Respecting patient choices

Advance care yarning

for Aboriginal and Torres Strait Islander people
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, nurses and Aboriginal Health Workers 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 if a time came when you were unable to decide.

Having a say about your future medical treatment is called **advance care yarning**. It enables you to clarify your values and choices, and gives your family, doctors, nurses and Aboriginal Health Workers 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

Aunty was an independent 65-year-old widow. She was fairly healthy and enjoyed the company of her family and the community she lived in. Aunty moved to the city almost 20 years ago to live with her man and his family in his community. Aunty’s man passed away two years ago. When his family organised the funeral they, at Aunty’s request, reserved a place for Aunty to be buried with her man when her time came.

A year ago, Aunty got really sick and passed away. Her family were notified from her community and invited to attend the funeral in the city. Aunty’s family were not happy that Aunty was not being buried on her own land and demanded she be returned to her community for sorry business and burial. Her other family in the city wanted to fulfil Aunty’s wishes to be buried with her man in the plot reserved for her.

Sadly, neither side of her family would agree, so a court order was sought after which took almost two months. If Aunty’s wishes were written down it would have been clear to everyone. As it stands, now Aunty’s two families do not get along and both blame the other for Aunty’s delay in being buried.

Having an advance care yarn can help in deciding what you want in terms of your future medical treatments and what happens to you when you pass away. Then you are able to record your wishes in your Advance Care Plan so that everyone knows what you want.
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 yarning is talking about your choices.
Think about the treatment you would want and talk about it with your family and your doctor and Aboriginal Health Worker. 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 yarning 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 yarning 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, nurses and Aboriginal health workers who do not know you.
Photo: Aboriginal health workers, (left to right) Ragina Williams, Doug Sansbury and Shane Burgess, discussing Advance Care Yarning for the Aboriginal Community.
Is it helpful to complete an Advance Care Plan?
Yes, it helps you to think and talk to your family, doctor and Aboriginal Health Worker about future medical care if you become seriously ill. It also means that if you do become seriously ill, your family, or those appointed by you, can yarn on your behalf and have something in writing for the doctors to follow.

Who do I yarn to?
Yarn 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.

Yarn to your Aboriginal Health Worker. They can help you with getting the information you need and also can advocate/yarn up on your behalf.

Yarn to a Respecting Patient Choices® Facilitator and they can help you to discuss these issues with your family, doctor and Aboriginal Health Worker. They can help you fill in your Advance Care Plan forms.

If you choose to get someone else to make decisions for you
The person(s) you nominate is called your representative (either a Medical Agent or Enduring Guardian). 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. You can appoint more than one representative. Usually a nominated representative 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 use of a representative can also be revoked at any time by telling them that their power is withdrawn and destroying all copies of your plan.

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, any appointed representative(s) and/or your family.

What if I become ill or I am injured while I am away from home and country?
The best way to ensure that you receive the type of care you want is to discuss your choices with your representative(s) and family. Also, make sure that they have a copy of your Advance Care Plan.

What happens in an emergency?
If your Advance Care Plan is available, it will be used to guide treatment decisions. If life sustaining measures have been started, following discussions with your representative(s) and/or family, treatment can be stopped if it is clear that it is not what you would have wanted.
How to complete your Advanced 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 and Aboriginal Health Worker about these issues.
6. You can make an Anticipatory Direction – which simply records your choices – and/or appoint a Medical Power of Attorney or Enduring Guardian(s) to be your representative(s), with or without providing written instructions for them.
7. Work with the Respecting Patient Choices® Facilitator and (if being appointed) any would be representative/s to complete the documents.
8. Provide copies of your Advance Care Plan to your representative/s, hospital and local doctor and anyone else you feel is appropriate.
9. If you make health decisions for someone else, you can ask for help to put a future care guide in place for them.
If you have questions or would like to discuss advance care yarning, please contact the person who had this discussion with you.

Your Respecting Patient Choices® Facilitator is...

Name: ____________________________________________

Telephone: _______________________________________

or

Your doctor: _______________________________________

Your Aboriginal Health Worker: _______________________

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For more information

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www.respectingpatientchoices.org.au

Government of South Australia
www.sa.gov.au/subject/Seniors/Legal+issues/Power+of+attorney+and+advance+directives

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Email: opasa@opa.sa.gov.au

Legal Services Commission of South Australia (free legal advice)
Monday to Friday, 9.00am - 4.30pm
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