

Talking about death and dying



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Talking about death and dying

It is important that everyone talks about death and dying.

Death and dying means that your life ends.



Sometimes people think people with disability will be too

- sad
- confused
- frightened
- angry

to talk about death.

Sometimes no one tells people with disability about death until someone dies.



This information will help you understand about death and dying.

It will help you talk about it.



You can 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 answer questions.

You can talk to them about how you are feeling.



What is death and dying?

Death means your body shuts down and stops working.

Death is a part of life.

Everyone will die.

Everyone will know someone who dies.

People can die at any age.

Some people die when they are young.

Some people die when they are old.



There are lots of reasons that people die

- 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 sometimes called other words.

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



This can be hard to understand.

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.



Why should I talk about death and dying?

It is good to talk about what happens when you die.



It helps your family, friends and supporters to know what you want when you get very sick or when you die.



Your family and friends can also tell you what they want to happen when they are very sick or dying.



My Will

You can write a Will so you can decide who gets the things you own when you die.

You can write a Will at anytime.

You do not have to be sick or dying to have a Will.



Funerals

A funeral is a way of saying goodbye to a person who has died.

You can decide what kind of funeral you want when you die.



You do not have to be sick or dying to think about your funeral.

There are different rules about funerals in different cultures and religions.



You might want to think about

- what music you want at your funeral
- who you want to come to your funeral
- if you want a religious funeral
- if you want to be cremated or buried.

You can tell someone you trust about these things or write them down.



Going to a funeral

When you go to a funeral it is OK to cry or show your feelings.

Sometimes people do not feel like crying at a funeral.

This is OK too.



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 with 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.

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

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 decisions into an Advance Care Directive.



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.



Your Advance Care Directive 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.

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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