

This factsheet has been developed for all health care professionals who may care for a child with a life-limiting illness. Our goal is to improve awareness of the NSW Paediatric Palliative Care Programme and how we aim to collaboratively work with other health care services to enhance the care for children with life-limiting illnesses and their families.

What is paediatric palliative care for children and young people?

It is an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on an enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement

Reference: <http://www.icpcn.org.uk/>

What is the NSW Paediatric Palliative Care Programme

There are three specialist paediatric palliative care services in the NSW Paediatric Palliative Care Programme:

- The Children's Hospital at Westmead
- Sydney Children's Hospital, Randwick
- John Hunter Children's Hospital, Newcastle

Each multidisciplinary service provides a range of supports for children and their families referred to palliative care living in NSW, including rural and remote areas

How can we support patients and families?

- Assessment and management of pain and other difficult symptoms experienced during the course of a child's illness
- Enhance communication to coordinate and link families with available home care, hospital and community services
- Information around respite options
- Facilitate discussions for goals of care and end of life care planning including resuscitation orders
- Provide care and support during different stages of a child's illness
- Advice about psychosocial support for siblings and other family members
- Advice about bereavement care referrals for parents, siblings and other extended family members

How can we support health professionals?

The specialist paediatric palliative care services are available to provide education, advice and support to a child's primary medical team and other involved health practitioners. The aim is to enhance the confidence of any health professional involved in managing the care needs of a child and family. After hours medical advice is available for health professionals if needed.

Palliative care services will not replace the medical teams who care for a child at hospital or in the community. Our goal is to work with you and other health services to enhance the care for children and their families.



Where can palliative care services support patients and families?

Most families can choose where they would like to care for their child. Most care is provided at home; however, as illness progresses more frequent admissions to hospital may be necessary. During these difficult times, the palliative care services can help coordinate care across these locations to ensure families are supported wherever they wish to be.

Inpatient respite and end-of-life care is an available option for children and their families at Bear Cottage located in Manly, Sydney.

All children who are not expected to live to adulthood should be considered for a referral to paediatric palliative care. This will ensure that appropriate care is provided at the right time and in the right place.

Palliative care can be integrated at any point in the disease trajectory.

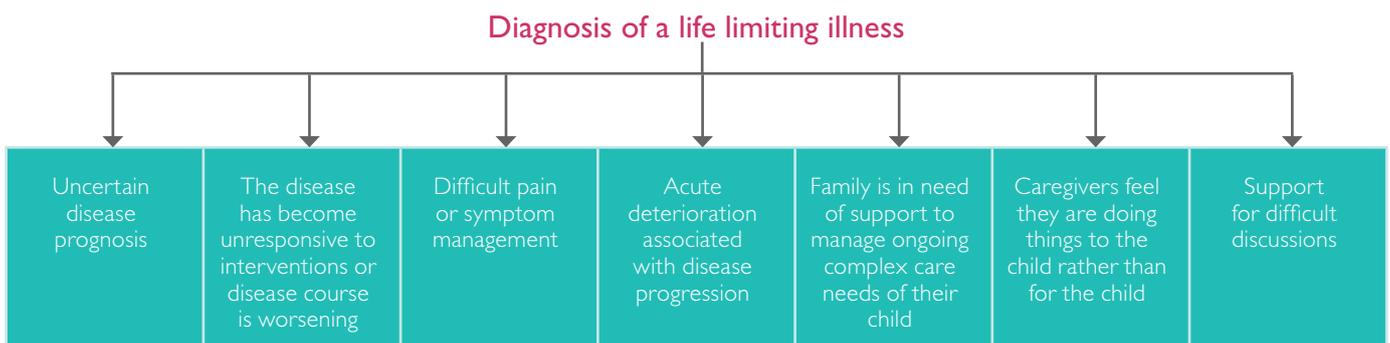
What are the benefits of an early referral to palliative care

It is often difficult to predict the progression of many childhood conditions even when medical treatment is provided as life prolonging or in the hope of cure. An early referral allows more time to establish a therapeutic and trusting relationship with families to ensure that care planning is guided by each family's unique and individualised goals and wishes.

A referral does not mean giving up hope. In fact, it allows for more time to plan care and provide the best possible support for a child, their family and other involved care givers.

Palliative care is not just about preparation for death, it is about improving the quality of life for a child with a life limiting illness and their family during the course of an illness.

Triggers for referral to palliative care



How to refer and contact us

For further information about how to refer a child and family to palliative care please contact:

**Sydney Children's Hospital,
Randwick**

Phone: (02) 9382 2095
Business Hours: 830am-5pm

**The Children's Hospital at
Westmead**

Phone: (02) 9845 0000 (page 6794)
Business Hours: 830am-5pm

**John Hunter Children's Hospital,
Newcastle**

Phone: (02) 4921 3387
Business Hours: 830am-5pm



**NSW Paediatric Palliative
Care Programme**



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