

# WA Cancer and Palliative Care Network

## Paediatric and Adolescent Palliative Care Model of Care

September 2009

Superseded by the WA End-of-Life and Palliative Care Strategy 2018 – 2028: for reference use only



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



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## Executive Summary

The WA Cancer and Palliative Care Network's *Palliative Care Model of Care* is the over arching Model of Care for palliative care in Western Australia (WA).<sup>1</sup> The principles of palliative care for adults, children and adolescents are similar, however, a number of differences exist that warrant development of a model specifically for children and adolescents with life-limiting illnesses, and their families. These differences include:

- significantly smaller patient numbers in comparison to the adult population<sup>2</sup>
- a wide range of life-limiting illnesses affecting children and adolescents, with uncertain illness trajectories<sup>3</sup>
- different physical and developmental stages which impact on care<sup>4</sup>
- increased decision-making and caring role of the family<sup>5</sup>
- risk of complicated grief and prolonged bereavement of family, including siblings.<sup>6</sup>

The Child and Adolescent Health Service (CAHS) provides specialist palliative care through the Department of Oncology/Haematology and, more recently, the Paediatric Palliative Care (PPC) Program at Princess Margaret Hospital (PMH). The current gaps in service provision addressed in the Model of Care are:

- the disparity between cancer and non-cancer patients' access to specialist paediatric and adolescent palliative care service
- limited access to appropriate community-based palliative care services
- lack of capacity within the community setting to provide paediatric and adolescent palliative care
- health professionals and care workers limited access to specialist paediatric and adolescent palliative care expertise and support
- lack of available data to specify the number of children and adolescents requiring specialist palliative care in WA
- limited access to appropriate respite services
- lack of professional bereavement services specialising in child and family grief
- adolescent patients limited transition from paediatric to adult health services.

The Model of Care proposes all children and adolescents with a life-limiting illness, and their families, will have timely access to specialist palliative care services and expertise. The Model demonstrates the need for specialist paediatric and adolescent palliative care services in WA which meet the standards of a Level 3 Palliative Care Australia (PCA) specialist palliative care service. Services will provide developmentally and culturally-appropriate palliative care regardless of underlying diagnosis, geographical location and chosen setting for care.



The principles underpinning the model are:

- The child/adolescent and the family/caregivers form the core of the model. Their physical, spiritual, psychosocial and cultural needs direct **the care** to be provided.
- Paediatric and adolescent palliative care is a specialist service within the model which can be accessed **at any stage** in the illness trajectory.
- The specialist **multidisciplinary team** with expertise in the child or adolescent's condition continues to manage care with support from specialist paediatric and adolescent palliative care services.
- All services (primary, secondary, tertiary and community) work **collaboratively** to provide multidisciplinary care, promoting **continuity of care** for the child/adolescent and their family.
- The model recognises the need for local **care coordination**.
- The model can be delivered in **any setting**; home or hospital, rural, remote or metropolitan, without affecting quality of care.

Five goals of care will guide specialist paediatric and adolescent palliative care delivery. Children, adolescents and their families will

1. receive evidence-based best practice paediatric and adolescent palliative care according to their needs
2. participate in decision-making and care planning throughout their care
3. have access to specialist paediatric and adolescent palliative care at any time during the illness trajectory
4. receive coordinated care across all sectors of health and other agencies/organisations
5. receive care and support in their preferred setting

The specialist paediatric and adolescent palliative care services will improve the capability of other health care services (primary, secondary and tertiary) and supportive care organisations to provide comprehensive care to children and adolescents with life-limiting illnesses and their families. The specialist palliative care services will:

- Assume a lead role in education and training in paediatric and adolescent palliative care in WA
- Facilitate or participate in relevant networks and partnerships

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### The key recommendations of the Model of Care are:

- The Paediatric and Adolescent Palliative Care Model of Care is endorsed for use in the Department of Health, Western Australia.
- Develop a plan for model implementation with the Child and Adolescent Health Service, WA Cancer and Palliative Care Network and local service providers.
- Initiate Transition Plans/Pathways for adolescents with life-limiting illnesses in line with the Department of Health, WA Transition Framework.
- Develop and implement statewide evidence based policies, protocols and clinical guidelines for best practice paediatric and adolescent palliative care.
- Review respite services for children and adolescents with life-limiting illnesses and their families in WA.
- Formalise networks and partnerships between specialist paediatric and adolescent palliative care services, other palliative care services and supportive care organisations in WA.
- Further development of the Paediatric Palliative Care Program at Princess Margaret Hospital to meet the Palliative Care Australia Standards of a Level 3 specialist palliative care service. This includes establishment of a multidisciplinary team, and development of palliative and home respite care packages.
- Develop a statewide paediatric and adolescent palliative care education plan and implementation strategy to provide access to a health professional workforce with palliative care knowledge and skills.
- Participate in ongoing research and evaluation focusing on the needs of paediatric and adolescent palliative care patients and their families in WA.
- Advocate for the implementation of the recommendations resulting from the review of respite services in WA.
- Build capacity within the community, and increasingly engage with primary health care providers to support and provide care to children and adolescents with palliative care needs, and their families, in the home setting.
- Strategies to provide culturally appropriate palliative care for Aboriginal children, adolescents and their families are developed in partnership with Aboriginal Health Services and other appropriate stakeholders.
- Review bereavement services in WA and implement the resulting recommendations relating to child, adolescent and family grief.
- Work with national organisations to develop processes for data collection to support service evaluation and monitor outcomes for patients and families.

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## Acronyms

ACT	Association for Children with Life Threatening or Terminal Conditions and their Families
APPCRG	Australasian Paediatric Palliative Care Reference Group
CAHS	Child and Adolescent Health Service
CACH	Child and Adolescent Community Health
KEMH	King Edward Memorial Hospital
LLI	Life-limiting illness
PCA	Palliative Care Australia
PMH	Princess Margaret Hospital
PPC	Paediatric Palliative Care
SCHCS	Silver Chain Hospice Care Service
WACPCN	WA Cancer and Palliative Care Network

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## 1. Paediatric and Adolescent Palliative Care Model of Care Overview

The Paediatric and Adolescent Palliative Care Model of Care outlines best practice palliative care for children and adolescents with life-limiting illnesses, and their families, in Western Australia (WA). It is a supplement to the WA *Palliative Care Model of Care*.<sup>1</sup>

The WA Cancer and Palliative Care Network (WACPCN) and the Child and Adolescent Health Service (CAHS) developed the Paediatric and Adolescent Palliative Care Model of Care. The Model builds on recommendations of Palliative Care Australia<sup>7</sup>, research in the palliative and supportive care needs of children and families in WA<sup>8</sup> and concepts outlined in the *Palliative Care Model of Care*.<sup>1</sup>

