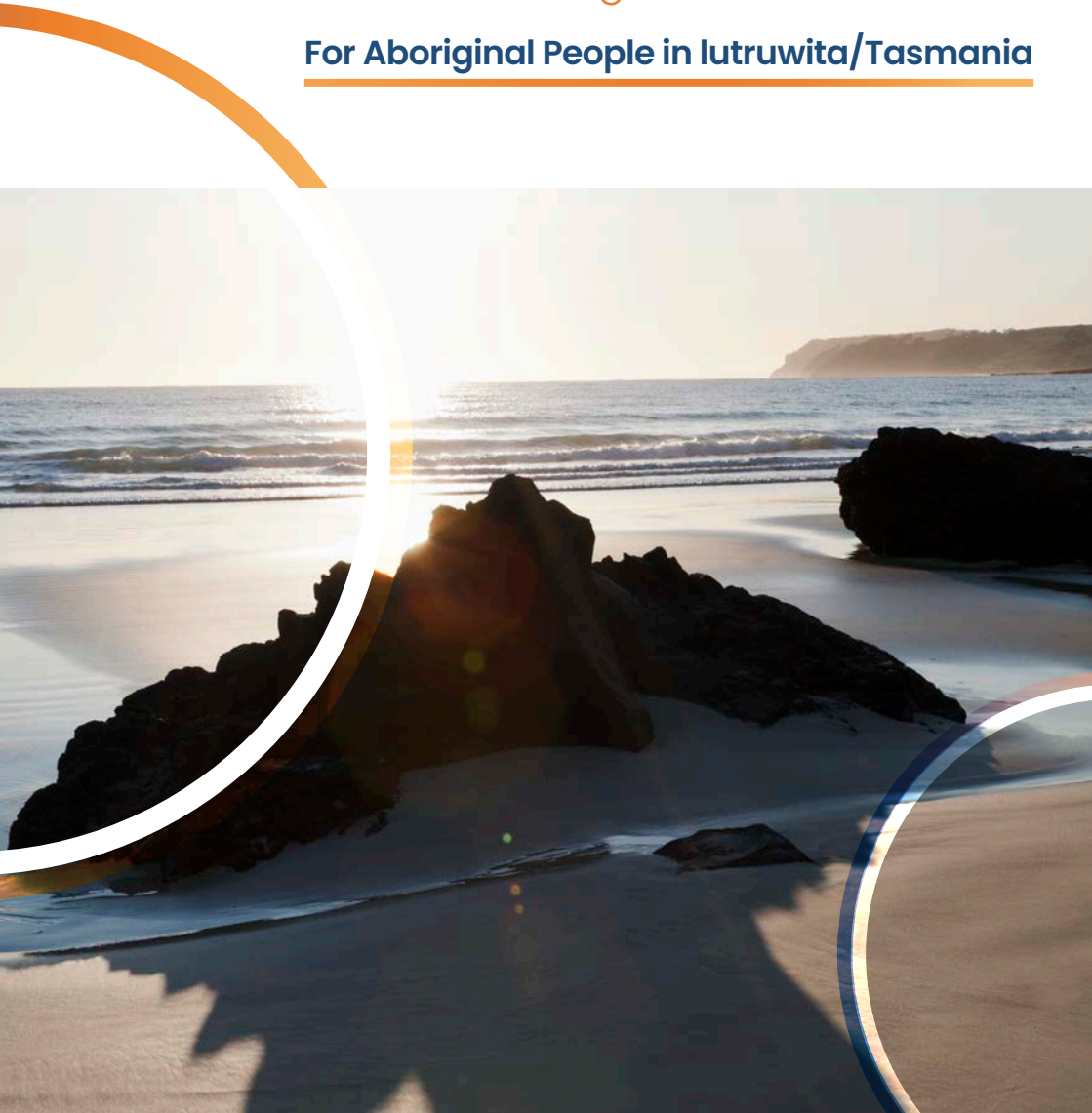




Advance Care Yarning

Decision Making for End of Life

For Aboriginal People in lutruwita/Tasmania



Acknowledgements and thanks

We acknowledge the traditional owners of the land on which we work and live, and respect Aboriginal people's ongoing custodianship of the land. We pay respect to Tasmanian Aboriginal people, and Elders past and present and emerging.

