Advance Care Planning

A Guide To Advance Care Planning and The Tasmanian Advance Care Directive
Who is this booklet for?

This booklet has been written as a guide for all Tasmanians to better understand their choices for end of life care and how to ensure their choices are known and respected using Advance Care Planning and the Tasmanian Advance Care Directive.

It also gives medical and community service practitioners a check list and reference guide to help them assist their clients with completing an Advance Care Directive.

Death and dying is a sensitive topic and it’s important that everyone has the opportunity to have the end of life care they want, regardless of their situation or background.

Advance Care Planning can help reduce the chance of disputes and disagreement about end of life care.

An Advance Care Directive can also give us greater peace of mind as we age, because our choices for the medical treatment and type of lifestyle we wish to have will be known and respected.
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’s 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 if you can’t?
Talking about what you want

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

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.

Talking with family and friends is the most important thing we can do. It is also important to talk with people such as your doctor who can give you information about the types of health issues you may have in the future and answer any questions you have about medical treatment.
Planning in advance

Talking about your health and care needs is important. But 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 type of 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.

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An Advance Care Directive can make end of life decision making easier
When is an Advance Care Directive used?

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

Capacity is a legal term. Here’s a straightforward explanation of capacity 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 doesn’t only mean being able to talk or write and help with communication difficulties can be given if needed. Assessment of capacity to make decisions about medical treatment and personal care will need to be made by a doctor.
Who should have an Advance Care Directive?

**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 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 person is your substitute decision maker and is called the Person Responsible.

Alternatively, if you believe that your Person Responsible may be challenged, or there may be a dispute about your care, you can choose to appoint an Enduring Guardian to act on your behalf.

To appoint 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.
Hierarchy of Substitute Decision Making

ENDURING GUARDIAN
appointed by the Person Concerned when they had decision making capacity. Appointment lodged with the Guardianship Board. If no Enduring Guardian appointed then...

PERSON RESPONSIBLE
1. Spouse or de facto who has a close and continuing relationship with the Person Concerned.
   If no spouse or de facto then...

PERSON RESPONSIBLE
2. An unpaid carer who provides care to Person Concerned, or did so prior to them entering residential care.
   If no unpaid carer then...

PERSON RESPONSIBLE
3. A close friend or relative who has an ongoing relationship with the Person Concerned, with frequent contact and who believes they know the Person Concerned’s wishes and is prepared to act in their best interests.
Who can I choose to be my substitute decision maker?

The person you choose as your substitute decision maker needs to be someone that you trust to make decisions for you.

It should be someone who will listen carefully to your values, wishes and beliefs and who will carry out your wishes when the time comes.

Choose 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.
What about financial decisions?

An Advance Care Directive or 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 talk to?

Talk to your family or others who are likely to be involved in making decisions if you lack capacity.

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

Talk to your doctor, they can help you get the information you need.
Edna was getting close to the end of her life.
At the age of 70 she had very bad lung disease and her health was quickly getting worse.

Edna had lived in her home for 45 years, but she knew that her family was worried because she couldn't look after herself properly anymore.

Edna felt that her house was her home and it was where she wanted to die. Edna talked with her family and her doctor who talked to her about her wishes, gave her support and helped her to write her Advance Care Directive.

Edna got the care services she needed so that she could stay at home. Her family were very happy with the services and support.

Edna said “I want to die at home with my family around me.”

By talking with her family and completing her Advance Care Directive, Edna was able to stay at home and die where she wanted. Her family knew and respected Edna’s choices and the medical and care services were able to support her in her end of life.
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 or your Enduring Guardian
    your doctor, hospital and family and friends who may be involved in your care; and
Fill in the wallet card and keep where it can be seen in your purse or wallet.
If you didn’t get a wallet card with the form, there is one that you can cut out on the back page of this booklet.

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 Advance Care Directive will need to be given to everyone who has the old version and all copies of the old one 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 your notes for the hospital staff.

