessment Program, available: <http://palliativecare.org.au/national-standards-assessment-program>

327. Palliative Care Australia, National Standards Assessment Program, available: <http://palliativecare.org.au/national-standards-assessment-program>

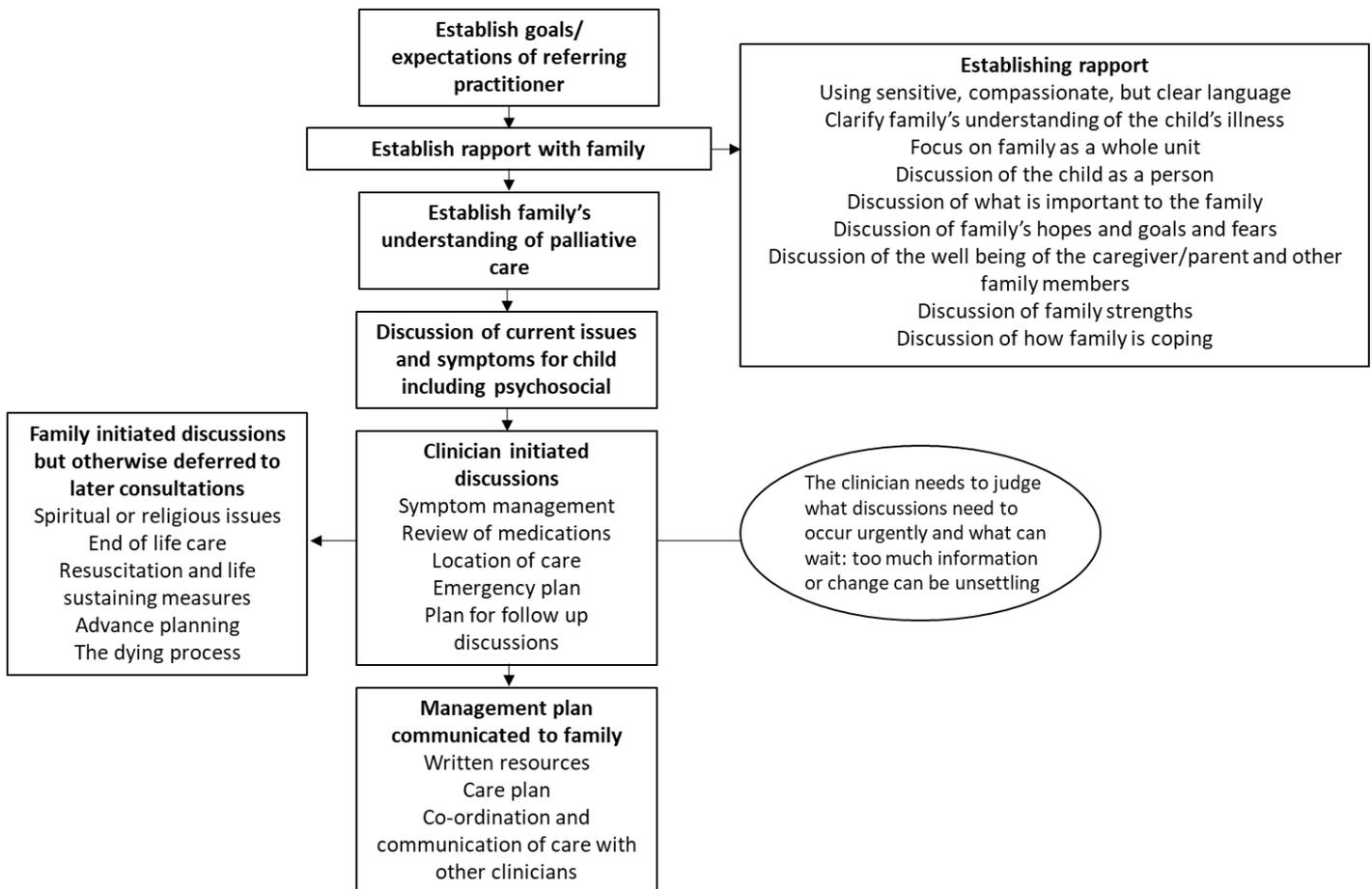
328. Solomon MZ, Dokken DL, Fleischman AR, Heller K, Levetown M, Rushton CH, Sellers DE, Truog RD. for IPPC, 2002. The initiative for paediatric palliative care (IPPC): Background and goals. Newton, MA: Education Development Center, Inc. Available at [www.ippcweb.org](http://www.ippcweb.org).

329. Solomon MZ, Dokken DL, Fleischman AR, Heller K, Levetown M, Rushton CH, Sellers DE, Truog RD. for IPPC, 2002. The initiative for paediatric palliative care (IPPC): Background and goals. Newton, MA: Education Development Center, Inc. Available at [www.ippcweb.org](http://www.ippcweb.org).

