



Palliative care for children



www.health.nsw.gov.au

Contents

How to read this information	1
What is a life limiting illness?	4
What does dying mean?	5
What is palliative care for children?	7
What does palliative care for children do?	8
What help can my family get?	9
Where can we get palliative care for children?	10
Special hospitals for children	11
Self care for families	12
Palliative care After Hours Helpline	14
Palliative Volunteer Support Services	15



This is information to help you understand what palliative care is for children.

It will help you if a child in your family needs palliative care.



How to read this information

It is good to read this information if a child in your family needs palliative care.

It will help you understand what is happening.



Thinking about a very sick child can make you feel lots of different things.

It might make you feel

- sad
- confused
- frightened
- angry.

You can feel different things at different times.



It can be very hard to understand why a child is very sick.



You should read this information with someone you can talk to.

They can give you support.



You could read it with

- a person in your family
- a friend
- a religious leader
- a social worker
- a counsellor
- your support worker.

They can help you understand the information.

You can talk to them about how you are feeling.



If you read this with someone

- they can answer questions
- they can comfort you if you are upset.



You do not have to read all this information at the same time.

You might only want to read some of this information now.

You can think about it and read the rest when you are ready.



What is a life limiting illness?

Palliative care helps children with a life limiting illness.

This means children who are very sick or have a condition that means they will die.

We will use the words life limiting illness here.

It can be hard to know how long a child will live.

Children who get palliative care might have a couple of weeks to live, a couple of months or a couple of years.



Palliative care helps children with a life limiting illness that means they will die.

It helps children live well and for as long as possible.

It can help you and people in your family.





What does dying mean?

Dying is part of life.

Dying means your life ends.

Everyone will die.

Not only old people die.



Children can die because of

- an accident
- an illness that cannot be treated
- a condition where there is no more treatment that will help
- a condition that gets worse over time.





People do not expect children to be very sick.

People are very sad when a child is very sick and might die.



It can be very hard for parents and family members to look after a very sick child.



It can be hard to think about dying or talk about it.

It helps to talk about it with people you trust.



What is Palliative Care for children?

Palliative care for children is special support when a child has a life limiting illness.

Palliative care for children is called paediatric palliative care.

Paediatric means medical care for children.

Palliative Care means there is no medicine or treatment that will help them live longer.



Palliative care does not make life longer or shorter.

Palliative care improves how a child lives while they are sick.

Palliative care for children helps reduce pain.

It cannot make a child better.

If there is treatment for their medical condition it can still happen.



A child can get palliative care as soon as their family is told that they have a life limiting illness.



What does palliative care for children do?

Palliative care service is a team of doctors, nurses and other people.

They help children and families.



Palliative care for children is different for every child and every family.

Your family can make their own decisions about Palliative care.



Palliative care for children can be

- medicine to help with pain
 - medicine for vomiting or problems breathing
 - things to help children enjoy life.
-



What help can my family get?

- Counselling for family members
 - Advice to help make decisions about medical treatment
 - Support with cultural issues
 - Support with religious beliefs.
-



Your family can make decisions about how much support they want.



Where can we get palliative care for children?

A doctor or palliative care service will talk to your family about palliative care.

They will give you and your family information about services.



Palliative care for children is available

- in your home
- in a hospital
- in a special children's hospital
- in a children's hospice.

A hospice is a special place for families.



Children who are dying can go to Bear Cottage in Manly with their families.

They can get special support.

Sometimes children and their families go to Bear Cottage for a break from home.



Special hospitals for children

There are 3 special hospitals for children who need palliative care in NSW.

- The Children's Hospital at Westmead
- Sydney Children's Hospital
- John Hunter Children's Hospital



You do not have to go to the hospital to get support.

The Palliative Health Team can give you telehealth support.

This is talking over a video call.



Self care for families

Family members caring for a child who is very sick need to look after themselves.

There are different things you can do to look after yourself.



You can talk to

- a person in your family
- a friend
- a religious leader
- a social worker
- a counsellor
- your support worker.

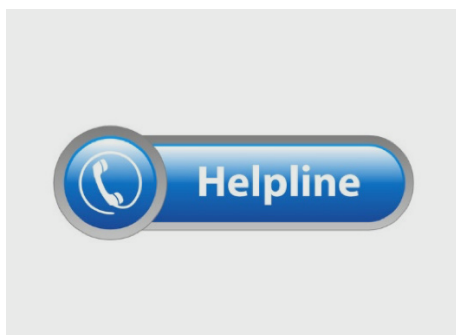
You should try to eat well, exercise and sleep.



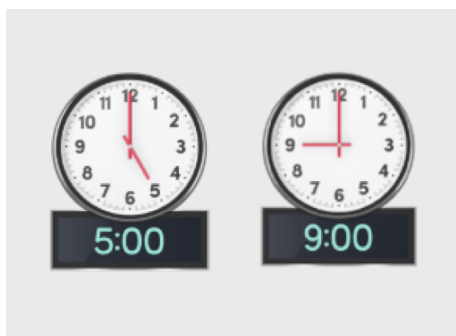
Palliative Care After Hours Helpline

During the day you can contact the palliative care teams at

- The Children's Hospital at Westmead
- Sydney Children's Hospital
- John Hunter Children's Hospital.



You can call the After Hours Helpline after hours.



The helpline is open every night.
You can call from 5pm to 9am.

It is also open on the weekends and on public holidays.



You can ring the helpline on **1800 548 225**.



Who will I talk to at the helpline?

You will be able to talk to a registered nurse or a palliative care nurse.

The After Hours Helpline is for

- people getting palliative care
 - families
 - carers.
-



The helpline can help if you cannot contact the usual doctor, nurse or palliative care service and

- the child is in pain or symptoms change
- you have questions about medicine
- you have problems with equipment
- you need support because you are worried or frightened
- you need information about services you can go to.



Palliative Volunteer Support Services

There are volunteers who can help you and your family.

The palliative care volunteers can

- look after children
- go with you to doctor's appointments
- write someone's life story
- help around the house
- make phone calls.



Your doctor or palliative care service can give you more information.

This fact sheet has been made easy to read by
Council for Intellectual Disability

CID has an information service.

Contact if you need help to understand this fact sheet
or anything.

Call **1800 424 065** or email **info@cid.org.au**

Copyright © NSW Ministry of Health