

Respecting Patient Choices

If we know your choices
for future health care
we are able to respect them

Advance Care Planning Information Booklet



Take time to consider

Imagine the following:

■ You are in a road accident and you suffer a severe brain injury which leaves you permanently unconscious. You have no awareness of your environment, yourself or other people and you are reliant on others for all your needs. It is not expected that you will regain consciousness but, with full time nursing care, you will be kept alive for an indefinite period of time.

or

■ You are diagnosed with a dementia, such as Alzheimer's Disease - a progressive disease of the brain that affects your thinking and behaviour. This means that you would not be able to understand what happens to you, nor communicate the treatment you want if you developed a serious illness.

or

■ You are in hospital with incurable cancer and your heart stops beating (cardiac arrest).

Think about the treatments that you would
or would not want in these situations

If something like this happens it is helpful for your family and the doctors and nurses to know your values in life, and your attitudes towards medical treatment.

There may be some circumstances where you would want all the treatments that can possibly be offered to you. In other cases, you may feel strongly about not being treated with certain things like tube feeding, a breathing machine, antibiotics, blood transfusion, dialysis or cardiac massage.

These are the sorts of things to talk to your family about, to help them make decisions in your best interests if a time came when you were unable to decide.

Having a say about your future medical treatment is called Advance Care Planning. It enables you to clarify your values and choices, and gives your family, doctors and nurses the opportunity to respect your choices.

It may be hard for you to face some of the questions and information, but thinking about the medical treatment that is important to you is no different to putting thought into your life insurance, your will or planning for many aspects of your future.

Talking about dying may make us feel uncomfortable, but we all eventually need to plan how we want to live near the end of our lives.



A dilemma

Mary is an independent 84-year-old widow. She is fairly healthy and enjoys the company of her children and grandchildren.

Since her husband died a year ago, Mary has tried to tell her family her thoughts about medical treatment – what is important to her. She wants to "just go quietly, no fuss and none of those machines". Her family say, "Now Mum, don't be talking like that", so she decides not to raise it again.

Now Mary has a stroke at home. Her family are shocked by her sudden deterioration. She is unconscious and the doctors at the hospital are talking about putting a tube down into her lungs and attaching her to a breathing machine. This gives Mary's family hope; they are desperate to have her back home.

One of the doctors approaches them to talk about Mary's condition. He explains that Mary is unlikely to recover consciousness and, if she does, she will be unable to speak, feed herself or attend to the most basic personal tasks.

The doctor explains that it may be kinder to Mary if they take away the machines and provide comfort care, so that she dies peacefully. He is seeking the family's thoughts – "did they know what Mary might have wanted? Had she ever talked about her choices if this sort of situation occurred?"

This creates a dilemma for Mary's family, they had never really paid attention to this sort of discussion. Some of Mary's children want everything done, whereas others believe that she wouldn't have wanted all this technology.



Why plan in advance?

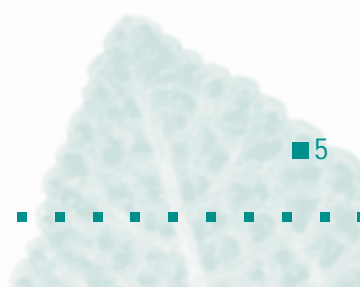
Planning your care in advance of any problems occurring gives those who will be caring for you the opportunity to respect your choices. Putting your family in a position of having to make decisions for you, without knowing what you would want, can be difficult for them. Whereas discussing your choices, can be a comfort to you now, and a comfort to your family in the future.

Advance Care Planning is talking about your choices.

Think about the treatment you would want and talk about it with your family and your doctor. Discussing these things with your family may not be easy for them because many people are uncomfortable talking about a time when you may be unwell. However, this planning becomes especially relevant if you are seriously ill and cannot make decisions yourself. Effective planning is the best way to make sure that your family, and the doctors and nurses caring for you, respect your wishes.

Advance Care Planning is writing down your choices.

An Advance Care Plan is one way of putting your plan into writing. The written Advance Care Plan helps people to accurately remember what you want and makes it easier to communicate these wishes to doctors and nurses who do not know you. It includes appointing a Medical Enduring Power of Attorney and a statement of your choices.



questions and answers

Frequently asked questions

Is it helpful to complete an Advance Care Plan?

Yes, it helps you to think about, and talk to your family and doctor about, future medical care if you become seriously ill. It also means that if you do become seriously ill your family, or someone appointed by you, have something in writing for the doctors to follow.

Who do I talk to?

Talk to your family and to those most likely to be involved in making decisions if you are very ill. A close or loving relationship does not always mean that the other person knows or understands your wishes for future medical care.

Talk to your doctor. They may assist you to make sure your Advance Care Plan is clear and complete. Give your doctor a copy of your completed Advance Care Plan.

Talk to a Respecting Patient Choices Consultant and they will help you to discuss these issues with your family and doctor.

Who should I choose to make decisions for me?

The person(s) you nominate as your Medical Enduring Power of Attorney is called your *agent* (and your *alternate agent*). They should be someone who you trust, who will listen carefully to your values and wishes for future care, and someone who will be comfortable making decisions in difficult situations. Usually the nominated *agent* is a family member, but it can be anyone you trust.

Do I need a lawyer to complete an Advance Care Plan?

No. The law does not require you to have a lawyer to complete your Advance Care Plan.

Can my Advance Care Plan be changed or revoked?

Yes. You can change your plan at any time. Your Advance Care Plan can also be revoked at any time by telling your *agent* that their power of attorney (medical treatment) is withdrawn and by destroying all copies.

When is an Advance Care Plan used?

It is only used if you are unable to make your own decisions. It would guide the decision making of your doctor, your *agent* and family.

What if I become ill or I am injured while I am away from home?

The best way to ensure that you receive the type of care you want is to discuss your choices with your *agent* and family. Also, make sure that they have a copy of your Advance Care Plan.

What happens in an emergency?

When there is an emergency, and your medical record is not available, life-sustaining measures may be started. Following discussions with your *agent* and family, treatment can be stopped if it is clear that it is not what you would have wanted.

How to complete your Advance Care Plan:

1. Think about the values that are important in your life.
2. Think about your current health and possible future health problems.
3. Think about what you would want from future medical care.
4. Talk to your family / next of kin about these issues.
5. Talk to your doctor about these issues.
6. Choose a Medical Enduring Power of Attorney (who becomes your *agent*).
7. Meet with your *agent* and the Respecting Patient Choices Consultant.
8. Work with the Respecting Patient Choices Consultant and your *agent* to complete your Advance Care Plan.
9. Provide copies of your Advance Care Plan to your family, your *agent*, hospital and local doctor and anyone else whom you feel is appropriate.

If you have questions or would like to discuss Advance Care Planning, please contact the person who had this discussion with you –

Your Respecting Patient Choices Consultant is.....

Name: _____

Telephone: _____

Or

Your Doctor: _____