



# Joint Health Select Committee Inquiry into Palliative Care in WA

Child and Adolescent Health Service Submission



- Compassion
- Accountability
- Excellence
- Equity
- Collaboration
- Respect

6 July 2020

## CAHS submission to the Joint Health Select Committee Inquiry into Palliative Care in WA. (July 2020 )

Palliative care for babies, children and young people (henceforward called children) was not specifically covered in the Joint Select Committee Inquiry into End of Life Choices. We welcome the opportunity to ensure it forms a part of this Inquiry into Palliative Care.

Palliative Care Australia defines paediatric palliative care as follows: -

*Palliative care for children with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks ad care through death and bereavement. (From Paediatric Addendum: Palliative Care Services Guide 2018)*

It is important to note that there are distinct differences between paediatric and adult palliative care. The differences outlined below are taken from The Paediatric Addendum Palliative care services guide 2018. Developed by Palliative Care Australia (PCA)

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

- Care embraces the whole family and uses a model of child and family-centred care;
- The family has an increased role in decision-making and care for the child;
- A substantial number of children have non-malignant conditions, many of which are specific to childhood;
- Life-limiting conditions in children can be extremely rare and sometimes there is no definitive diagnosis;
- The child usually always remains under the care of their primary treating team, with specialist paediatric palliative care providing support through a consultative model;
- Perinatal palliative care may be provided alongside the antenatal care that a mother receives from the obstetric team;
- Provision of care across a wide range of care settings and healthcare teams can complicate care coordination and communication;
- Predicting a prognosis can be difficult and deterioration can be episodic and unpredictable;
- The number of children dying is smaller; in turn the lower volumes mean that non-specialist health care providers have less familiarity and experience in palliative care;
- A child is learning, growing and developing along a continuum toward becoming a functional adult which requires social, emotional and spiritual needs;
- A child's ability to communicate and understand varies according to their age or stage of development and underlying condition;
- The provision of education and play is essential;
- There may be financial life-changing costs to families when parents withdraw partially or completely from the workforce to become caregivers;

- Siblings are vulnerable, with parents often providing care for them while providing 24-hour care to a child with a life-limiting condition;
- Grandparents are susceptible to reduced psychological wellbeing through 'doubled worry': worry about the well-being of their grandchild as well as their own child (the child's parent);
- Conditions are sometimes familial. Other children in the family may be conceived with, living with, or have died from, the same condition;
- There can be numerous, evolving losses experienced throughout the illness trajectory requiring grief and bereavement support prior to death; and
- The death of a child defies what is considered to be the natural order of life; parents do not expect to bury their children and this loss can lead to prolonged, or even lifelong grieving.

Here in Western Australia the WA Paediatric Palliative Care Service (WA PPCS) is the only specialist palliative care service for children. Specialist paediatric palliative care is defined by PCA as follows:

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

The WA PPCS has been block funded by WA Health for a number of years and is hosted by the Child and Adolescent Health Service (CAHS). CAHS has recently further invested in this service by raising FTE from 2.9FTE to 3.8FTE and introduced a 24/7 professionals advice line staffed by WA PPCS staff to support professionals caring for children in WA. The service operates as a consultative service.

We would like to submit the following responses to the Joint Health Select Committee Inquiry into Palliative Care around the findings and recommendations from the End of Life Choices Report which are relevant to children, their care and that of their families.

## **Recommendation 7**

**The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.**

There are no specialist paediatric palliative care beds in WA. This is not inappropriate in a hospital setting as the WA PPCS team work closely with other health services and teams within Perth Children's Hospital to support the palliative care needs of children and families. However, the current lack of a children's hospice in WA has an adverse effect on choice, and quality of care offered to children and families in WA. This is not merely about a bed in any hospice; it reflects the need for a place of care which can address the specialist, holistic needs of palliative care children and their families, during illness, at end of life and for the family who live on.

## **Recommendation 8**

The Minister for Health should ensure that community palliative care providers, such as: Silver Chain, are adequately funded to provide for growing demand.

In Perth Metro WA PPCS works collaboratively with Silver Chain Hospice to support end of life care in the home for those children and families for whom home is their preferred place for end of life care.

In the regions WA PPCS work collaboratively with the regional palliative care teams to support care close to home if this is the child and families preferred place of care.

The number of children who die is small and therefore the required knowledge, skills and competence are not routinely held and maintained by adult colleagues working with children. To ensure safe, efficient, and high-quality care it is important that specialist paediatric palliative care services support colleagues in adult services who deliver care to children and families.

We have not observed a change in the way our community palliative care colleagues are able to deliver care secondary to additional funding. We believe this may be, in part, due to the highly responsive and flexible manner for which they undertake the care of children.

### **Recommendation 9 &10**

WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care.

Recognising the importance of contemporary models of care, in June 2019 CAHS, in collaboration with the WA Cancer and Palliative Care Network and Curtin University commenced a project to develop a Paediatric addendum to the WA Palliative and End of Life Care Strategy 2018 – 2028, together with an Optimal Care Pathway for Paediatric Palliative Care. The project included state-wide consultation with consumers and service providers in rural and metropolitan areas. Consumers included bereaved parents and parents of current palliative care patients. Over 160 people contributed to the project.

