Government of **Western Australia**
Department of **Health**
WA Cancer and Palliative Care Network

Advance Care Planning

A Patient's Guide

Version 2

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We acknowledge the website of the Office of the Public Advocate http://www.publicadvocate.wa.gov.au/E/enduring_power_of_guardianship.aspx as a valuable source of information

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Important disclaimer

The information in this Guide is not intended to be comprehensive. Similarly, it is not intended to be, nor should it be, relied upon as a substitute for legal or other professional advice. If you have a legal problem, you should seek independent legal advice tailored to your specific circumstances.

Advance Care Planning

Advance Care Planning is an ongoing discussion between a patient and their carers, family and health professionals about the patient's values, beliefs, treatment and care options. It focuses in particular on the patient's wishes for their future treatment and care should they no longer be able to make or communicate their decisions at the time they are needed.

This guide provides an overview of Advance Care Planning.

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Talk to someone close to you

Talking to your loved ones about your wishes at the end of life, or in case of incapacity, is a conversation not many feel comfortable about. However for most of us, incapacity or end of life does not always occur the way we would like it to.

A chronic or terminal illness can take away our capacity to make decisions about how we would like to be treated in our final months and days, so it's important to let those close to you know your wishes beforehand.

The best way to do this is by having conversations with someone close to you such as partners, relatives and friends about your wishes for your care and treatment.

You may have strong opinions about what you would like to happen. Some questions to consider are:

- What kind of care would you prefer or find unacceptable?
- Would you want to be revived if your heart or breathing stops?
- Where would you prefer to be cared for?
- Is there anything special you would like to have with you?
- Is there anything or anyone you would not want to have with you?

There may be many thoughts and feelings raised when talking to loved ones. It can be both confronting and comforting.

It is natural to avoid talking about issues that make you feel uncomfortable, however, the time to have the conversation will likely happen eventually. While avoidance may provide short-term comfort, in the end it will likely increase anxiety in you, your family and friends. If those who are close to you are faced with making big decisions about things that impact on your life, it can be very stressful for them. Give them guidance on what you really want.

There may come a time when you are unable to convey your wishes. Let your loved ones know now so it is easier for them and for you.

Gather your thoughts

Explore your options for care and consider all circumstances. For instance, it may not be possible for you to be cared for at home if your condition deteriorates. You therefore may perhaps wish to explore the alternatives available to you with your treating health professionals, Enduring Guardian, or family.

Some of your wishes will be about your medical care and others will be about other personal matters.

Some examples to consider may include:

- your choice about whether you would like to be cared for at home, in a hospital, nursing home or hospice
- who you would like to have visiting you when you have lost capacity or are approaching end of life
- how you might like religious or spiritual beliefs reflected in your care
- your comfort – for example, whether you prefer a bath or a shower, sleeping with the light on or off
- solutions for practical concerns, such as who looks after your pet
- making a will and/or communicating its location
- communicating any details or preferences for funeral arrangements
- possessions you would like around you when you have lost capacity or are approaching end of life:
  - favourite photos
  - items of clothing or familiar or favourite objects of significance to you
  - your choice of music to be played
- personal messages to family and friends
- treatment decisions which are acceptable or not acceptable to you
- things you do not want.

This is the time to stop, think and talk. It may be helpful to gather information from health professionals, family and friends, or others such as your spiritual advisor, counsellor, support group or the internet.

Talk to your doctor

You've had the discussions with your family, friends and/or Enduring Guardian and you've outlined your wishes. Now you need to convey your wishes to your doctor and/or other treating health professional/s.

Be frank with your treating health professional/s. They are there to help and will appreciate clear instructions about your future care. Take someone along for support if you wish.

Find out from your treating health professional/s what your illness means if you don't already know.

Some questions to consider about your illness:

- How will it affect you?
- What will be the effects of any potential treatment?
- What palliative care will be available?

This is the time to let your treating health professional/s know about your own views and feelings and the treatment options available, such as:

- Would you like to be revived if your heart stops?
- Would you like to be fed or receive fluids through a drip?
- Will you donate your organs?

Now is the time to have that conversation and put a plan in place

Others who can help

You can find out more about Advance Care Planning by speaking to a health professional or by finding more information on useful websites.

Sometimes a different perspective can be useful in helping you prepare your Advance Care Plan.