330. Kaye E, Abramson Z, Snaman J, Friebert S, Baker J, Productivity in paediatric palliative care: measuring and monitoring an elusive metric, *Journal of pain and symptom management*, 2017, 53(5);952-961

331. Kaye E, Abramson Z, Snaman J, Friebert S, Baker J, Productivity in paediatric palliative care: measuring and monitoring an elusive metric, *Journal of pain and symptom management*, 2017, 53(5);952-961

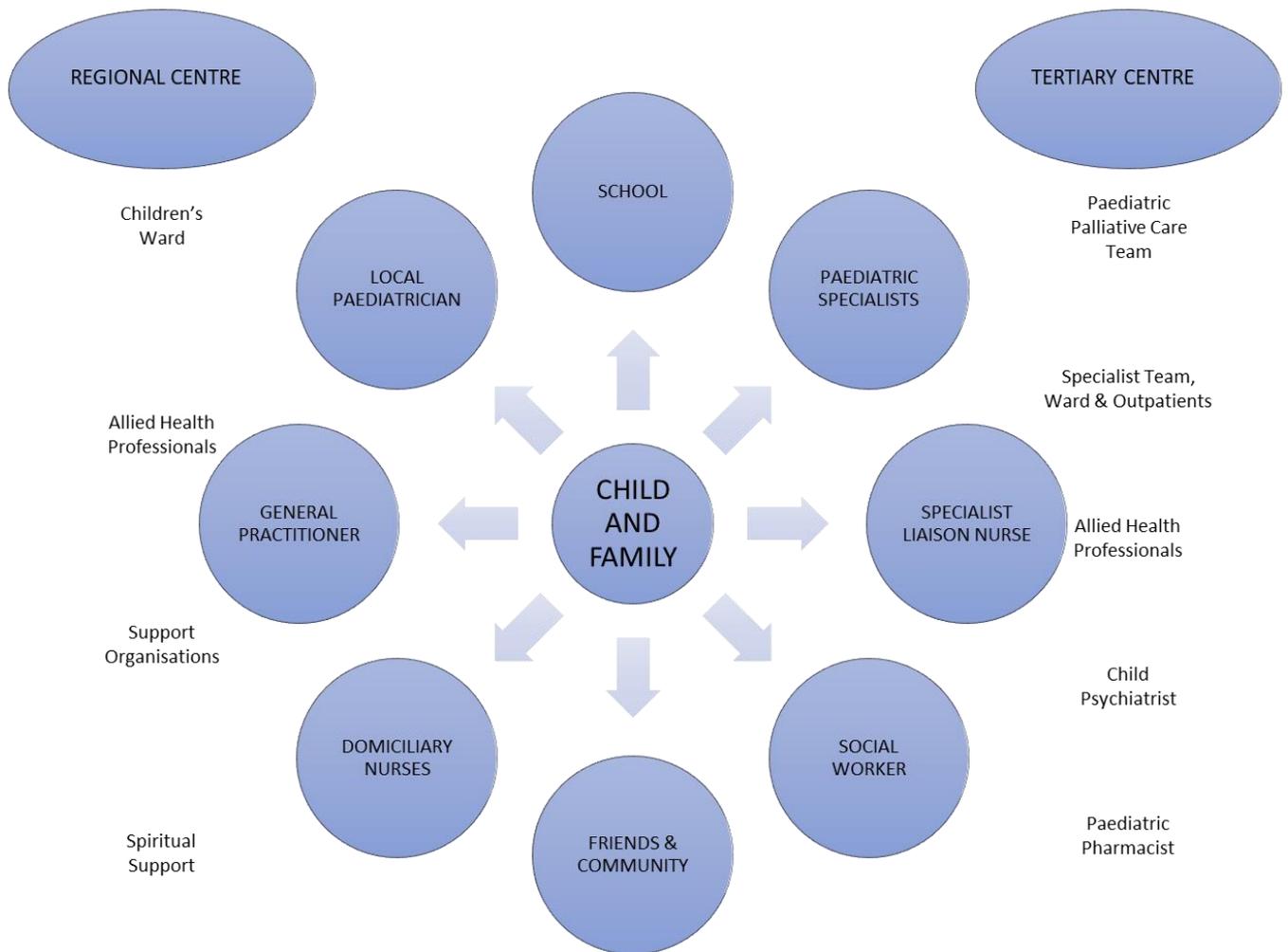
# A1. Components of a paediatric palliative care consultation<sup>332</sup>



332. Based on diagram by Bradford N, Herbert A, Mott C, Armfield N, Young J, Smith A., Components and principles of a paediatric palliative care consultation: results of a Delphi study, J Palliat Med. 2014 Nov;17(11):1206-13.

## A2. Coordination of care<sup>333</sup>

### Model of family centred paediatric palliative care



333. Based on diagram by Children's Health Queensland Hospital and Health Service Paediatric Palliative Care Service, A practical guide to Palliative Care in Paediatrics, 2014.

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