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## 2. Methodology

Methods used in the development of the Paediatric and Adolescent Palliative Care Model of Care were:

- the formation of the WA Cancer and Palliative Care Network (WACPCN) Paediatric Palliative Care Reference Group, to support the implementation of a Paediatric Palliative Care Project funded by the Australian Government Department of Health and Ageing
- a literature review, including a review of national and international model of care documents for paediatric and adolescent palliative care
- a review of relevant reports, frameworks and Models of Care from the Department of Health, Western Australia (Our Children Our Future: Framework for Child and Youth Health Services in Western Australia 2008-20129; Transition Framework<sup>10</sup>; Paediatric and Adolescent Cancer Model of Care)
- a WACPCN review of national and international paediatric palliative care services (June 2007). This work reviewed services in four Australian states (South Australia, New South Wales, Victoria and Queensland) and one service in New Zealand<sup>11</sup>
- a WACPCN survey of community-based organisations that provide supportive and palliative care to children and adolescents with life-limiting illnesses and their families in WA<sup>12</sup>
- consultation meetings between WACPCN, Child and Adolescent Health Service (CAHS), WA Country Health Service (WACHS), North Metropolitan Area Health Service (NMAHS), South Metropolitan Area Health Service (SMAHS) and River Chain Hospice Care Service (SCHCS) during the planning phase of the Model of Care
- consultation with other Health Networks, including the Child and Youth Health Network
- the distribution of the draft Model of Care to key stakeholders
- Completion of the WA Aboriginal Health Impact Statement and Guidelines<sup>13</sup>
- a review of the final Model of Care by the Palliative Care Network Advisory Committee and the WACPCN Paediatric Palliative Care Reference Group.

The Palliative Care Network Advisory Committee is accountable for the Paediatric and Adolescent Palliative Care Model of Care.



### 3. Current State of Play for Paediatric and Adolescent Palliative Care

#### 3.1 Overview of Paediatric and Adolescent Palliative Care

A child or adolescent's life-limiting illness has a profound effect on all dimensions of family life.<sup>14</sup> Caring for a chronically sick or dying child is an enormous and complex task. Families in these care situations feel the effects of the child's illness emotionally, psychologically, and financially. When a child dies, it is one of the most traumatic events a family can experience, with lasting physical and emotional effects.<sup>15</sup> Ensuring families receive the appropriate care prior to and following their child's death is essential to their long term well being.<sup>16, 17</sup>

'Paediatric palliative care is not about dying, rather it is about helping children and families to live to their fullest while facing complex medical conditions.'<sup>16</sup>

The principles of palliative care for children, adolescents and adults are similar; however, a number of differences exist that affect the planning and delivery of palliative care for children and adolescents (Refer Table 1).<sup>18</sup> Their unique palliative care needs are recognised nationally and internationally and have led to the development of paediatrics as a specialty area within palliative care.<sup>19</sup> The Australasian Paediatric Palliative Care Reference Group (the national advisory group for paediatric and adolescent palliative care) endorse the following definition of Paediatric Palliative Care:

'...the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.'<sup>20</sup>

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**Table 1: Factors Influencing the Provision of Paediatric and Adolescent Palliative Care Services**

<b>Factors</b>	<b>Rationalisation</b>
<i>Patient numbers</i>	A small number of children and adolescents require specialist palliative care in comparison with the adult population. <sup>2</sup>
<i>Nature and variation in diagnoses of life-limiting illnesses</i>	Approximately 40% of children and adolescents with palliative care needs have a cancer diagnosis, compared with 90% of the adult palliative care population. <sup>3, 21</sup> Non cancer diagnoses can be rare, specific to children and adolescents and may have a genetic component, resulting in more than one child in the same family diagnosed with the condition. <sup>3, 22</sup>
<i>Uncertain illness trajectories</i>	The lengths of illnesses vary from days to years and there may be a fluctuating and uncertain disease trajectory. <sup>22</sup> Identifying the point of transition to a palliative stage may be difficult and this uncertainty can act as a barrier for referral to palliative care services. <sup>23</sup>
<i>Developmental stages and physical development</i>	Physical, emotional and cognitive development of children and adolescents influences the palliative care approach, pharmacology and decision making abilities. <sup>3, 4</sup> Children and adolescents with non-cancer life-limiting illnesses may have significant intellectual and physical disabilities which further complicate their care. For adolescents, living with a life-limiting illness can delay their development towards adulthood. Physical changes resulting from medical treatments and interruptions to their social and educational lives can affect their socialisation, education and self-esteem. <sup>24</sup>
<i>Role of the family</i>	Parents/primary caregivers play an active part in decision making for their child/adolescent <sup>4</sup> as well as providing their ongoing care.
<i>Grief and bereavement</i>	The death of a child or adolescent is uncommon in developed countries. Communities and health care providers have a reduced exposure to child mortality and are often unable to provide the support families need. Families can become isolated from the community and are at risk of complicated grief. <sup>6</sup>

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A number of international organisations developed models and guidelines for paediatric palliative care which reflect current principles of best practice. These include:

- Association for Children with Life Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Pediatrics and Child Health, in the United Kingdom, A Guide to the Development of Children's Palliative Care Services<sup>25</sup>
- European Association for Palliative Care, IMPaCCT core standards for paediatric palliative care<sup>26</sup>
- United States Congress, Children's Program for All-Inclusive Co-ordinated Care Act of 2008 (ChiPPAC) developed by Children's Hospice International<sup>27</sup>
- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care, Palliative Care for Children<sup>28</sup>.

The best practice principles include the promotion of an integrated model of care, where all children and adolescents with life-limiting illnesses are considered for referral to palliative care services regardless of the expected or eventual outcome.<sup>8, 28-30</sup> Best practice care incorporates multidisciplinary, flexible, and coordinated palliative care regardless of geographic location.<sup>31, 32</sup> This is particularly relevant as families increasingly care for their child/adolescent at home.<sup>8, 29</sup>

In Australia, there are specialist paediatric palliative care services in four states (excluding WA). In 2007, the WACREN reviewed these services, and one in New Zealand, to establish their models of care delivery (Refer Appendix 1). Health professionals from these services, including services in WA, are members of the Australian Paediatric Palliative Care Reference Group (APPCRG), established in 2004. The APPCRG is working to create national standards, guidelines and protocols which include systems for quality improvement and collection of clinical indicators, to support evidence-based care. More recently, the Victorian Government identified the need to address the particular needs of children and adolescents with life-limiting illnesses by developing a statewide policy for health, children's services and community care providers.<sup>33</sup>

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### 3.2 Burden of Disease

The types of life-limiting illnesses that affect children and adolescents and for which palliative care is required were categorised by ACT in the United Kingdom:<sup>25</sup>

1. Life threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails. Children in long-term remission or following successful curative treatment are not included (Examples: malignancies, irreversible organ failures of heart, liver, kidney).
2. Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities (Example: Cystic Fibrosis).
3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (Examples: Batten disease, mucopolysaccharidoses, muscular dystrophy).
4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord insult).

