

Palliative Care: Factsheet for Families

Do you have a child with a life-limiting illness?

Does your child experience pain or other difficult symptoms related to their illness or disease progression?

Would you like more professional support to help make decisions for planning the care of your child?

Do you want to give your child and family the best possible quality of life?

Do you often experience these common events?

- Isolation
- Anxiety
- Depression
- Exhaustion
- Feeling trapped
- Family life stress factors
 - Financial stressors
 - Loss of work
 - Time away from home and other children
 - Difficulties coordinating the health system

**Remember you are not alone.
There is lots of support available!**

Shared thoughts from families

"It's a BIG, big psychological help to know palliative care is always there. It's just a matter of a phone call and they will do anything to help along the way."

"Palliative care has supported our son and family since 1999. It has been a long journey. The team have been a big support and helped us to advocate for our son's needs with other medical teams."

"At a time when we thought our world was falling apart, we were introduced to the Paediatric Palliative Care Team who has been a true blessing ensuring the best care and quality of life for our child".

Supporting families through a child's illness

Caring for a child with a life limiting illness can be difficult for parents, siblings, grandparents and other involved care givers.

Paediatric Palliative Care provides support to families caring for a child with a life limiting illness. Care is tailored to each family's unique and individualised needs to help make decisions about the planning of care throughout a child's illness. This can reduce some of the fear and anxiety experienced during this difficult time.

Paediatric Palliative Care is different to adult palliative care. When children are diagnosed with rare medical conditions it can be difficult to predict how an illness will progress. Some children may be patients of a palliative care service over many years due to the complex care needs experienced over the course of a child's illness.

What is the NSW Paediatric Palliative Care (PPC) Programme?

The NSW PPC Programme is a state-wide programme providing specialist care for children with life limiting conditions. Care is available to children and their families from all cultures and backgrounds living in NSW.

The NSW PPC Programme will not replace the medical teams who care for your child at the hospital. We work with these teams and other medical services outside the hospital.

Who is in the NSW PPC Programme?

There are three specialist services in The NSW PPC Programme. These are:

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

Each service has a team of health care professionals. Some of these include Doctors, Nurses, Social Workers, Bereavement Coordinators, Physiotherapists and Occupational Therapists.



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What do we provide?

- Ongoing communication to support families and health care providers throughout NSW, including those in rural and remote areas
- Assessment and management of pain and other difficult symptoms experienced during the course of a child's illness
- Education and support to help administer unfamiliar drugs that are prescribed to care for your child at home
- Ongoing coordination of care at home to link families with available hospital and community services
- Information about available respite options
- Psychosocial support for siblings and other family members
- Support and care to facilitate discussions for end of life care planning
- Care and support during the terminal stages of a child's illness
- Bereavement care for parents, siblings and other extended family members

Where can care be provided?

In many situations families can choose where they would like to care for their child. Most care is provided at home, however, as an illness progresses it may be necessary to spend more time in hospital. Our palliative care services can help by coordinating care across these locations to ensure families are supported wherever they wish to be.

Respite and end of life care is also available from Bear Cottage located in Manly, Sydney. Children with life limiting illnesses and their families can stay at Bear Cottage to rest and receive medical care in a home-like environment.

When is a good time to access palliative care?

A referral to a palliative care service can be made at any stage during the course of your child's illness. It is often difficult to predict the progression of many childhood conditions. It is a good idea to think about a palliative care referral early, even at the time of diagnosis when medical treatment is given to treat or cure an illness.

A referral to palliative care does not mean you have given up hope. In fact, it allows for more time to plan your child's care and provide the best possible support for you and your family.

How do I organise a referral?

If you think paediatric palliative care could be helpful for your child and family, a medical referral is needed. Talk to one of your child's doctors (for example a General Practitioner or Paediatrician) and an appointment can be arranged.

Contact details for palliative care services

Sydney Children's Hospital, Randwick
Phone: (02) 9382 2095
Business Hours: 830am- 5pm

John Hunter Children's Hospital, Newcastle
Phone: (02) 4921 3387
Business Hours: 830am-5pm

The Children's Hospital at Westmead
Phone: (02) 9845 0000 (page 6794)
Business Hours: 830am-5pm

Links for other helpful website information

- www.bearcottage.chw.edu.au/
- www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys%202010%20full%20document.pdf
- [www.act.org.uk/-](http://www.act.org.uk/)
- www.rch.org.au/rch_palliative
- www.sidsandkids.org/
- www.vsk.org.au/
- www.sesamestreet.org/parents/topicsandactivities/topics/grief