Thank you to everyone who contributed to this Advance Care Yarning guide, especially Aboriginal people in lutruwita/Tasmania who shared their experiences. We understand for some it was hard to relive experiences of illness, pain and death.

Thank you to the Aboriginal people and organisations that guided us with consultation:

Helen Woodbridge	Program of Experience in the Palliative Approach – PEPA Program
Lorraine Webb	Karadi Aboriginal Corporation
Tracey Cleaver	Aboriginal Health Liaison Officer Royal Hobart Hospital
Diane Hopper	Tasmanian Aboriginal Centre
Tasmanian Department of Communities	Office of Aboriginal Affairs

Tasmanian Aboriginal Health Reference Group

Members include:

- Cape Barren Island Aboriginal Association
- Circular Head Aboriginal Corporation
- Flinders Island Aboriginal Association
- Karadi Aboriginal Corporation
- South East Tasmania Aboriginal Corporation

Front cover picture provided by Photographer, Lucia Rossi
luna tunapri workshop 2011
Collection: Tasmanian Museum and Art Gallery

Who is this booklet for?

This booklet was developed as a guide for Aboriginal people, their families and their community, who live in lutruwita/Tasmania, to better understand their choices at end of life and how to explain these choices to medical and health professionals through Advance Care Planning (Yarning).

Palliative Care Tasmania (PCT) understands that death and dying is a culturally sensitive topic, and in many cases it is assumed that a person's end of life choices and preferences are known.

This is often not the case and in some situations the Guardianship and Administration Board (GAB) has had to become involved in end of life treatment decisions due to family disputes. Through increased awareness of Advance Care Yarning, Aboriginal people; their family; friends; and community, will have a greater understanding of a loved one's choices and preferences for end of life care and will be better able to communicate these to medical and health professionals.

Considerations

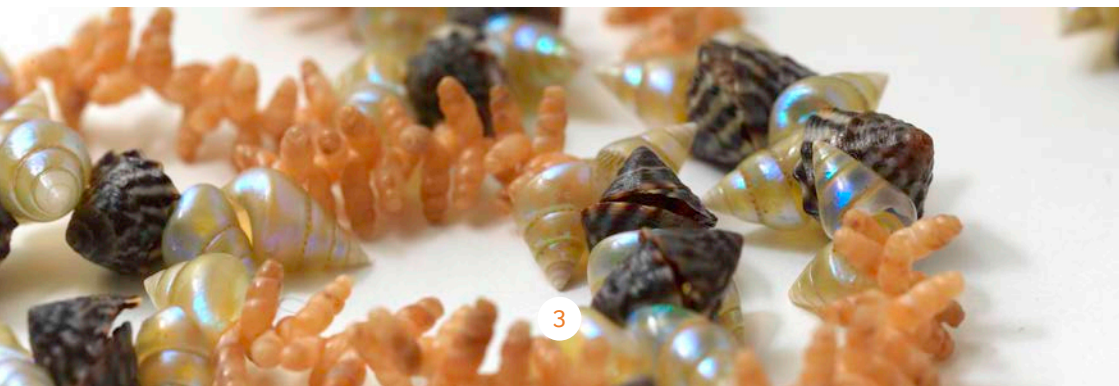
All Aboriginal people are different. It is important not to make generalisations and assumptions about the choices and preferences of Aboriginal people. For example, for some it is okay to speak about a person who has died, while for others it is not okay.

lutruwita/Tasmania is the country of Tasmanian Aboriginal people. The cultural and spiritual connections to country may be felt more strongly in some cases depending on the person. This is important for medical and health professionals to consider when supporting a dying person.

