Advance Care Yarning

Decision making for end of life for The Tasmanian Aboriginal Community

A guide to Advance Care Planning and the Tasmanian Advance Care Directive
Acknowledgement

We acknowledge and pay respect to the Tasmanian Aboriginal Community as the traditional and original owners and continuing custodians of the land and acknowledge Elders past and present.

We acknowledge the contemporary Tasmanian Aboriginal Community, who have survived invasion and dispossession and continue to maintain their identity, culture and Indigenous rights.

This booklet has been developed by Palliative Care Tasmania for the Tasmanian Department of Health and Human Services as part of the Better Access to Palliative Care in Tasmania Program, funded by the Australian Government. Material for this publication has been adapted with permission from ‘Advance Care Yarning’ published by the Government of South Australia.

Thanks to the Tasmanian Aboriginal Centre for use of photographs.

Contents

Who is this booklet for? 3
Why Advance Care Yarning is important 4
Talking about what You want 5
Planning in advance 6
When is an Advance Care Directive used? 7
Who should have an Advance Care Directive? 8
What about financial decisions? 9
What about financial decisions? 10
Who do I Yarn to? 10
Aunty’s story 11
Who can I choose to be my substitute decision maker? 12
Can I change my Advance Care Directive? 13
What happens in an emergency? 13
What do I do with my Advance Care Directive? 14
Writing your Advance Care Directive 15
Your Notes 17
Further information and ACD Wallet Card 18
Who is this booklet for?

This booklet has been written as a guide for the Tasmanian Aboriginal community to better understand their choices at end of life and how to talk about these by Advance Care Planning (Yarning).

Similar booklets have been written in other states but none specific to Tasmania.

Death and dying is a culturally sensitive topic and it’s often thought that a person’s end of life wishes are known. This may not be the case and in some situations, the Guardianship and Administration Board may become involved in end of life treatment decisions because of family disputes.

Advance Care Yarning can increase understanding about what a person wants as they near their end of life.

This can lead to better understanding and fewer disputes.
Why Advance Care Yarning Is important

Think about the following…. 

*Your father has a stroke and can’t speak for himself. You have been told that it’s unlikely that he will recover, but he can be kept alive with the support of medical equipment and full time nursing care.*

Do you know what his wishes are?

Or

*You have dementia which will cause you to deteriorate quite quickly and you know that it is only a matter of months before you won’t be able to understand about the treatment that is available to you.*

What type of treatment do you want, or not want?

Who else knows about this?

and

Who will speak for you when you can’t?
Talking about what you want

If something happens to you it’s useful for family and friends, as well as the doctors and nurses, to know your wishes, values and attitudes towards your care and medical treatment.

Talking about the type of treatment that you may, or may not want and how and where you want to die, is called **Advance Care Yarning**.

It’s important to talk about these things now, because this will help with decision making if you can’t make treatment choices for yourself later on.

Most people don’t want to think about dying, that’s normal. But planning for the end of our lives is as important as planning for how we live.
Planning in Advance

Planning in advance through Advance Care Yarning gives the people who will care for you the opportunity to understand your wishes.

Yarning is the most important thing we can do with family. Writing down what we want is important too.

An **Advance Care Directive** is a way to write down what is important to you and what care and treatment you want, so that if you can’t decide for yourself, your choices are clear and your wishes can be respected.

If you don’t have an Advance Care Directive people may have to make decisions for you without knowing what you want.
When is an Advance Care Directive used?

An Advance Care Directive will only be used if you lack capacity.

Capacity is a legal term and is explained in the following extract from the book the ‘Capacity Toolkit’.

Broadly speaking, when a person has capacity to make a particular decision, they are able to do all of the following:

- understand the facts involved
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- communicate their decision.

(DHHS, 2009. Capacity Toolkit)

The ability to communicate does not only mean being able to talk or write, but will be assessed according to the situation.

When you write an Advance Care Directive you save your family and friends the stress of making decisions for you without knowing what you want.
Everyone should have one, but especially people who:

- Have a chronic or life-limiting health condition;
- Are entering a residential care facility;
- Believe their family may have different views, beliefs or values;
- or
- Have a condition that may lead to a loss of capacity, such as Dementia.
In your Advance Care Directive, you can name one or more people that you want to speak on your behalf if you lack capacity.

This is known as a Substitute Decision Maker and is called the Person Responsible.

You can also choose an Enduring Guardian to act on your behalf if you should lose the ability because you lack capacity.

To name an Enduring Guardian you need to complete a form from the Guardianship and Administration Board of Tasmania. Once it's signed and witnessed you will need to lodge it with the board.
What about financial decisions?

An Advance Care Directive or an Enduring Guardianship only covers medical treatment, personal care and life-style matters.

