

Policy Statement

Paediatric Palliative Care



February 2019

This is a joint policy statement from Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ).

Palliative Care Australia is the national peak body for palliative care in Australia. PCA provides leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

Paediatric Palliative Care Australia and New Zealand comprises paediatric inter-disciplinary representatives from states and territories within Australia and New Zealand, and serves to provide advocacy and raise awareness of issues relating to paediatric palliative care.

PCA and PaPCANZ highlight that paediatric palliative is child and family-centred, focusing on improving quality of life for children (infant, child, or young person) with life-limiting illnesses or conditions, managing symptoms and providing support for the whole familyⁱ.

Paediatric palliative care enables the child to receive a holistic approach to care which supports the physical, emotional, social and spiritual aspects of the child and their family and carers. Importantly, it requires the input of specialist health professionals specifically trained in paediatric palliative care.

PCA and PaPCANZ support that children may receive palliative care alongside medical treatment aimed at a cure, and can be integrated at any point in the illness trajectory. Some children receive palliative care for a short time, while others are supported for many years. Children differ from adults in many ways and the needs of a child vary considerably based on developmental stage, from perinatal through to adolescence. Predicting prognosis and when they may die can be difficult.

PCA and PaPCANZ highlight that children die from a range of illnesses or conditions, many of which may be rare, and this diversity can lead to a variety of illness trajectoriesⁱⁱ. This may include neurological, metabolic, genetic, or cardiac life-limiting illnesses or conditions, with malignant conditions only a small proportion of overall referrals.

PCA and PaPCANZ maintain that children are a potentially vulnerable group. All children and families are unique, and no illness, child, family or situation is the same. All children have the right to appropriate, compassionate and timely care at the end-of-life, which includes pain relief and symptom management, and the prevention and relief of suffering. The dignity, comfort and privacy of a child, their family and carers is paramount, and care should be carried out with respect and compassion.

PCA and PaPCANZ considers that referral to Palliative Care Services continues to support hope for families and carers and encourages the ongoing development of their goals. Palliative care is not just focused on preparation for death; it is committed to improving the quality of life for a child with a life-limiting condition, their family and carers over the course of an illness. It should be available and accessible and align with the values, diversity and wishes of the child, their family and carers, regarding both the type and place of care and place of death.

PCA and PaPCANZ believe that integrated grief and bereavement support is a critical element of care for the child, their family and their community. This includes support in preparing for the death of the child, understanding the process of dying, and bereavement support after death. Conversations about death, dying and a child's end of life require specialist skills, knowledge and experience and must be delivered with care, compassion and sensitivity.

PCA and PaPCANZ recommend the integration of palliative care as a fundamental component in the treatment of children with life-limiting illnesses or conditions. This includes:

- Early consultation with the palliative care team for children, their families and carers to discuss and plan for the management of future palliative care needs. This includes antenatal consultation for parents expecting a child who has a life-limiting illness or condition.
- Effective collaboration between treating teams and health professionals in the assessment, planning, care plan implementation, monitoring and review of the child, their families and carers.
- Support for clinicians to work with children, their families and carers to prepare, review, update and implement age appropriate advance care plans.
- Investment in workforce development and training to build the capacity of all health professionals who provide support to children receiving palliative care, their families and carers. This includes increasing the number of specialist paediatric palliative care clinicians, and ensuring health professionals working primarily within Paediatric Palliative Care and in bereavement support are appropriately trained.
- The availability of referral pathways to assist families and carers in preparing for the death of a child and to provide appropriate bereavement follow-up support, or more intensive counselling as required.
- Identification of patient cohorts for which referral to paediatric palliative care services should be routine.
- Health service organisations ensure timely access to peer support, mentoring, and appropriate clinical supervision for paediatric palliative care staff, to prevent or resolve distress and manage workplace stress.
- Appropriate support is available to families and carers who wish to take care of their child at home, and improved systems and processes to enable transition between places of care. This includes access to required aids, equipment and respite care.
- An increased focus on improving after-hours access to:
 - Paediatric palliative care services in the community
 - Medicines, equipment and appropriately trained staff for pain and symptom relief.
- Improved funding for paediatric palliative care research which acknowledges the unique illness trajectories and experience of children in palliative care.
- Investigation into technology based solutions to improve access to specialist paediatric care clinicians for example, telehealth and home based monitoring.

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

ⁱⁱ 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.