Here are some helpful organisations:

Carers WA

182 Lord Street, PERTH WA 6000
Telephone: (08) 1300 227 377
Email: info@carerswa.asn.au
Website: www.carersaustralia.com.au

Palliative Care WA Inc

15 Bedbrook Place, SHENTON PARK WA 6008
Telephone: 1300 551 704
Email: pcwainc@palliativecarewa.asn.au
Website: www.palliativecarewa.asn.au

Cancer Council WA

420 Bagot Road, SUBIACO WA 6008
Telephone: 131120
Website: www.cancerwa.asn.au

Health Consumers' Council Western Australia

Unit 6 Wellington Fair, 40 Lord Street, EAST PERTH WA 6004
Telephone: 1800 620 780
Email: info@hconc.org.au
Website: www.hconc.org.au

Organ Donation

DonateLife Western Australia
Suite 3, 311 Wellington Street, PERTH WA 6000
Telephone: (08) 9222 0222
Email: donatelife@health.wa.gov.au
Website: www.donatelife.gov.au

Ethnic Disability Advocacy Centre

Website: www.edac.org.au

Make your thoughts known – put them in writing

Once you are clear about your wishes for future treatment, care and personal matters, it is recommended you put these in writing.

The Advance Care Planning process may identify that several different documents should be completed so that your wishes are properly recorded and may (or must) be followed when the time comes.

Consider which of the following may be required in your case.

Advance Health Directive

An Advance Heath Directive (AHD) is a form recognised at law (under the *Guardianship and Administration Act 1990*) that contains a person's decisions to provide or withhold consent to specific health care treatments or procedures, including life-sustaining measures and palliative care.

To make an AHD you must:

- be 18 years of age or older
- have full legal capacity. The treatment decisions contained in an AHD will come into effect only if or when you are unable to make reasonable judgments about a treatment decision at the time that the treatment decision is required. In these circumstances and subject to some limitations, the health professional must provide or withhold treatment in accordance with your wishes as specified in the AHD.

If you wish to make legally binding treatment decisions, then it is recommended that you make an AHD.

To make an AHD, you may obtain a form by:

1. Downloading and printing the form at www.healthywa.wa.gov.au/advancecareplanning
2. Email: acp@health.wa.gov.au

Alternatively, you can speak to someone from WA Cancer and Palliative Care Network (WACPCN) of the Department of Health on **(08) 9222 2300** to get a copy of the form or for further information.

Enduring Power of Guardianship

Another option you may wish to consider is the Enduring Power of Guardianship (EPG). An EPG refers to both a power of guardianship and the form which officially records that power, as recognised at law (under the Guardianship and Administration Act 1990). An EPG authorises a person of your choice to make important personal, lifestyle and treatment decisions on your behalf should you ever become incapable of making such decisions yourself. This person is known as an Enduring Guardian.

For example, you might wish to authorise an Enduring Guardian to make decisions about things such as where you live, the support services you have access to and the treatment you receive.

An Enduring Guardian cannot be authorised to make property or financial decisions on your behalf; these things can be dealt with under an Enduring Power of Attorney (see below).

To make an EPG you must:

- be 18 years of age or older
- have full legal capacity.

The person you appoint as your Enduring Guardian must also be 18 years of age or older and have full legal capacity.

You can appoint more than one Enduring Guardian as joint Enduring Guardians, but they must act jointly which means they must reach agreement on any decisions they make on your behalf.

The scope of authority given to your Enduring Guardian is determined by you when you make your EPG.

An Enduring Guardian cannot make decisions about matters you have already addressed in an AHD. You can obtain further information about appointing an Enduring Guardian by telephoning the Office of the Public Advocate on 1300 858 455 or by accessing the website: www.publicadvocate.wa.gov.au.

Advance Care Plan

An Advance Care Plan is a record of your advance care planning discussion and a way of informing those who are caring for you of your personal wishes.

An Advance Care Plan may include detail of personal wishes which are not covered in other formal documents mentioned above. Any special requests or messages may be recorded here as a useful guide for those persons involved in your care and managing various matters for you.

This includes personal wishes that are not necessarily health or treatment related which guide your treating health professionals, Enduring Guardian and or family as to how you would like to be treated and any special requests or message, such as:

- where you would like to be cared for
- who you would like to visit you
- your favourite music.

You can make your Advance Care Plan by filling out the form attached to this guide.

Living will

The term 'living will' is an expression sometimes used to describe a record in which a person communicates their views regarding their anticipated future healthcare decisions, such as whether the person consents or withholds consent in relation to specified treatment decisions which they anticipate will arise in the future. Living wills are intended to come into effect when their maker can no longer make and communicate decisions about their healthcare.

Living wills may include:

- AHDs which are formally recognised at law and binding upon persons responsible for care
- 'Common law directives' (CLD), that is written or verbal communications which convey a person's wishes regarding health treatment to be provided or withheld in specified future circumstances. There are no formal requirements in relation to common law directives. However, there can be considerable difficulties in establishing that a particular CLD is valid at law and can be followed. For this reason they are **not** recommended.

If there are specific treatment wishes that you wish to be followed once you've lost the ability to make decisions, it is recommended that you complete an AHD.

Other matters

In the course of making decisions in anticipation of diminished capacity and/or end of life, you may also wish to make arrangements concerning matters other than health care.

For example, you can nominate a person to manage your property and financial matters if you become unable to do it yourself. A formal document called an Enduring Power of Attorney (EPA) is required. The Office of the Public Advocate has more information on EPAs (See page 10 for their contact details).