There is a lack of data nationally and internationally identifying the number of children and adolescents diagnosed with life-limiting illnesses.<sup>34, 35</sup> In 2005 it was estimated that in WA, over 200 children and adolescents per year may require specialist palliative care services. The estimate was based upon an equation to estimate numbers of children and adolescents with life-limiting illness in the United Kingdom.<sup>36</sup>

Activity statistics were collated from the Australian and New Zealand paediatric palliative care services initially reviewed by the WACPCN in 2007 (Refer Appendix 1). New referrals to each service ranged from 15 to 120 per year and services recorded 17 to 80 patient deaths per year.

In WA, The Department of Oncology/Haematology at Princess Margaret Hospital (PMH) provides palliative care to approximately 22 patients per year, diagnosed with cancer or non-malignant haematological conditions. The new Paediatric Palliative Care (PPC) Program at PMH, for patients with non cancer life-limiting illnesses provided palliative care for 22 patients in the first 6 months of commencing clinical services.



### 3.3 Current Service Provision

#### 3.3.1 Tertiary services

##### Children and Adolescents With Cancer

The Child and Adolescent Health Services (CAHS) Department of Oncology/Haematology at PMH provides a statewide service of ongoing care from diagnosis to death for children and adolescents with terminal cancer or non-malignant haematological conditions. Palliative care services are delivered by the Department's multidisciplinary team using an evidence-based case management approach.

The Department aims to deliver best practice home-based palliative care in collaboration with Silver Chain Hospice Care Service (SCHCS) and regional palliative care services where geographically feasible. This includes provision of palliative care in remote communities using local and regional-based visiting community nurses and physicians. The Department provides family-oriented bereavement support and a range of bereavement programs.

##### Children and Adolescents With Non Cancer Life-Limiting Illnesses

In 2005, WA based research identified the need to provide specialist paediatric palliative care services for children and adolescents with non cancer life-limiting illnesses.<sup>8</sup> This led to the establishment of the CAHS Paediatric Palliative Care (PPC) Program in June 2008.

The PPC Program provides a statewide consultative model working in partnership with the patient's specialist medical team to provide specialist paediatric and adolescent palliative care. Staffing resources are limited to one Clinical Nurse Consultant and one medical session per week. There is a need to procure permanent funding for additional resources that will enable the provision of multidisciplinary care for this group of children and adolescents.

##### Neonates

Neonatal tertiary services are provided by King Edward Memorial Hospital (KEMH) and PMH. Perinatal palliative care is available to women and their families where a prenatal lethal fetal abnormality has been diagnosed, indicating that palliative care will be required following the birth of the baby. Diagnoses include anomalies such as Trisomy 13 and 18, and other complex fetal conditions such as renal anomalies. The Perinatal Loss Service comprises a multidisciplinary team with a coordinated family-focused approach. Specialist medical teams at KEMH or PMH manage critically ill babies who are expected to die. When appropriate, these babies are referred to the Perinatal Loss Service, PMH PPC Program and/or community-based services for ongoing palliative care.





### 3.3.2 Secondary services

Secondary metropolitan hospitals with paediatric units or departments include Swan Districts Hospital, Armadale Kelmscott Health Service, Rockingham General Hospital, Joondalup Health Campus, Peel Health Campus and Fremantle Hospital. Regional hospitals in Geraldton, Port Hedland, Kalgoorlie, Bunbury, Broome, Derby and Albany have paediatric inpatient beds. Prior to the PPC Program, these units and departments did not have the support of a specialist palliative care service specifically for children and adolescents with life-limiting illness, unless the patient was diagnosed with cancer. Where specialist palliative care support is not readily available or accessed, patients may be unnecessarily transferred to PMH.

### 3.3.3 Community services

In the metropolitan area of Perth, Silver Chain Hospice Care Service (SCHCS) provides palliative care to adult patients, and has extended a community-based service to children and adolescents. The SCHCS has developed a partnership with the Department of Oncology/Haematology at PMH to provide care for children and adolescents with cancer at home at the end of life. The SCHCS palliative care service is limited to patients who have an active progressive terminal illness requiring symptom control. The uncertain illness trajectory and medical complexity of paediatric and adolescent palliative care patients with non cancer illnesses means these patients may require access to specialised palliative care services over months and possibly years. The length of time these patients require services falls outside the current intent of the SCHCS community palliative care contract.

In rural and remote regions, children and adolescents with life-limiting illnesses may be referred to local palliative care services. The *Rural Palliative Care Model in Western Australia* provides an overview of regional palliative care services.<sup>37</sup> These services predominantly care for adult patients, and historically have had a 'cancer focus.' Rural health services in WA infrequently care for children or adolescents with palliative care needs.<sup>38</sup> Many staff working in rural and remote regions lack training in paediatric and adolescent care and some regional palliative care coordinators identified a lack of expertise to confidently care for children and adolescents with complex needs. The specialist palliative care doctors visiting rural regions provide clinical assistance to rural and remote health care professionals. More recently they have been referred child and adolescent palliative patients. There is an opportunity to establish formal partnerships between these palliative care doctors and the specialist paediatric and adolescent palliative care services at PMH for support of rural and remote patients.

Government and non-government community-based organisations in metropolitan, rural and remote regions provide limited supportive care for children and adolescents with life-limiting illnesses and their families. These services may include nursing care, allied health care, counselling, care coordination, respite, information, advice, financial assistance or education and training. The organisations vary according to referral processes, eligibility criteria, geographical boundaries, services provided and funding criteria.



### 3.3.4 Primary Care

Primary care services include General Practices, Aboriginal and Torres Strait Islander health care services and Child and Adolescent Community Health (CACH). These services provide supportive care for children and adolescents with life-limiting illnesses. Health professionals in these areas may have limited access to clinical advice and support regarding paediatric and adolescent palliative care. Some primary health care professionals have expressed a lack of confidence in providing palliative care to children and adolescent patients when ongoing support from specialist palliative and paediatric services is not readily available. In many situations, families may contact the medical specialists and acute care services directly for their child or adolescent's care.<sup>39</sup> As a result, primary care providers, including General Practitioners (GPs) may not be fully informed of nor involved with the care of the child/adolescent and their family.<sup>29</sup>

### 3.3.5 Aboriginal and Torres Strait Islander families

Aboriginal and Torres Strait Islander people are disadvantaged in relation to health care services. Socioeconomic and geographical factors may impact on Aboriginal families access to health care services.<sup>40</sup> Aboriginal people are also less likely to be referred to palliative care services in comparison to non-Aboriginal people<sup>41</sup> and their cultural needs in relation to death and dying are not well understood in mainstream health care services.<sup>42</sup>

Aboriginal families from rural and remote regions have expressed a wish to die at home, where they are connected to community and land.<sup>43</sup> Engaging with health care services and care workers in metropolitan, rural and remote communities is essential to supporting ongoing and culturally sensitive care at home. Formal relationships between specialist palliative care services, Aboriginal Health Workers and health professionals are required to support culturally-appropriate palliative care for Aboriginal children, adolescents and their families.