The most important thing is to respect Aboriginal people's choices and preferences, and to yarn. Care must be undertaken if you intend to ask about culture, family, and traditions. Please ensure support is provided based on what you know and not on what you assume.

It is important that our own cultural bias does not impact on the way we support other people, regardless of their culture, customs and beliefs.

Dulcie Greeno (b.1923)
stripy buttons, marina and rice shells
Collection: Tasmanian Museum and Art Gallery



Why could Advance Care Yarning be important to you?

If something happens to you, or your family, it is useful for loved ones and the doctors, nurses and Aboriginal health workers/practitioners to know a person's choices, preferences, values and attitude towards medical treatment, and their feelings about cultural, spiritual and emotional support.

In some instances, you may want all available treatments. In other circumstances, you may believe that medical interventions such as tube feeding, breathing machines or cardiac massage are not what you would want.

To reduce anxiety for you and your family, it is important to talk about these things early. This helps the decision making if you become unable to make health care decisions for yourself in the future.

Having a conversation about possible future medical care and support is called Advance Care Yarning. Yarning helps to provide clarity for loved ones on your choices and preferences and gives your family, doctors, nurses and Aboriginal health workers/practitioners the opportunity and time to respect your choices and help to carry them out.

It can be difficult to think about and discuss some of these issues. However, writing down your choices and preferences, including your spiritual care, along with the things that you consider to be important, will help you to have control over your quality of life if you lose capacity to make decisions about your health care in the future.

Losing or lacking capacity means you cannot understand or communicate your choices, preferences and decisions about medical treatments, lifestyle choices and spiritual care.

It is normal not to want to think about dying but we all need to understand and plan how we want to live including what is important to us at the end of our lives.

It may be easier to consider it similar to having health insurance or planning for other important occasions or aspects of your life.



Think about the following...

Your father has had a stroke and is unable to speak for himself. You have been told it is unlikely he will recover. He can be kept alive with the support of medical equipment and full-time nursing care.

Do you know what his choices and preferences would be?

Or....

You have dementia which is causing you to deteriorate quite quickly and you know it is only a matter of months before you will not be able to understand or communicate the treatment you want.

What would your treatment wishes be?

Who needs to know what you would or would not want?

Who would you want to speak on your behalf if you could not speak?

Planning in Advance...

Planning in advance through Advance Care Yarning gives those who will be caring for you the opportunity to understand your wishes. Yarning is the most important thing we can do with family, however, when someone is unwell this can bring about emotions and confusion.

After we yarn it is important to write down our decisions, choices and preferences. These should be recorded in an "Advance Care Directive" (ACD).

Therefore, if you become too unwell to make decisions and your family are finding the decision-making process hard, the decisions you made in advance can still be communicated accurately to doctors, nurses and Aboriginal health workers/practitioners and your ACD will then be followed.

If you do not have an ACD, this puts your family in the difficult position of having to make decisions for you without knowing what you want. This can be hard for them, whereas yarning about what's important to you and writing this down when you are able to, can provide comfort to you and your family in the future.

What is an Advance Care Directive?

An ACD is a written record of your choices and preferences for the care and support you will receive. Your ACD will guide family, doctors, nurses and Aboriginal health workers/practitioners when certain things happen during

your Advance Care Journey. It is to ensure your choices and preferences are continuously followed accurately by doctors, nurses and Aboriginal health workers/practitioners.

When is an Advance Care Directive used?

An ACD will only be used if/when you lack capacity. If this happens then others will need to make decisions for you if you do not have an ACD in place.

If you have not yarned with your family, friends or others, and have not written down anything to guide them, they might not know what you would want them to do for you.

In Tasmania, ACD's are legally-binding under common law. They allow you to stay in control of what happens to you if you lose capacity and are unable to make decisions.

If you write an ACD, you may also save your family from extra stress if an emergency should happen.

Who would speak for you?

Through Advance Care Yarning you can talk with your family about who would be the most appropriate person to make decisions for you if you could not.