If treatment that you don’t want is started, you or your Person Responsible can ask for the treatment to be stopped.
If you need help with your Advance Care Directive and:

- you have recently arrived in Australia either as a migrant, asylum seeker or refugee;
- English is not your first language,
- you have trouble reading and writing.
- you are Aboriginal,
- you have any type of disability.,
- or if you feel for any reason that you need help to write your Advance Care Directive. Talk with a doctor or other community service provider first.

If you identify as LGBTI, or you believe that for any reason the directions in your Advance Care Directive may not be followed, contact the Guardianship and Administration Board of Tasmania, or the Community Legal Service. Details are on the back page.
Writing your Advance Care Directive

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

**For example:**
- seeing family, especially grandchildren;
- being able to get outside every day and sit in the garden;
- being able to talk with friends;
- being able to meditate or pray daily.

**Talk** to your GP or someone else who knows about your health and will have an idea of what kinds of medical 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, (there is a page for notes at the back of this book).

**Talk** to the people who are important to you about your thoughts and feelings. As you talk, add things to your list that you want to include in your Advance Care Directive.

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

**For example:**
“If I can’t recognise my friends or family any more, then I don’t want life prolonging treatments, just pain relief and comfort care.

or

“If I can die without pain and with dignity, then I would want drugs to be used to achieve this, even if it means that I need to be kept unconscious.”
Choose who you want to have as your Person 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 friends and anyone else who should know about your Advance Care Directive.

Talk to family and friends and tell them where the form is kept at home.
Check list for health and community service professionals assisting clients to complete an Advance Care Directive.

- Does your client have capacity? If there is doubt, this needs to be addressed.
- Be aware of, and sympathetic to, any cultural, religious or other sensitivities your client may have; especially in the areas of medical treatment at the end of life and choosing a substitute decision maker. The notes resource list at the back of this book may help. Also listed are two more books in this series that are specific to Tasmanian Aboriginal people and for service providers working with people from a culturally and linguistically diverse (CALD) background.
- Discuss and identify current and desired practices, beliefs and values as well as the things that are most important for your client in their day to day life.
- Your client needs to have an understanding of their current health status as well as an idea of medical problems that may arise in the future.
- Discuss the preferred outcomes of possible medical care or intervention.
- Who will be the substitute decision maker for your client? Have they spoken to them about the role?
- Check who the completed Advance Care Directive will be given to and where a copy will be kept at home.
- Does your client have a wallet card for quick reference in an emergency? (see back page).
Information about Substitute Decision Makers

The Person Responsible or Enduring Guardian has a responsibility to support the values, wishes and preferences of the person they represent, so it’s important they understand those choices.

The substitute decision maker will only make decisions if the person lacks capacity at the time any decision is being made.

They will need to talk with the health professionals providing care to find out what the likely outcomes of treatment might be. And should use the Advance Care Directive to guide the discussion and decisions.
References used in this book and where to find more information

advanced_care_directive_pamphlet

Palliative Care Tasmania. (PCT) http://www.tas.palliativecare.org.au/
http://www.tas.palliativecare.org.au/content/information-languages-other-english
http://www.tas.palliativecare.org.au/content/advance-care-planning-understanding-your-choices-and-
making-your-wishes-known

Guardianship and Administration Board of Tasmania, ph 1300 799 625

Tasmanian Aboriginal information

DHHS&PCT. Advance Care Yarning and the Tasmanian Advance Care Directive
http://www.tas.palliativecare.org.au/content/advance-care-planning-understanding-your-choices-and-making-your-
wishes-known


Legal services
http://www.lclc.net.au/

http://www.tas.palliativecare.org.au/content/information-languages-other-english
Cultural Diversity

Migrant resource centre  http://mrchobart.org.au/contact-us/
DHHS&PCT 2017, Advance Care Planning - A Guide for Service Providers working with people from Culturally and Linguistically Diverse Cultures
http://www.tas.palliativecare.org.au/content/advance-care-planning-understanding-your-choices-and-making-your-wishes-known

LGBTI
http://www.workingitout.org.au/
http://rainbowtas.org/links/links.html

People with a disability  http://www.livetasm.com/