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### 3.3.6 Gaps in service provision

Specialty paediatric and adolescent palliative care services are evolving in WA; however, the lack of critical mass together with the geographical area of the state impact on service delivery. This affects economies of scale and limits the practice of health professionals in this specialty area. This is most problematic in rural and remote regions, where health professionals infrequently encounter children and adolescents with palliative care needs.<sup>29</sup> Current gaps in services provision have been identified (refer Table 2) and the future Model of Care will address these challenges.

**Table 2: Current gaps in paediatric and adolescent palliative care service provision**

Current gaps	Issues
A disparity between cancer and non cancer patients' access to specialist paediatric and adolescent palliative care services	Access to specialist paediatric and adolescent palliative care services in WA is often dependant upon diagnosis with a distinction between services for cancer and non cancer patients. <sup>30</sup> The ongoing development of the PPC Program is essential to reduce these inequities. Additional resources are required to ensure children, adolescent and their families have equal access to best-practice specialist paediatric and adolescent services, regardless of diagnosis.
Limited access to appropriate community-based specialist palliative care services	Palliative care for children and adolescents in the community generally occurs on a 'case by case' basis, and can be limited to 'end-of-life' or terminal care. Community-based organisations do not have the flexibility to guarantee that all children and adolescents with life-limiting illness can access the same level of services.
Lack of capacity within the community setting to provide paediatric and adolescent palliative care	The lack of community capacity leads to a reliance on paediatric tertiary hospital-based care and may limit engagement with primary health care providers, in particular GPs. This can limit a family's options for care at home and result in delays in discharge or readmission to secondary and tertiary health care settings.
Health professionals and care workers limited access to specialist paediatric and adolescent palliative care expertise and support	A lack of access to specialist palliative care support for health professionals can result in staff anxiety, impact on their confidence and reduce ability to provide appropriate care. <sup>16</sup> This is relevant to existing palliative care services caring predominantly for adults, and non-palliative health care settings (primary, secondary and tertiary).
Lack of available data to specify the number of children and adolescents' requiring specialist palliative care in WA	Consistent data, detailing the number of children and adolescents diagnosed with life-limiting illnesses as well as those accessing specialist palliative care services should be easily accessible. This data should include information on the number of Aboriginal and Culturally and Linguistically Diverse people accessing these services.

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Current gaps	Issues
Limited access to appropriate respite services	Where care is delivered in the home setting, families can be faced with long-term care regimens which are complicated and isolating. Access to appropriate respite services are required to support families in the delivery of this type of care. Currently, few providers in WA can offer respite services for children and adolescents with complex care needs.
Lack of professional bereavement services specialising in child and family grief.	There are few professional bereavement services available in WA, limited numbers of practitioners with specialised experience of child and family grief, and limited access to long-term publicly funded services. Grief and bereavement support should be available to all members of the family, including siblings throughout the palliative care continuum. There is also a need for culturally appropriate grief and bereavement services for Aboriginal families, however, there is little evidence as to the best model for service delivery.
Adolescent patients limited transition from paediatric to adult health services	Increasing technology, earlier diagnosis and improvements in management suggest that children and adolescents' with life-limiting illnesses are living longer. <sup>29, 44</sup> Adolescents should be supported by specialist paediatric and adolescent palliative care services to transition to adult medical and palliative care services for ongoing care.
Limited understanding of the cultural needs of Aboriginal families in relation to palliative care for children and adolescents.	Health care professionals and care workers within palliative care services should be trained to provide culturally appropriate care to Aboriginal families. Palliative care services should develop formal partnerships with Aboriginal health organisations, community and hospital based Aboriginal Liaison Officers and health professionals to assist in meeting the cultural needs of these families and communities.

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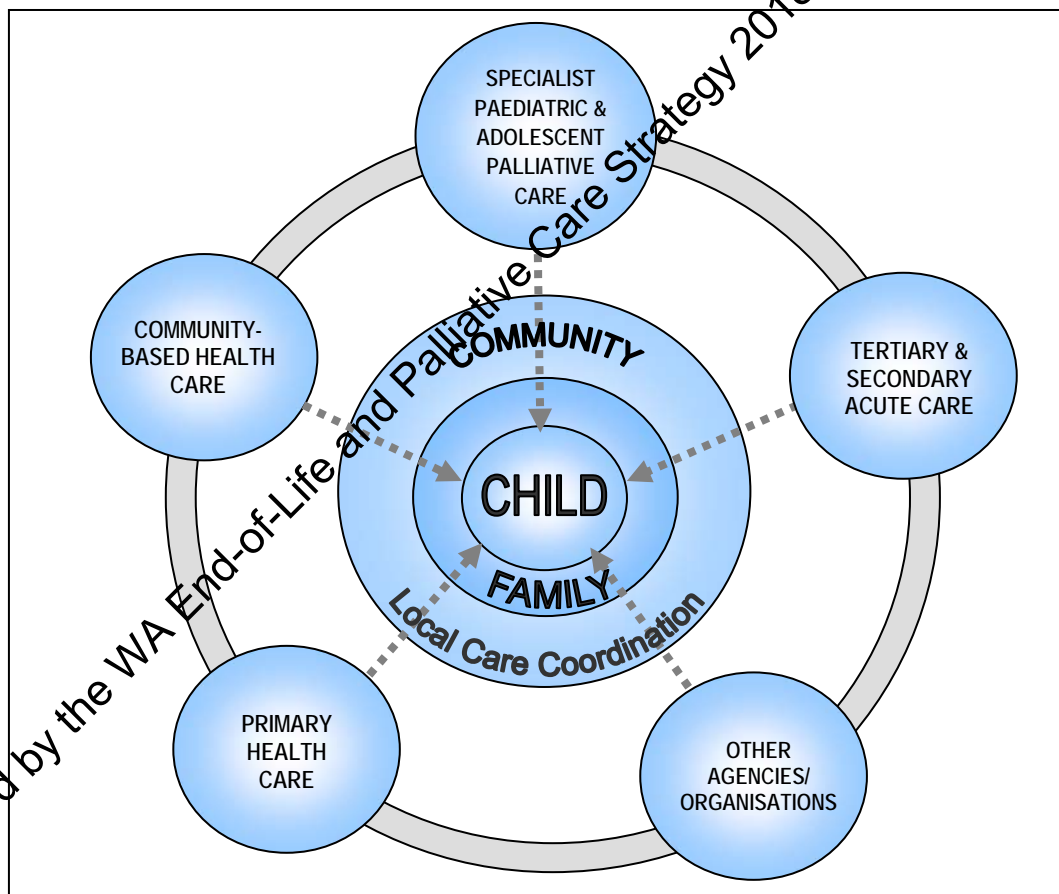
#### 4. Future Paediatric and Adolescent Palliative Care Model of Care