You can appoint an Enduring Power of Attorney to deal with your finances and property on your behalf if you lose the capacity to manage these things.

A Will is a document that states how you want your property distributed after death. The contents of a will has no legal status until after death.

Who do I yarn to?

Yarn to your family and people who are likely to be involved in making decisions if you are very ill and lack capacity.

Remember, because people love and care for you doesn’t mean they understand your needs and wishes.

Yarn to your doctor or Aboriginal Health Worker, they can help you get the information you need.
Aunty was getting close to the end of her life.

At the age of 70 she had chronic lung disease and her health was quickly getting worse.

She was regularly in contact with the Aboriginal Liaison Officer at the local hospital who talked to her about her wishes, gave her support and linked her into the care services she required.

Aunty had lived in her home for 45 years, but she knew that her family wanted to take her back to country because she couldn't look after herself anymore. She felt that her house was her home and was where she wanted to die, but she was happy to go back to country to be buried.

Aunty yawned with her family and her doctor and they were able to arrange personal care and home help. Aunty’s family stayed with her and were very happy with the services and support.

Aunty said “I want to die at home with my family around me.” By yarning with her family, Aunty was able to stay at home and die where she wanted.
Who can I choose to be my Substitute Decision Maker?

The person you name as your Substitute Decision Maker is called your Person Responsible.

The person who makes your decisions for you must be someone that you trust.

Someone who will listen carefully to your values, wishes and beliefs for future care and will carry out your wishes when the time comes.

It must be someone who is comfortable making decisions in a difficult situation.

You can appoint more than one Person Responsible.

The Person Responsible can be a family member, or it can be anyone that you trust to do this important job.
Can I change my Advance Care Directive?

Yes, you can. You should check it regularly and it should be updated when situations change.

You can also change your Person Responsible at any time.

Your new Directive will need to be given to everyone who has the old version and all copies of the old Advance Care Directive should be destroyed.

What happens in an Emergency?

The paramedic’s role is to save lives and they will take you to hospital if it is needed.

If your Advance Care Directive is available, it can be used as a guide. If you go to hospital ask the paramedic to take it with you.

If treatment that you don’t want is started, you or your Person Responsible can ask for the treatment to be stopped.
What do I do with my Advance Care Directive?

Keep the original at home, make sure people know where it is;
Keep a copy with you if you travel.

Give copies to:

Your Person Responsible and your Enduring Guardian if you have one,
Your doctor, hospital, family and friends who may be involved in your care;

and

Fill in and keep in your wallet, the wallet card that comes with the form, (or cut out the one on the back page) that says you have an Advance Care Directive.
Writing your Advance Care Directive

Think about the things in your life that are most important to you.

Think about your health and what health problems you may have in the future.

Think about what type of medical care and treatment you would or wouldn’t want.

Write these thoughts down, a simple list is good, (you can use the notes page in the back of this book).

Yarn to your GP or someone else who knows about your health and may have an idea of what kinds of medical problems you may have in the future.

Yarn to people who are important to you, your family and friends, about your thoughts and feelings.

As you yarn, add things to your list that you want to include in your Advance Care Directive.

Use “if......... then.........” statements to help make your wishes clear.

For example:

“If I can’t recognize or know my friends or family any more, then I would not want life-prolonging treatments, but on”

“If I can’t recognize or know my friends or family any more, then I would not want life-prolonging treatments, but only pain relief and comfort care.”
**Choose** who you want to have as your Person or People Responsible; check with them that they are happy to do the Job.

**Fill in the Form,** give copies to your doctor, local hospital, Your Person Responsible, family and other people who should know about your Advance Care Directive.

**Yarn to family and friends and tell them where the form is kept at home.**
Advance Care Directive

I ………………………………………

have completed and Advance Care Directive so that if I am unable to speak for myself, my health care wishes are known.

My preferred ‘Person Responsible’ is:

NAME………………………………………………………….

PHONE……………………………………………………...

References used in this book and where to find more information

Advance Care Yarning for Aboriginal and Torres Strait Islander People
Government of South Australia 2006.

and

Respecting Patient Choices, Austin Health.
http://www.pallcare.asn.au/upload/info-resources/aboriginal-palliative-care-resources/Advance_Care_Yarning_ATSI_SA.pdf

Palliative Care Tasmania www.tas.palliativecare.org.au/


Taking Control of Your Health Journey - Advance Care Planning for Aboriginal and Torres Strait Islander Community

Cut out and keep in your wallet or purse

Advance Care Directive

I…………………………………………………………

have completed and Advance Care Directive so that if I am unable to speak for myself, my health care wishes are known.

My preferred ‘Person Responsible’ is:

NAME………………………………………………………….

PHONE……………………………………………………….