Several themes are apparent in the initial evaluation.

Lack of choice of place of care was strongly voiced. IN WA the lack of a children's hospice means care can only be delivered at home or in hospital. This is of importance in end of life care but also it was identified that a children's hospice would provide a greater depth to the experience of PPC patients and families. This includes the need for specialised out-of-home respite provision, greater support to families and extended family members, access to broader range of therapies (e.g. music, play, art and pet), opportunities to connect families sharing similar experiences, support to siblings and extended family.

Inequity between disease groups regardless of location (whether metropolitan, regional or remote) as the child's diagnosis has significant impact on accessibility and availability of

services. Families of children with rare and undiagnosed, neurological and/or metabolic diseases recognised that when compared to other disease groups (particularly cancer) they received a lesser level of support from NGO's or not for profit organisations, access to specific therapies, allied health services and financial support.

The access, support and advocacy of the WA Paediatric Palliative Care Service was identified as a crucial element of optimal PPC. Recognition that the death of a child is a rare event, and therefore is something that many staff outside WA PPCS are unlikely to develop confidence in when caring for these children, as well as the distressing nature of supporting children and their families.

Support for families in grief and bereavement was also identified as an area that requires additional consideration. Families describe feeling poorly supported by healthcare staff, community staff and their friends and families. Development of a means to better coordinate support, ensuring that families are well cared for, as well as supporting staff who care for their families to care well. Acknowledging that professionals maybe fearful, distressed and lack confidence in this area is important, together with strategies to address this, with provision of support.

Overwhelmingly parents were looking to ways in which they could connect with other families. This included as a means to access support for themselves, to offer support and education to others, as well as to provide a source of comfort and form part of their own child's legacy. Parents want to lessen the pain and sadness of others, they wish that others can learn from the challenges or mistakes they faced, they really want to share their positive experiences and remind everyone it is possible to maintain hope.

## **Recommendation 11**

To improve understanding of palliative care in Western Australia, WA Health should:

- establish a consistent definition of palliative care to be adopted by all health professionals;
- provide comprehensive, accessible and practical information and education services
- about palliative care to health professionals and the community;
- encourage knowledge sharing by palliative care specialists with their generalist colleagues; and
- establish a palliative care information and community hotline

The current work to develop a Paediatric addendum to the WA end of life and palliative care strategy (2018- 2028) and the WA Paediatric Palliative Care Optimal Care Pathway go some significant way to employing a consistent definition of paediatric palliative care for use in WA.

It is appropriate to deliver comprehensive and accessible practical information and education sessions to health professionals. The federally funded Quocca (Quality of Care Collaborative Australia) hosted by CAHS which provides an education resource delivering "pop up" and scheduled education to professionals about paediatric palliative care has been funded for a

further 3 years from January 2021. The WAPPCS continue to deliver regular education sessions to colleagues across disciplines.

In Paediatrics a whole community education approach to education re paediatric palliative care may not be appropriate. We would encourage a targeted approach to educating the community to ensure knowledge and understanding of palliative care for children within the community supporting the child and family.

A collaborative approach around the newly established Palliative Care Information and Support Line with Palliative care WA and WA PPCS has led to calls specifically regarding paediatric care to re-directed to the WA PPCS. We welcome the initiative to respond and direct calls re paediatric palliative queries in a timely manner by specialist nursing and medical professionals.

### **Finding 18**

**There is a gap in care for people who are seriously unwell but not close enough to death to be admitted for inpatient hospice care.**

Children who are seriously unwell (but not close to end of life) can only be cared for in the hospital setting. Furthermore, the lack of hospice care for children means that children with particularly challenging symptoms requiring high input nursing and medical care can only be managed in the hospital setting. Accessing acute care beds for this can be a source of delay and therefore distress and frustration for child and family.

### **Finding 16**

**Access to hands-on specialist palliative care is limited for metropolitan and nonmetropolitan patients.**

There is a lack of nursing and allied health including but not limited to music therapy, art therapy, play therapy etc specialists in paediatric palliative care in metro and regional and remote areas.

### **Finding 19**

**There is limited access to palliative care medical specialists in regional Western Australia.**

There is only one paediatric palliative medicine specialist in WA.

## Recommendation 12

The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.

The management of children and their families with palliative care needs in regional and remote WA requires paediatric clinical collaboration and oversight by specialist Paediatric palliative care service to support the adult palliative work services. This is necessary due to the small numbers of children in each area, rare conditions and hence the ability for local teams to develop appropriate skills to manage such children is challenging. Despite funding increases into regional services investment in developing stronger process for paediatric patients has not occurred.

## Recommendation 14

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:

- The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.
- The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service
- providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.

We believe it is essential to include activity from the paediatric sector in the audits above. Improved processes to capture bereavement care provided to parents and siblings could also be considered.

Should you require any further information in relation to this submission please contact me directly.



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