The Paediatric and Adolescent Palliative Care Model of Care is a supplement to the “Palliative Care Model of Care”.<sup>1</sup> The Model of Care proposes all children and adolescents with a life-limiting illness, and their families, will have timely access to specialist palliative care services and expertise.

The Model acknowledges that no single organisation or service can provide the level of care required to meet the complex needs of these children, adolescents and their families. Specialist paediatric and adolescent palliative care services must work in partnership with primary, secondary and tertiary health care services and supportive care organisations to meet these needs.

The figure below displays the Model of Care for Paediatric and Adolescent Palliative Care in WA.

Figure 1. Paediatric and Adolescent Palliative Care Model of Care





## Ensuring the right care, at the right time, by the right team and in the right place

The principles underpinning the model are:

### The right care:

- The child/adolescent and the family/caregivers form the core of the model. Their physical, spiritual, psychosocial and cultural needs direct **the care** to be provided.

### The right time:

- Paediatric and adolescent palliative care is a specialist service within the model which can be accessed **at any stage** in the illness trajectory.

### The right team:

- The specialist multidisciplinary team with expertise in the child or adolescent's condition continues to manage care with support from specialist paediatric and adolescent palliative care services.
- All services (primary, secondary, tertiary and community) work **collaboratively** to provide multidisciplinary care, promoting **continuity of care** for the child/adolescent and their family.
- The model recognises the need for local **care coordination**.

### The right place:

- The model can be delivered in **any setting**; home or hospital, rural, remote or metropolitan, without affecting quality of care.

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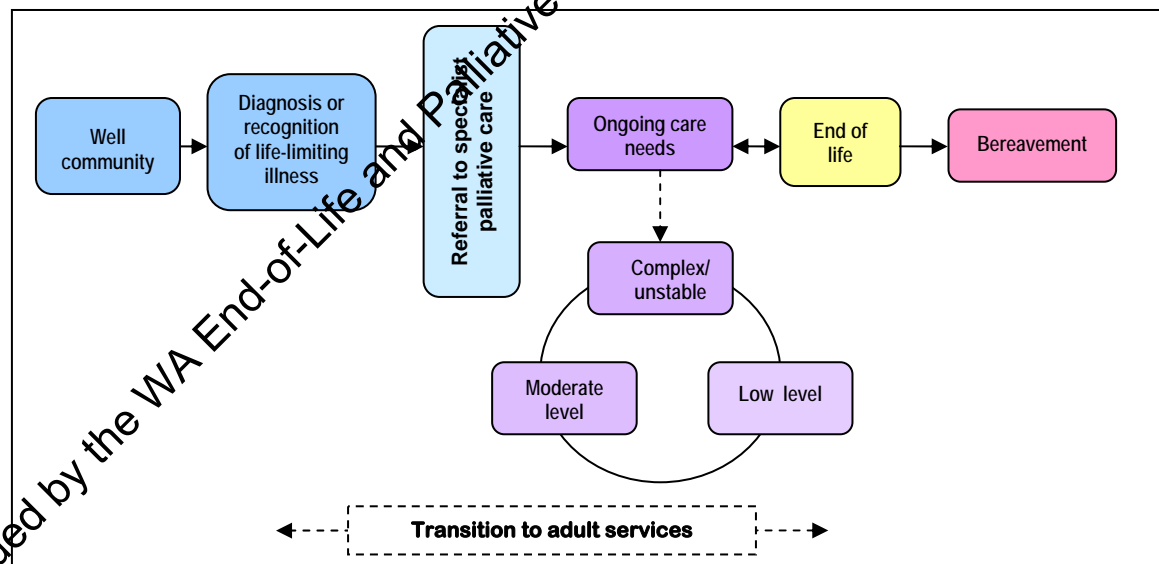


#### 4.1 Stages for Paediatric and Adolescent Palliative Care

The stages of paediatric and adolescent palliative care are depicted in figure 2. The stages are similar to those described in the *WA Palliative Care Model of Care*, with changes that highlight the special needs of children, adolescents and their families.<sup>1</sup> The key components of the Model are the patient and family's physical, spiritual, psychosocial and cultural needs. These needs influence the stages of palliative care and direct the care provided.

Children and adolescents can be referred to specialist palliative care services after the diagnosis is made or at a time when it is recognised the child/adolescent has a life-limiting illness.<sup>45</sup> The variety of life-limiting illnesses and uncertain illness trajectories affects the transition between the remaining stages, which are not necessarily sequential or predictable. This is illustrated in the 'ongoing care needs' stage, which encompasses the fluctuating needs of the patient and the family during this period, ranging from 'low level' to 'complex/unstable' care needs. Recognition that the child or adolescent will die may occur suddenly, within only days to hours of death.<sup>45</sup> Conversely, clinical experience shows that health professionals may consider the child or adolescent has progressed to the end-of-life stage, only for the patient to recover later in the illness trajectory. Services must be flexible in order to respond to these sudden changes in the child/adolescent's condition and the family's needs. Transition to adult medical and palliative care services should be considered and planned in the patient's early teenage years.<sup>10</sup>

Figure 2. Stages for Paediatric and Adolescent Palliative Care



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## 4.2 Specialist paediatric and adolescent palliative care service provision

Specialist paediatric and adolescent palliative care services will be available to all children and adolescents with life-limiting illnesses and their families in WA. The specialist services in WA will operate through the Child and Adolescent Health Service (CAHS) providing a statewide clinical and consultative service model. The services will meet the Palliative Care Australia (PCA) standards for a Level 3 specialist palliative care service.<sup>7</sup> Specialist palliative care services will be flexible and responsive to the needs of the child, adolescent and their family and will not be dictated by the stage of illness alone.

Five goals of care *guide* specialist palliative care delivery for children, adolescents, and their families in WA.

