



Palliative care for you



Easy Read

www.health.nsw.gov.au

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



How to read this information

Thinking about dying 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.



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

They can give you support.



You can 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.

They can answer questions.

You can talk to them about how you are feeling.

They can comfort you. You can comfort them too.



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 does dying mean?

Dying is part of life.

Dying means your life ends.

Everyone will die.

Not only old people die.

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People can die at any age 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
- old age.



Death is a normal part of life.

It will be a sad time for you and your family and friends.



Death and dying are sometimes called other words

- passed away
- passed over
- departed
- gone
- lost.

People with intellectual disability have told us they want to use the words death or dying so they understand. We will use these words here.



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

It helps to talk about it with people you trust.



Support at the doctors

When your doctor or specialist tells you you will die you will need a lot of support.



Dying means that there is no medicine or treatment that will help you live longer.



Your doctor might suggest you bring someone to the appointment to support you.

It will be a sad time for you and your family and friends.

It is important that you have people to support you.



Who can I talk to?

You will need people to talk to about decisions you need to make.



You will need people so you can talk about how you feel.

You can decide who you talk to.



You can talk to people close to you

- parents
- husband, wife or partner
- boyfriend or girlfriend
- children
- brother or sister.

You can talk to other people

- good friends
- support worker
- social worker
- religious leader
- local doctor
- specialist doctor
- counsellor.



What is palliative care?

Palliative care is special support when you are near the end of your life.



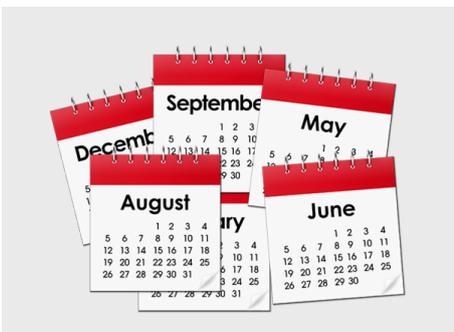
End of life means you have an illness or a condition that means you will die soon.

Your doctor will talk to you about this.



Palliative care reduces suffering.

You can get palliative care as soon as you are told that you are dying.



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

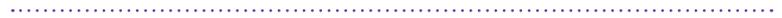


What does palliative care do?

Palliative care does not make you get better.

Palliative care helps to reduce pain.

It also offers you support in different ways.



Palliative care can be

- medicine to help with pain
- medicine for problems caused by the illness
This could be things like vomiting or problems breathing
- advice from a counsellor to help you understand you are dying
- counselling for people who are close to you
- advice to help you make decisions about medical treatment
- support with cultural issues
- support with religious beliefs.



Palliative care is different for every person.

You can make your own choices and decisions about your medical care.

Your family or people you trust can support you to make choices.



Palliative care helps you live as well as possible until you die.

Palliative care does not make your life longer or shorter.

It cannot make you get better.



If there is treatment for your medical condition you will still get it.

You can make decisions about how much support you want.



Who does palliative care?

Palliative care can be given by

- your doctor
 - a specialist doctor
 - Palliative Care nurses
 - Palliative Care services.
-



They can help if your illness becomes too hard to manage.



They can link you to other services and supports.



Where can I get palliative care?

Your doctor or palliative care service will talk to you about palliative care.

It depends on the services and supports in your area.

You should think about what you want.



You can ask about palliative care

- in your home
- in a hospital
- in a special palliative care part of a hospital
- in a hospice.

A hospice is a home for people who are close to dying.



Will I be able to decide what palliative care I get?

You will be asked what you want.

You will be able to make decisions about your care and where you get it.

You will be given information about services you can use by your doctor or a palliative care worker from the hospital.

You will get support to help you make decisions.



Making decisions about medical treatment

If you are dying you can decide if you want to have medical treatment.

Some people decide they do not want medical treatment even if it might help them live longer.



Some people who are dying want to have these medical treatments.



There is no right or wrong decision.
Everyone is different.

You can change your mind about medical treatment at any time.

It is important that you talk to someone who can give you information. They can help you decide what to do.



Your doctor is a good person to talk to.

You can bring someone you trust when you talk to the doctor.

This could be a family member or a friend.
You can ask them to take notes to help you remember what the doctor said.



What is advance care planning?

Advance care planning means making decisions about the care you want. This plan will help if you cannot communicate anymore.



You might not be able to make a decision if you are very sick or have a serious injury.

Advance care planning means talking to your

- family
- husband, wife or partner
- friends
- supporters
- doctor

about medical treatment.

You should talk to people you trust.



You can tell them how much treatment you want if you are dying and are too sick to make your own decisions.



When can I talk about advance care planning?

You do not have to be sick to talk about this.



It is good to talk about advance care planning when you are healthy.



You can write down your advance care plan or get someone you trust to write it for you.

You can think about things like

- what matters to you
- your religious beliefs
- how you want to be treated if you are very sick.



What is an Advance Care Directive?

An Advance Care Directive lets people know what medical treatment you want if you are very sick or dying.

An Advance Care Directive is something written. It tells people what you want to happen.

You can write it before you are sick or injured.



It is more powerful than an advance care plan.

You have to be 18 years or older to write an Advance Care Directive.



An Advance Care Directive is a legal document.

This means that people have to do what it says unless a court changes it.



Your Advance Care Directive will be followed if these things happen.

1. You understood what it said when you signed it.

Your doctor can say they talked to you about the Advance Care Directive and you understood it.



2. Your Advance Care Directive is clear about

- what treatments you want
 - what treatments you do not want.
-



3. Your Advance Care Directive is relevant to what is happening to you.



You can talk about making an Advance Care Directive with someone you trust.

You can get more information from NSW Health.



You can talk to your doctor about your health and medical treatments.

They can give you information that can help you make decisions about medical treatments if you are very sick or badly injured.



You can put your decision into an Advance Care Directive.

You can have a family member, carer or friend that you trust come with you when you talk to your doctor.



If you cannot consent to medical treatment

Consent means you say yes or no to medical treatment.



If you cannot consent to medical treatment because you cannot communicate in any way

- a doctor will ask your person responsible for consent
- your person responsible will use your Advance Care Directive to make decisions for you if you have one.



It says what treatment you want if you cannot tell anyone yourself.



Your person responsible is

- your guardian if you have one
- your husband, wife or partner
- an unpaid carer
- a close relative or friend.



An Advance Care Directive helps this person to know what you want.

You can change the Advance Care Directive at any time.



No one can make you write or sign an Advance Care Directive.

It is against the law if they do.

If this happens tell someone you trust.

You can write an Advance Care Directive at any time. You do not have to be sick or dying.



It can be helpful to have your doctor witness an Advance Care Directive.

The doctor can say you understood the Advance Care Directive.



Palliative care is not euthanasia

Some people are worried that palliative care is the same as euthanasia.

It is not.

Euthanasia is ending the life of a person who is dying or is very sick.

It means that you choose to die and someone helps you with it.

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Palliative care makes the time before a person dies as comfortable as possible.

Palliative care does not end your life.





Telephone Support

You can call Telephone Support any time of day or night.

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



You can call telephone support on **1800 022 222**.

You can talk to a registered nurse

Telephone Support is for

- People getting palliative care
- Families
- Carers.



Telephone Support can help if you

- cannot contact the usual doctor, nurse or palliative care service
- have any questions about your medicine
- have problems with equipment you are using
- need support because you are worried or frightened
- 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**

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