

FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

Paediatric 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 experience any of the following?

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

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

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.

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

The NSW PPC Programme is represented by the three specialist services; The Children's Hospital at Westmead, Sydney Children's Hospital, Randwick, John Hunter Children's Hospital, Newcastle and Bear Cottage children's hospice, Manly.

The NSW PPC Programme is a state-wide approach to improving the delivery of care for children with life limiting conditions and their families.

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



NSW Paediatric Palliative
Care Programme

the
children's
hospital at Westmead

The Sydney children's
Hospitals Network

 **SYDNEY
CHILDREN'S
HOSPITAL**
RANDWICK

The Sydney children's
Hospitals Network

 **HNEkidshealth**
Children, Young People & Families

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. Care is available to children and their families from all cultures and backgrounds living in NSW.

What do we provide?

- Ongoing communication to support your family and health care providers (home visits, telephone calls, videoconferencing and emailing)
- Assessment and management of pain and other difficult symptoms your child may experience during the course of their illness
- Education and support to help administer unfamiliar drugs that are prescribed to care for your child at home
- Coordination of care to link your child and family with local hospital and community services (including rural and remote areas)
- Assessment of equipment needs
- Information about available respite options
- Psychosocial support for siblings and other family members
- Support to establish your goals of care (including during end of life)
- Care and support during the terminal stages of your 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.

What are the contact details for palliative care services in NSW for further information?

Sydney Children's Hospital, Randwick

Phone: (02) 9382 5429/ 0412 915 089

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: 800am-430pm

Shared thoughts from families:

- When you are emotionally and physically exhausted, the palliative care team are absolutely amazing. There are times in the journey we've really needed them to go in and bat hard for our family. Other times they walk quietly but strongly supportive by our side.
- Initially I had a fear of the doctors "giving up" on my son, but the palliative care team have been very supportive, always offering a helping hand. They liaise with other health professionals so that my son can receive the best care and management.
- One of the biggest aspects for us is the social isolation and lack of understanding from those around you.... the palliative care team fill in those huge gaps by being there and just seem to know what you are going through.

The NSW PPC Programme Website

If you would like to learn more about Paediatric Palliative Care we encourage you to visit our website. You will find a range of information we have written to help families and health professionals.

www.nswppcprogramme.com.au