Advance Care Planning

Taking control of your health journey
Acknowledgements

Advance Care Planning Australia acknowledges All Aboriginal Nations as the traditional owners and custodians of the land. We pay respect to their Elders, stories and traditions. The majority of this publication was created on Wurundjeri land in Heidelberg, Victoria.

Throughout this publication, the word ‘Aboriginal’ is inclusive of all Aboriginal and/or Torres Strait Islander people.
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Loddon Valley Highway, near Kerang
Introduction to advance care planning

If you got real crook, and you couldn’t speak for yourself, would your family and doctor (or Aboriginal Health Worker) know your preferences about your health care?

There is something available to help you plan for such times. It’s called ‘advance care planning’, and the first (and most important) step is just having a Yarn about your health and ideas around health care. Letting everyone know what you want is the best way to influence the way you are cared for in times of illness.
Why it’s a good idea

This is not about end of life. This is about taking control of your health journey.

Experience tells us that when someone has a clear plan for how they want to be cared for, the person and family experience is better because there is no guessing. You can make an Advance Care Directive so that everyone knows exactly what you want and who does what. It may be hard for you and your family to talk about it, but it can give you peace of mind about your treatment and experiences in the future.

An Advance Care Directive is called different things, depending on the state or territory you are in. It may be called an Advance Care Plan, an Advance Health Directive, or an Advance Personal Plan.
Consider

You may have diabetes and need to be on regular dialysis from now on. This means there are risks and possible complications. Having your preferences understood and recorded will ensure things go as well as possible in the bad times.

OR

You suffer a major stroke. You end up in hospital for weeks and you can’t move or speak. The doctors need to do lots of tests and procedures.

Does anyone know what you do or don’t want?
Anyone with (or at risk of) chronic illness should consider completing an Advance Care Directive.
The guessing game

This story shows how advance care planning could have helped when an Elder was crook and his family didn't know what care he would have wanted.

Uncle lived a good life, well into his seventies. He was a widower with two sons, four daughters, and a whole mob of nieces, nephews and grandkids. Unc always thought that when his journey came to an end, his kids would know what to do, and he never liked talking about these things because it felt like bad luck.

Uncle moved on to the Dreaming one morning and there was a family meeting that night. Everybody was asked, ‘Do you know what he wanted?’ and ‘Did he ever say anything to you?’ Just about every single person in that room gave a different response and no one could actually say for sure what Uncle really wanted. Some of the family became very frustrated and by the time decisions had been made, many arguments had occurred. Some of these people still feel disappointed by the things that happened in that meeting.

Right or wrong, these decisions were based on guessing. If Uncle had told his family what he wanted done, people may not have argued about his preferences. Having an Advance Care Directive can make things less stressful for your family.
Above: Whisky Beach, Wilsons Promontory

Right: Windmill, Loddon Valley, near Kerang
The benefits of advance care planning

- You continue to have a say in your health care, even if you become too crook to speak for yourself.

- You will have peace of mind, knowing that you are more likely to receive the medical treatment and other care that you would want, and not receive the treatment you would not want.

- Your family and friends are relieved of the burden of having to make decisions without knowing your preferences.

- Talking about these things can help to strengthen your relationships with family and friends.
Frequently asked questions

**Is this the same as a Will?**

No. Although an Advance Care Directive is sometimes referred to as a ‘living Will’, the basic difference between an Advance Care Directive and a Will is that an Advance Care Directive is made to help your medical and care experiences. A Will is specifically about your preferences to be carried out once you have died.

**Do I need a lawyer?**

No. Your Advance Care Directive can be completed independently, with family, or with someone trained in advance care planning. Your doctor or Aboriginal Health Worker can help.

**Can I change my Advance Care Directive?**

Yes. You can change your Advance Care Directive as much as you like. If you do change it, it’s really important that you destroy older copies of your Advance Care Directive, to avoid confusion.
Who should I choose to make decisions for me?
The person(s) you choose should be someone who you trust, who will listen carefully to your preferences for future care, and someone who will be comfortable making decisions in tough situations. Often they are a family member. This person is called a substitute decision-maker.

Do I need to fill out a form to say who I’ve chosen?
It is better to fill out a legal form because then you are clearly telling your family and your doctors who to talk to. The legal forms are different based on where you are in Australia.

Who should have a copy of my Advance Care Directive?
Your family and your main healthcare providers (e.g. your doctor and your hospital) should have a copy of your Advance Care Directive. The person that you have selected to make decisions for you if you are unable to speak for yourself (your substitute decision-maker) will need a copy of the Advance Care Directive too.

What is the most important step to take?
Yarning! Talk to your family and loved ones about what you expect. It might be a hard topic, but it’s better to do it while you’re still here to tell everyone what you want. If you choose a substitute decision-maker then make sure that person understands exactly what you want.
The steps

THINK
Think about how you want to be cared for if you get really crook. How well do you understand different treatments (like Cardiopulmonary Resuscitation, tube feeding, breathing machines, antibiotics, blood transfusions, dialysis or cardiac massage)? Ask your doctor or Aboriginal Health Worker if you are unsure.

YARN
Talk to your family. Make sure everyone understands what you expect. Your Aboriginal Health Worker or Aboriginal Hospital Liaison Officer may be able to help you with the family Yarn Up. Many hospitals have advance care planning staff who can help. You can talk with your doctor about it too.

CHOOSE
Choose your substitute decision-maker. They will need to be over 18 years old and someone who will listen carefully to your values, beliefs and preferences for future care. Depending on the state or territory you are in, the substitute decision-maker may also be known as the:
- Enduring Guardian
- Enduring Power of Attorney
- Medical Power of Attorney or Medical Agent.

WRITE
Once you have thought and talked about what kind of health and personal care you would want, write it all down in an Advance Care Directive. That way, your doctors, family and others will know what kind of care you want. In the Advance Care Directive you can include any Cultural values and requests that are important to you as an Aboriginal person.
(e.g. Smoking Ceremony, Connection to Country). Remember, the hospital may not be aware of your beliefs, so having them written down can help others to respect them.

**REVIEW**

You can change your Advance Care Directive any time. If you do make changes to it, make sure that older copies of your Advance Care Directive are destroyed.

Review your Advance Care Directive:
- if your goals for care and medical preferences change
- if you change your substitute decision-maker
- when your medical condition changes.

Remember to give copies of your new Advance Care Directive to your doctor, the hospital, your family and your substitute decision-maker.
### Contact info

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### More info

For information specific to your state or territory, click on **Resources and forms** at www.advancecareplanning.org.au

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Above: Healesville  
Right: Aire Crossing, Otway National Park
Photography by James Henry

James is from a strong family line of talented artists of various fields. In 2010, backing himself, James followed his passion to become a professional photographer. He feels his work as a photographer compliments his history as a musician and event organiser.

James has an extensive knowledge of the artistic landscape throughout Victoria and indeed Australia. He has developed a keen eye for identifying where the action takes place and the ability to offer exactly what his client seeks. This unique knowledge together with being a familiar face in the Melbourne Aboriginal community, has lead to James' high demand to shoot community events, including but not limited to children, Elders and festivals.

www.jameshenryphotography.com.au

Other links

NACCHO (National Aboriginal Community Controlled Health Organisation)
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NATSILS (National Aboriginal and Torres Strait Islander Legal Services)
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