

This information sheet has been developed for all health 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 services to enhance the care for children with life-limiting illnesses and their families.

What is paediatric palliative care for children and young people?

Palliative care for children and young people 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/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Reference: togetherforshortlives.org.uk/assets/0000/4089/CPC_definitions.pdf

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.

Our model of care



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 including resuscitation planning
- Provide care and support during the different stages of a child's illness
- Advice about psychosocial support for siblings and other family members
- Advice about bereavement support 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. We aim to enhance the confidence of any health professional involved in managing the care needs of a child and family.

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.

After hours medical advice is available for health professionals if needed.



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 an 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.

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.

NSW PPC Programme Medical On-call Service.

Available to any health professional requiring specialist paediatric palliative care advice outside business hours. To contact the Medical On-call After Hours Service please call one of the following hospital switchboards:

1. The Children's Hospital at Westmead: (02) 9845 0000
2. Sydney Children's Hospital, Randwick: (02) 9382 1111
3. John Hunter Children's Hospital, Newcastle (02) 4921 3000

For more information about the NSW PPC Programme, please visit our website

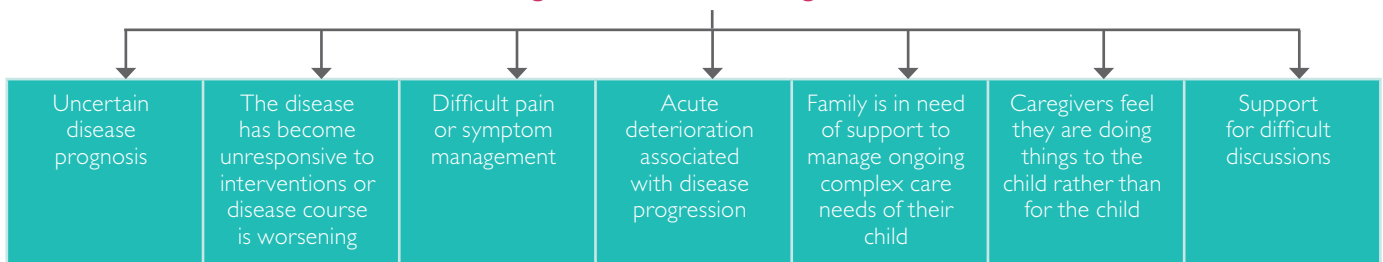
www.nswppcprogramme.com.au

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.

Triggers for referral to palliative care

Diagnosis of a life limiting illness



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 5429

Mobile: 0412 915 089

Business Hours: 8.30am-5pm

The Children's Hospital at Westmead

Phone: (02) 9845 0000 (page 6794)

Business Hours: 8.30am-5pm

John Hunter Children's Hospital, Newcastle

Phone: (02) 4921 3387

Business Hours: 8.30am-5pm



NSW Paediatric Palliative
Care Programme



The Sydney children's
Hospitals Network



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