

**Palliative Care Australia and
The Australian and New Zealand Paediatric Palliative Care
Reference Group**

Paediatric *Palliative Care*



Position Statement



PalliativeCare
AUSTRALIA

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australia and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care for all at the end of life.

The Australian and New Zealand Paediatric Palliative Care Reference Group comprises paediatric inter-disciplinary representatives from states and territories within Australia and New Zealand, and serves as a reference group for issues relating to paediatric palliative care.

ANZPPCRG & PCA believe

- All children and families are unique, and no illness, child, family or situation is the same.
- Paediatric palliative care¹ aims to provide the best quality of life for children and adolescents with life limiting conditions.
- Palliative care services for children, adolescents and their families should be delivered when needed, in the form needed and in the place of their choosing.
- Palliative care is a necessary element in the treatment of children and adolescents with life limiting conditions.
- Accessing palliative care services does not mean that hope has been abandoned.

ANZPPCRG & PCA call for

- The promotion of palliative care services as a necessary element in the treatment of children and adolescents with life limiting conditions.
- Early consultation with palliative care specialists for children or adolescents and their families to discuss and plan for the management of future palliative care needs. This includes ante-natal consultation for parents who find out during their pregnancy that their expected child has a life limiting condition.
- Effective case management through the efficient collaboration of health professionals, the patient, their families and carers.
- Implementation of the recommendations of the 2004 Model of Care Review undertaken by the Commonwealth Government including:
 - o The development of a national framework for palliative care in children and adolescents including standards and guidelines;
 - o Dedicated funding for paediatric and adolescent palliative care research;
 - o Additional funding for practical supports such as equipment and respite care;
 - o Investment in workforce development and training; and
 - o Formal recognition and support for the Australian and New Zealand Paediatric Palliative Care Reference Group.

¹Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes. (World Health Organisation, "WHO Definition of Palliative Care for Children" Cancer: WHO Definition of Palliative Care, 1998. Accessed from <http://www.who.int/cancer/palliative/definition/en/> 19/02/2014)

Background

Paediatric palliative care is an emerging field that is still relatively underdeveloped compared to its adult equivalent. Developments in the practice of paediatric palliative care have been hindered due to the limited evidence base and relatively uncommon occurrence of terminally ill children and adolescents. Despite this, a number of important initiatives and models of care have emerged internationally in recent years. Australia needs to embrace these developments and further add to paediatric palliative care research in order to provide the best quality of care for the children and adolescents who have life limiting conditions, and their families.

Children and adolescents with life limiting conditions continue to suffer significantly from inadequate recognition and treatment of symptoms, aggressive attempts at cures, fear and sadness. Similarly, the trauma experienced by parents, siblings and the wider family from the suffering and death of a child is also profound. There is increased potential for complicated grief reactions, impaired long term adjustment and even increased mortality.

The provision of effective palliative care should directly benefit the child or adolescent but also have the potential to be a preventive health intervention for the family, with long term implications for family functioning, mental health, education and employment.

Paediatric palliative care aims to provide the best quality of life for neonates, infants, children and adolescents faced with life limiting conditions.² Caring for young people with life limiting conditions brings specific demands and challenges.

Children and adolescents differ from adults in many ways. Their developmental stages mean that caring for them in the context of life limiting conditions requires an approach that reflects and considers their unique needs.³ Children and adolescents experience disease differently according to their stage of

development. The processing of information, the assessment and management of pain and other symptoms, and the ability of the child or young person to participate in decision making are all affected.⁴

Providing palliative care is complex and can include a number of people who are invested in the caring process. For health professionals, the complexities include supporting and respecting the authority of the parent or carer in the situation, while at the same time facilitating the wishes of the child or adolescent (if and where possible).⁵

At a systems level, the provision of palliative care to children and adolescents in Australia generally requires collaboration between clinicians from a range of disciplines, specialties in the paediatric and adult sector and colleagues in the palliative care sector.

The majority of children and adolescents with palliative care needs experience longer and more variable illness trajectories than those of adults with life limiting conditions.⁶ Emerging medical advancements may extend life expectancy, meaning that some of these patients are now living longer and have increasingly complex care needs.⁷ Furthermore, many conditions affecting young patients have uncertain prognoses. This complicates decision making for all involved.

Health providers and families frequently believe that palliative care is only for those in the final stages of their condition.⁸ These negative associations may deter or prevent access to care. All too often the referral to palliative care services is perceived as the time when hope is abandoned, as the parents may not consider that their child has a 'terminal' or 'eventually fatal condition'.⁹

This misconception about the role of palliative care can deprive a suffering patient of their right to a broad range of supportive services. It can mean a family declines palliative care and pursues a purely curative approach,

when the two need not be mutually exclusive. A combination of curative and palliative approaches can provide the best quality of life for the child or adolescent living with a life limiting illness, while still allowing hope for recovery.

In situations where a child or adolescent is faced with a life limiting condition, one must "hope for the best, but prepare for the worst."¹⁰ Delaying the provision of palliative care until there is absolute certainty can mean that many engage with palliative care too late or not at all.¹¹ Similarly, it can be helpful to plan care in advance to avoid decision making in a crisis. This can give the family the power to decide on treatments or interventions that they *do* want rather than ones they *don't* want.¹²

Palliative care enables the child or adolescent to live in an environment where curative treatment can be part of their life, but not their entire focus. It aims to provide the best quality of life through an holistic approach which supports the physical, emotional, social and spiritual aspects of the child and their family. "The goal is to add life to the child's years, not simply years to the child's life."¹³

Working together to overcome misconceptions about the role of palliative care is essential to providing quality care to paediatric and adolescent patients. Palliative care aims to provide the best quality of life possible for all involved. Children and adolescents need to experience the best life possible regardless of their prognosis, and especially if their time is limited.

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²Flavelle, Shauna C. "Experience of an Adolescent Living and Dying of Cancer" *American Medical Association* 2011, 165:1 p. 28

³Caresearch: Palliative Care Knowledge Network Paediatrics: What is Paediatric Palliative Care? Accessed from <http://www.caresearch.com.au/caresearch/tabid/602/Default.aspx> 14/05/2013 p.1-2

⁴Hynson, Jenny L. et al. "The dying child: how is care different" *Medical Journal of Australia (MJA)* 179:S20-S22 September 2003 p.20

⁵Junger, S. et al. "Barriers and needs in paediatric palliative home care in Germany: a qualitative interview study with professional experts" *BMC Palliative Care* 2010 9:10 accessed from <http://www.biomedcentral.com/1472-684X/9/10> 13/05/2013 p.4

⁶Junger, S. et al. "Barriers and needs in paediatric palliative home care in Germany" p.4

⁷Caresearch: Palliative Care Knowledge Network Paediatrics: Scope of Paediatric Palliative Care Accessed from <http://www.caresearch.com.au/caresearch/tabid/737/Default.aspx> 10/05/2012

⁸Hynson, Jenny "Palliative Care for Children" *Health Voices: Journal of the Consumers Health Forum of Australia* 4, 2009 p.22

⁹Ibid.

¹⁰Ibid.

¹¹Ibid.

¹²Ibid.

¹³Committee on Bioethics, American Academy of Pediatrics "Palliative Care for Children" *Pediatrics* 2000, 106 (2): 351-357 p.353