In Tasmania, it is important to appoint this person as your Enduring Guardian. You need to have a particular form from the "Guardianship and Administration Board". When the form is signed and witnessed, you need to register it with the Board. You can appoint single or joint Guardians. You can revoke an Enduring Guardianship. You can also change your Enduring Guardian at any time you wish, as long as you have capacity to do so. For example, your children may now be adults and can make decisions your behalf, or you may have divorced and now you do not want your divorced spouse to make decisions on your behalf.

It is important to note that you will need to complete and register new forms. Information and forms are available from www.guardianship.tas.gov.au

Your Enduring Guardian can make decisions about medical treatments and place of care, if you have authorised them to do so. They can yarn on your behalf.

If you do not have an Enduring Guardian, then the *Guardianship and Administration Act 1995* sets out a hierarchy of people to make decisions for you including:

- Spouse; or
- Unpaid Carer; or
- Family Member; or
- Person who knows you well

This person is called the 'person responsible'.

Who should have an Advance Care Directive?

Everyone should have one, but especially people who:

- have chronic or life-limiting health conditions or illnesses;
- are entering residential care facilities;
- believe their family may have different views, beliefs or value systems to them; and
- have a condition that may lead to a loss of capacity to make decisions (e.g. Alzheimer's Disease).

Advance Care Yarning and the Law?

Under common law in Tasmania, it is expected that medical practitioners should comply with the wishes expressed in an Advance Care Directive, taking the clinical situation into account at the time.

They would also talk to the 'Person/s Responsible' or 'Enduring Guardian' who can speak on your behalf about what they know of your wishes if an issue comes up that is not mentioned in your Advance Care Directive.

The law is different across Australia so it is important to check and understand the law in your relevant State or Territory.

Ashlee Murray (b.1987)
king marina shells
Wynard 2016
Collection: Tasmanian Museum and Art Gallery



What about financial decisions?

An ACD is only about medical treatment and emotional, social, spiritual and cultural matters. You cannot provide financial directives in your ACD. Neither an Enduring Guardian, nor a 'Person Responsible' can make financial decisions.

You need to appoint an Enduring Power of Attorney to deal with finances and property in case you cannot manage these things for yourself in the future.

A "Will" is a document that states how you want your property and assets and belongings distributed after death. A Will is not legally valid until after death. Do not put instructions in your Will about the care you wish to receive when you are dying. No one will see this until after you die.

Frequently asked questions...

Is it helpful to complete an Advance Care Directive?

Yes, it helps you to clarify your thoughts, values and beliefs around medical care and lifestyle choices if you became seriously ill. Yarn to your family, doctor and Aboriginal health worker/practitioner to understand what you might need to include or to consider, based on your current health and situation.

Your Person Responsible or Enduring Guardian will be able to yarn on your behalf to ensure your wishes are respected if you lose capacity to do so yourself.

Who do I yarn to?

Yarn to your family and to those who are likely to be involved in making decisions if you lose capacity. Just because you love and care for others does not mean they clearly understand your needs and wishes. One of the most distressing things that can happen is when your family are asked to make decisions for you and they don't know what you would have wanted.

Yarn to your Health Service Provider or Aboriginal Health Worker/Practitioner.

They can help you get the information that you need and can also advocate/yarn on your behalf.

Who will I choose to be my Enduring Guardian?

The person who makes your decisions for you must be someone you trust; someone who will listen carefully to your values, wishes and beliefs for future care; and someone who will be comfortable making difficult decisions in a difficult situation. You can appoint more than one Enduring Guardian. Often they are a family member, but it can be anyone you trust.

Do I need a lawyer to complete my Advance Care Directive?

No, the law does not require you to get a lawyer to complete your ACD and there is no cost involved. It is better to talk to a health professional about your ACD, as a lawyer cannot provide you with medical advice or information that you may need to complete your ACD.

Can I change my Advance Care Directive?

Yes, you can. You should review it regularly and it should be updated when situations change, for example; if you are diagnosed with a life-limiting condition, or if your condition is deteriorating, or as you are getting older.