Children, adolescents and their families will:

1. receive evidence-based best practice paediatric and adolescent palliative care according to their needs
2. participate in decision-making and care planning throughout their care
3. have access to specialist paediatric and adolescent palliative care at any time during the illness trajectory
4. receive coordinated care across all sectors of health and other agencies/organisations
5. receive care and support in their preferred setting

1

### Receive evidence-based best practice paediatric and adolescent palliative care according to their needs

The specialist paediatric and adolescent palliative care services will meet the criteria for Palliative Care Australia (PCA) specialist palliative care Level 3 service capability and resource matrix, and Standards (Refer Appendix 2 & 3).<sup>7</sup>

Best practice palliative care will include:

- comprehensive, multidisciplinary assessments
- palliative care planning with regular reviews
- symptom management
- access to twenty-four hour telephone support
- psycho-social care
- cultural and spiritual care
- respite care
- grief and bereavement support
- Transition pathway/plan for adolescents

Specialist palliative care services will participate in research, evaluation and quality improvement activities, which are key elements of a Level 3 service. In particular, the palliative care needs of Aboriginal families should be explored due to the lack of research evidence within this area nationally. This will assist services to meet the needs of patients and families.





2

## **Participate in decision-making and care planning throughout their care**

Authentic and honest relationships between health professionals and parents, and between health professionals and children and adolescents are critical aspects of paediatric palliative care.<sup>30, 46</sup> Communication between health professionals, patients and parents should include provision of honest and timely information regarding diagnosis, longer term outcomes, treatment plans and treatment changes. Care planning for Aboriginal families should be undertaken in collaboration with the appropriate Aboriginal Health Professional or Worker involved with the families care. The need for trained interpreters for consultations should also be considered. This may improve communication between the family/carer and health professionals, and ensure the cultural needs of the family are recognised in decision-making processes and care planning. Health professionals must identify the appropriate person within the family or community to lead decision-making.

All children and adolescents with life-limiting illnesses and their families will be involved in decision-making including care planning throughout the illness trajectory. In the event of difficult and/or complex ethical decision making, input from a Clinical Ethics Committee is recommended.

3

## **Have access to specialist paediatric and adolescent palliative care at anytime during the illness trajectory**

All children and adolescents with life-limiting illnesses and their families will be able to access specialist palliative care at any stage in the illness trajectory. In paediatrics, the transition from curative to palliative care is not always clear, therefore, integration of the palliative care approach from the beginning of the child/adolescent's illness is recommended.<sup>28</sup> Introducing the palliative care approach early in the illness trajectory can promote early discussions in relation to medical decision making, palliative and end-of-life care.

The child/adolescent's specialist medical team and other health professionals can access the expertise of the specialist palliative care service staff. To promote accessibility, the specialist palliative care services will accept self-referrals by families or primary caregivers as well as the child or adolescent's specialist multidisciplinary team or other health care providers. Specialist palliative care services will respect existing relationships between families and health care professionals by working in collaboration, through a 'shared-care' approach.

4

## **Receive coordinated care across all sectors of health and other agencies/organisations**

Multiple organisations are involved in the care of a child or adolescent with a life-limiting illness, and their family. Specialist palliative care services will work collaboratively with all health care sectors (primary, secondary and tertiary) and other organisations/agencies throughout WA to facilitate coordinated care. Where new services are required by the family, the specialist palliative care service will assist with access or referral to the appropriate organisation.

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A palliative care plan will assist in clarifying the roles of the multiple care providers involved. Telehealth and other mediums will assist communication between care providers, particularly in rural and remote regions.

Each patient will have a single point of coordination, preferably in their local community. This is particularly relevant to Aboriginal families and Culturally and Linguistically Diverse peoples, where local community support is considered fundamental in meeting their special needs. Where this is not in place, specialist palliative care services will work with the family and the specialist medical team to identify the most appropriate care coordinator or act as a care coordinator if necessary. Aboriginal Community Controlled Health Organisations (ACCHO) and other Aboriginal primary health services will be included in care coordination for Aboriginal families. Where available, Aboriginal Liaison Officers will be included in the multidisciplinary team for Aboriginal families and will be instrumental in assisting with discharge planning for Aboriginal families returning to the community for ongoing care.

General Practitioners require timely communication regarding the needs of the child, adolescent and family, as well as discharge information, palliative care plans and prognosis.<sup>29</sup> Where a GP is not yet involved in the patient and family's care, a local primary health care provider will be contacted.

## 5

### Receive care and support in their preferred setting

Specialist palliative care services will provide care to children and adolescents across WA in the location preferred by the child/adolescent and family. This includes establishing the family's preferred place of death for their child or adolescent. For many families, this will be in the child/adolescent's family home. However, a small proportion of families may not wish to provide care at home. Services must adapt to changing circumstances, providing alternatives, such as respite or hospital beds, which will still meet the needs of the patient and family.<sup>29</sup>

When a child or adolescent returns home from a hospital setting for ongoing care, specialist palliative care services will often be involved in discharge planning. An assessment of the needs of the family and child/adolescent will indicate which home-based service is most appropriate to provide the ongoing care. Where home-based services do not have paediatric or adolescent expertise, specialist palliative care services will provide the necessary education, training and support to health professionals and care workers to assist in the patient's care. Families and local health care providers will have access to twenty-four hour telephone support and be provided with a palliative care plan. The plan will include processes for management of symptom escalation and medical emergencies.

Families providing care in the home require access to appropriate respite services to enable them to address their own physical, social and psychological needs. The specialist palliative care services will work with existing organisations to support respite provision that is accessible, planned, well coordinated and delivered in the family's preferred setting, which is usually in the family home.<sup>8</sup>



#### 4.2.1 Working with other organisations

The specialist paediatric and adolescent palliative care services will improve the capability of other health care services (primary, secondary and tertiary) and supportive care organisations to provide comprehensive care to children and adolescents with life-limiting illnesses and their families. The specialist palliative care services will:



##### **Assume a lead role in education and training in paediatric and adolescent palliative care in WA**

Specialist paediatric and adolescent palliative care services will work in partnership with organisations statewide to raise awareness of palliative care in the community. Communities will be made aware of the special needs of children and adolescents requiring palliative care, and the effects on the family and local community.

The specialist paediatric and adolescent palliative care services will work with other palliative care services in WA to support statewide palliative care education and training. This will include formal and informal education sessions, mentoring and participation in undergraduate and post graduate education.

Education and training of health professionals and care workers may, on occasion, also be targeted to the needs of individual patients with highly specific and specialised care needs. Specialist paediatric and adolescent palliative care services will facilitate and/or deliver education and training as the need arises. All education and training will include formal evaluation processes to assess the clinical relevance of education and assist in determining the specific needs of organisations and professions in this specialty area.