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

What if I become ill when away from home and country?

The best way to ensure that you receive the care you want is to discuss your choices with your Enduring Guardian or Person Responsible and your family. Make sure they have copies of your ACD. You can also keep a copy with you when travelling.

What happens in an emergency?

If your ACD is available, it should be used. However, the paramedic's role is to save lives and if treatments have started that do not follow your wishes and your Enduring Guardian or Person Responsible are there, they can speak on your behalf if it is clear the treatment is something you would not want. It is important to keep your ACD in a prominent position at home, like on the fridge. That way, paramedics can find it easily.

Guide to writing an Advance Care Directive

1. Think about and identify desired practices and beliefs, values and the things that are most important in your life. Note things down in brief dot point form at this stage.
2. Think about your current health and what future health problems may need to be considered.
3. Think about what kinds of outcomes you would or would not want from future medical care. Using "if..... then....." statements help to make clear what your wishes really are, i.e. "If I can't hold a normal conversation with people anymore, I see little point in living, so I would not want life-prolonging treatments and would only want to receive pain and comfort measures."
4. Talk to important people about your thoughts and feelings. What would you want if you were unable to express your wishes at some point in your future?
5. Talk to your health service provider or Aboriginal health workers/practitioners or someone else who knows about your current health status and may be able to give some idea of what kinds of medical problems may arise in your future.
6. Appoint someone you trust and who knows you well as your Enduring Guardian. If you do not, you will have a 'Person Responsible' based on the hierarchy in the Guardianship and Administration Act. Make sure you ask them first if they are prepared to do this for you.
7. If you think that your wishes may not be followed, or there might be disagreements amongst the people who might want to be involved in making decisions about your care, it is best if you appoint an Enduring Guardian using the form from the Guardianship Administration Board. The form needs to be registered with the Board and a fee paid.
8. ACDs need to be understood by all decision makers so they can advocate/yarn for you. Remember: as long as you can understand, and communicate (have capacity) you can make your own decisions.
9. Give copies of your ACD to your doctor, local hospital, Aboriginal health worker/practitioner, family and other people who should know about your ACD. Tell them where the copies of this document are kept at home.

"If you needed to make health decisions for someone else (i.e. mother, sister) you can ask for help from your Aboriginal health worker/practitioner, or from their doctor with their family, to put a future care guide in place for them. You are acting as the 'Person Responsible' in this situation.



Photographer, Lucia Rossi
Tayenebe workshop Bicheno
Collection, Tasmanian Museum and Art Gallery

Scenario:

Aunty was approaching end of life. At the age of 70 she had chronic emphysema and her health was deteriorating rapidly. She was regularly in contact with the Aboriginal Liaison Officer at the local hospital who was able to talk to her about her wishes, provide support and link her into the care services she required.

Aunty had lived in her current home for 45 years, however, she knew that her family wanted to take her back to country as she was unable to look after herself anymore. She felt that her house was her home and where she wanted to die but was happy to go back to country to be buried.

By expressing her wishes to her family, her doctor and her Aboriginal Health Service, they were able to arrange personal care and domestic assistance. Aunty's family stayed with her and they were very happy with the services and her support worker.

Aunty said; "I want to die at home with my family around me." With the assistance she had from the community, and by expressing her wishes early, her family were able to keep her at home, and she was able to die at home like she wanted.

Where to find more information on Advance Care Yarning

Palliative Care Tasmania

www.pallcaretas.org.au

Palliative Care Australia

www.palliativecare.org.au

Advance Care Planning Australia

www.advancecareplanning.org.au

Program of Experience in the Palliative Approach

www.pepaeducation.com

Tasmanian Aboriginal Centre

www.tacinc.com.au

Health Infonet

www.healthinfonet.ecu.edu.au

Aboriginal and Torres Strait Islander, Discussion Starter:

www.dyingtotalk.org.au



For more information visit www.pallcaretas.org.au or call (03) 6231 2799