##### **Facilitate or participate in relevant networks and partnerships**

The specialist paediatric and adolescent palliative care services will form partnerships with rural, remote and metropolitan palliative care services. This includes partnerships with palliative care doctors visiting rural and remote regions in WA, to support child and adolescent patients. Partnerships aim to improve the knowledge and skills of palliative care staff in paediatric and adolescent care and improve the continuity of care for patients and their families. Improving communication between these services will provide an opportunity to implement self-care strategies for health professionals and care workers involved in the care of a child or adolescent.

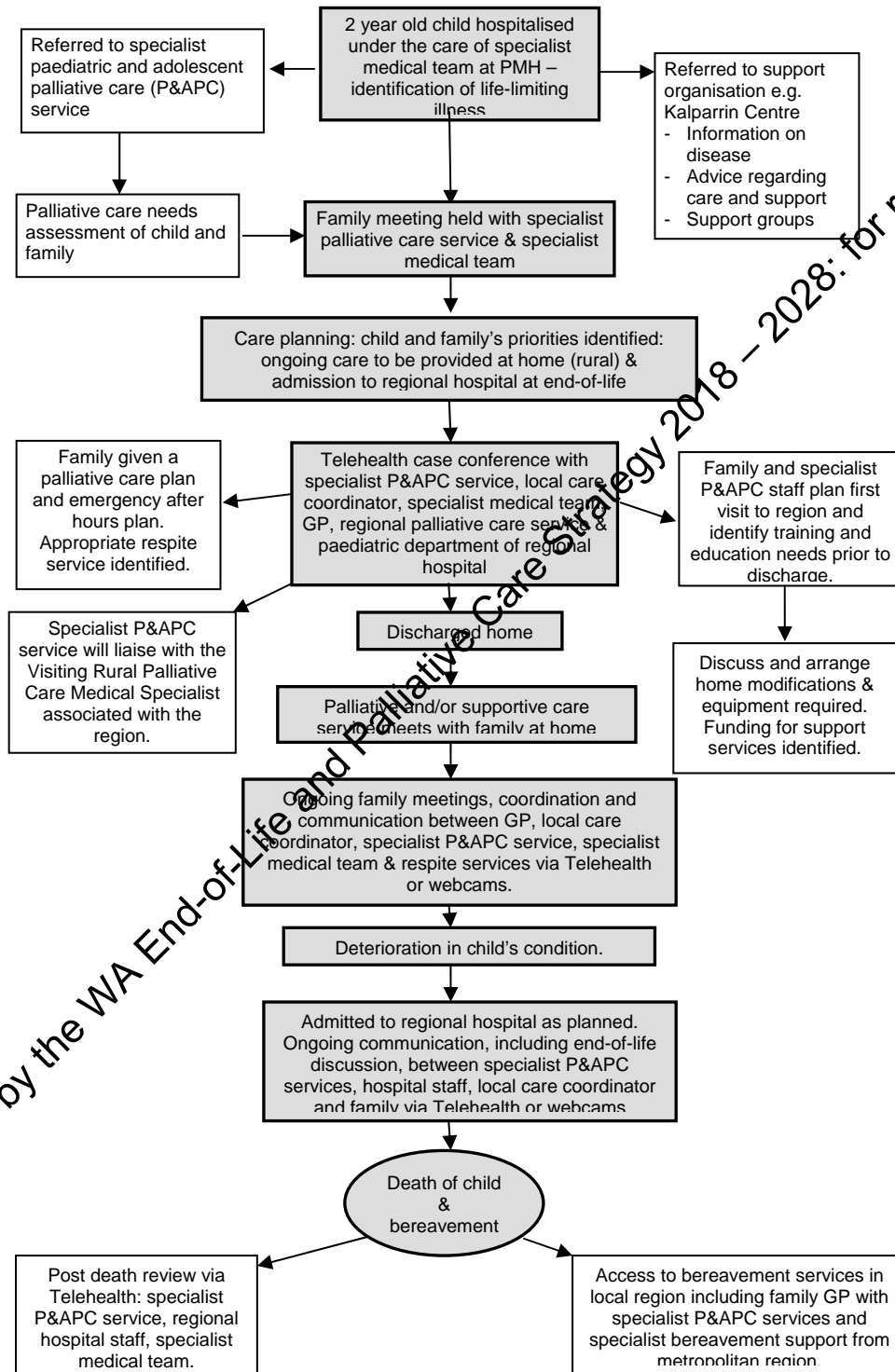
Paediatric and adolescent palliative care services will continue to be represented on both the child, adolescent and palliative care health networks in WA to provide expert consultation.



### 4.3 Patient Journey

The following diagram illustrates the journey of a patient and family, from a rural region, under the Model of Care.

**Figure 3: Paediatric and Adolescent Palliative Care Model of Care: Patient journey**



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## 5. Evaluation

The WA Cancer and Palliative Care Network's Palliative Care Advisory Committee will be responsible for evaluating the Paediatric and Adolescent Palliative Care Model of Care. The Palliative Care Advisory Committee will work in partnership the CAHS representative on the committee and the CAHS specialist paediatric palliative care service staff to complete the evaluation.

The aim of the evaluation will be to:

1. review the Model of Care to determine if it continues to consist of best evidence practice
2. assess whether the Model of Care has been implemented in the Department of Health, WA.

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## 6. Key Recommendations

### Achievable within existing resources and service delivery model:

- The Paediatric and Adolescent Palliative Care Model of Care is endorsed for use in the Department of Health, Western Australia.
- Develop a plan for model implementation with the Child and Adolescent Health Service, WA Cancer and Palliative Care Network and local service providers.
- Initiate Transition Plans/Pathways for adolescents with life-limiting illnesses in line with the Department of Health, WA Transition Framework.
- Develop and implement statewide evidence based policies, protocols and clinical guidelines for best practice paediatric and adolescent palliative care.
- Review respite services for children and adolescents with life-limiting illnesses and their families in WA.
- Formalise networks and partnerships between specialist paediatric and adolescent palliative care services, other palliative care services and supportive care organisations in WA.

### Require further planning and development:

- Further development of the Paediatric Palliative Care Program at Princess Margaret Hospital to meet the Palliative Care Australia Standards of a Level 3 specialist palliative care service. This includes establishment of a multidisciplinary team, and development of palliative and home respite care packages.
- Develop a statewide paediatric and adolescent palliative care education plan and implementation strategy to provide access to a health professional workforce with palliative care knowledge and skills.
- Participate in ongoing research and evaluation focusing on the needs of paediatric and adolescent palliative care patients and their families in WA.
- Advocate for the implementation of the recommendations resulting from the review of respite services in WA.
- Build capacity within the community, and increasingly engage with primary health care providers to support and provide care to children and adolescents with palliative care needs, and their families, in the home setting.
- Strategies to provide culturally appropriate palliative care for Aboriginal children, adolescents and their families are developed in partnership with Aboriginal Health Services and other appropriate stakeholders.

### Require additional human resources, funding and endorsement:

- Review bereavement services in WA and implement the resulting recommendations relating to child, adolescent and family grief.
- Work with national organisations to develop processes for data collection to support service evaluation and monitor outcomes for patients and families.



## 7. Glossary

### End of life

'The phase 'end of life' ends in death. Definition of its beginning is variable according to individual child/young person and professional perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient.'<sup>47</sup>

### Family

'The family is defined as those who are closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets).'<sup>7</sup>

### Life-limiting illness

'...to describe illnesses where it is expected that death will be a direct consequence of the specified illness. This definition is inclusive of illnesses of both a malignant and non-malignant nature.'<sup>7</sup>

### Palliative care

'Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of the early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.'<sup>48</sup>

### Specialist medical team

The specialist medical team, for the purposes of this Model of Care, is the multidisciplinary team which specialises in the care of the child or adolescent's underlying medical condition or specific diagnostic group.

### Specialist palliative care services

'...is used to denote a multi-disciplinary health care service whose substantive work is with patients who have a life limiting illness.'<sup>49</sup>

### Supportive care

'Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people with life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised.'<sup>47</sup>

### Transition

'The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems.'<sup>50</sup>



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## 9. Appendices

### Appendix 1: Summary of specialist paediatric palliative care services in Australia (excluding WA) and New Zealand

STATE	HOSPITAL	PALLIATIVE CARE SERVICE	AVAILABLE STATISTICS
New South Wales	Sydney Children's Hospital Randwick	Provide a combined pain & palliative care service led by a specialist paediatrician. Consultative service with a multidisciplinary team.	(2008) Referrals: 42 Deaths: 17
	The Children's Hospital Westmead	The Department of Pain Medicine & Palliative Care provides a Level 3 consultative multidisciplinary specialist paediatric palliative care service. It operates an integrated system of care for children receiving paediatric palliative care and their families at home in the children's hospice (Bear Cottage, Manly) and in hospital.	Referrals: 100 - 120 per year Deaths: approximately 40-50 per year
Queensland	The Royal Children's Hospital, Brisbane	Currently provide oncology palliative care services only. Planning for a statewide, dedicated mode of service for all of Queensland by 2011.	
South Australia	Women's and Children's Hospital, Adelaide	A state-wide Nurse Practitioner led service model with consultation from a Palliative Care Consultant.	(2006/2007) Referrals per year: 30 to 50 Deaths per year: 20
Victoria	Royal Children's Hospital, Melbourne	An alliance between the Royal Children's Hospital Melbourne, Very Special Kids hospice and the Monash Medical Centre. A consultation/liaison service led by a Case Manager/Social Worker with a Paediatrician and Paediatric Nurse.	(2007/08) Referrals: 115 Deaths: 80
New Zealand	Starship Children's Hospital	A consultative service with a multidisciplinary team (Specialist PPC Paediatrician, Clinical Nurse Specialists, Social Worker, Child Psychiatrist and Grief and Bereavement Therapist).	(2008) Referrals: 39 Deaths: 23

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## Appendix 2: Palliative Care Australia Standards: Capability and Resource Matrix<sup>49</sup>

Level	Capability	Typical resource profile
Primary care	<p>Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care.</p> <p>Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.</p>	<p>General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff.</p> <p>Specialist health care providers in other disciplines would be included at this level.</p>
Specialist Palliative Care Level 1	<p>Provide palliative care for patients, primary carers and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers.</p> <p>Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients, carers and families with complex problems. Has quality and audit programme.</p>	<p>Multi – disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available, coordinates a volunteer service.</p>
Specialist Palliative Care Level 2	<p>As for level 1, able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the community.</p> <p>Has formal links with primary care providers and level 3 specialist palliative care services for patients, primary carers and families with complex needs.</p>	<p>Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.</p>
Specialist Palliative Care Level 3	<p>Provides comprehensive care for the needs of patients, primary carers and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has a comprehensive research and teaching role.</p> <p>Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.</p>	<p>Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.</p>

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### **Appendix 3: Palliative Care Australia: Standards for Providing Quality Palliative Care for All Australians<sup>7</sup>**

#### **Standard One**

Care is based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, caregiver and family needs and wishes are acknowledged and guide decision-making and care planning.

#### **Standard Two**

The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to meet those needs, in line with their wishes.

#### **Standard Three**

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

#### **Standard Four**

Care is coordinated to minimise burden on patient, their caregiver/s and family.

#### **Standard Five**

The primary caregiver/s is provided with information, support and guidance in their role according to their needs and wishes.

#### **Standard Six**

The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

#### **Standard Seven**

The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

#### **Standard Eight**

Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement counselling, information and support services.

#### **Standard Nine**

Community capacity to respond to the needs of people who have a life limiting illness, their caregiver and family is built through effective collaboration and partnerships.

#### **Standard Ten**

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

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**Standard Eleven**

The service is committed to quality improvement and research in clinical and management practices.

**Standard Twelve**

Health professionals and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

**Standard Thirteen**

Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

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#### Appendix 4: WA Cancer and Palliative Care Network Paediatric Palliative Care Reference Group

Name	Area
Ms Janet Bradshaw	Child Hospice Association
Ms Marnie Chellew-Hawley	Paediatric Palliative Care Project Officer WACPCN
Ms Kerry Cousins	Clinical Nurse Consultant Silver Chain Hospice Care Services
Ms Stephanie Dowden	Paediatric Palliative Care Clinical Nurse Consultant Princess Margaret Hospital
Ms Belinda Jennings	Clinical Midwife Consultant King Edward Memorial Hospital
Ms Jennifer Mace	Head of Social Work Princess Margaret Hospital
Ms Suzanne Momber	Paediatric & Adolescent Oncology and Palliative Care Clinical Nurse Specialist Princess Margaret Hospital
Dr Leanne Monterosso (Chair)	Senior Health Researcher Princess Margaret Hospital
Ms Sue Peter	Nursing Director Ambulatory Care Princess Margaret Hospital
Dr Marianne Phillips	Paediatric & Adolescent Oncologist and Palliative Care Specialist Princess Margaret Hospital
Ms Meg Plaster	Adolescent and Young Adult Cancer Nurse Coordinator WACPCN
Ms Ranita Sidhu	Senior Occupational Therapist Princess Margaret Hospital
Ms Helen Walker	Palliative Care Program Coordinator WACPCN
Ms Jacinta Williamson	Consumer

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Delivering a **Healthy WA**

**WA Cancer & Palliative  
Care Network  
Level 1, 1 Centro Ave  
Subiaco  
Western Australia 6008**

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