If you have not already done so, it is important to make a will so that your possessions and property can be distributed after your death in accordance with your wishes. EPAs do not cover this. Wills should be reviewed and revised from time to time if relevant circumstances have changed (for example, deaths of executors or beneficiaries, divorces). The Public Trustee may be able to assist with the formalities and/or suggest some relevant resources.

Informing others

Informing others of your care decisions will give you an opportunity to discuss these decisions with those close to you.

If you have completed an Advance Care Planning document (for example, an Advance Health Directive, an Advance Care Plan or an Enduring Power of Guardianship), it is important that those who are close to you and those involved in your care are aware that you’ve completed these documents, and where they are located. A copy should be readily available to key people.

Remember, others won’t know your wishes unless you communicate them.

You may also consider:

- providing a copy to your specialist and/or General Practitioner (GP) as well as any hospital you regularly attend
- placing an alert card, such as the AHD alert card, in your purse or wallet which tells your health professional where to obtain a copy
- registering with Medic Alert www.medicalert.org.au Telephone 1800 882 222
- registering with eHealth www.ehealth.gov.au Telephone 1800 723 471
- informing those who are close to you where you have placed a copy of your documents so they know where to easily find them (for example, on the front of your fridge or wherever you usually put your unpaid bills)
- writing a list of all the people who have a current copy of your Advance Care Planning documents.

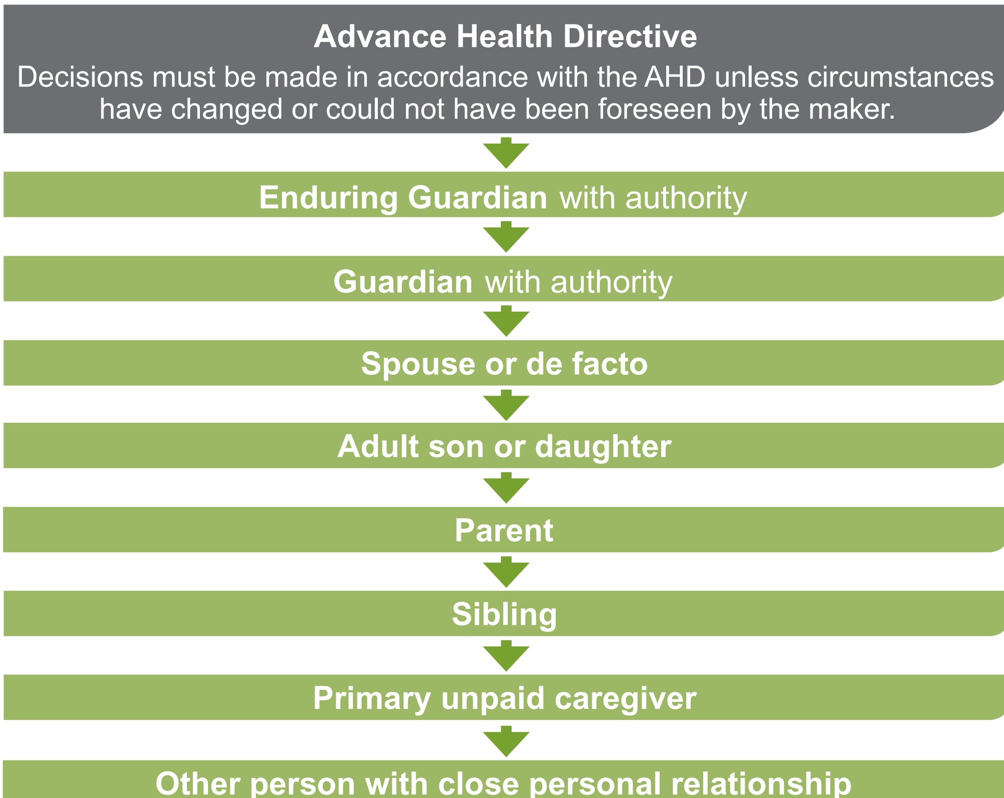
Process for making non-urgent treatment decisions

If you are 18 years of age or older and capable of making your own decisions, you can make your own treatment decisions (consent to or refuse a treatment). If you are unable to make decisions for yourself and non-urgent treatment is needed, treatment decisions will be made according to the 'hierarchy of decision makers' below.

If you do not have an appropriate or valid AHD, the health professional will seek a treatment decision from the first person on the list who is 18 years of age or older, has full legal capacity and is willing and available to make the decision. This person is also known as the 'person responsible'.

If urgent treatment is required to save your life or prevent unnecessary pain, health professionals can provide this treatment without seeking consent, however, they will need to seek consent for ongoing treatment.

Hierarchy of decision makers



Further information

For further information about any of the documents below, you may wish to contact the following:

Advance Health Directive

Department of Health – Office of the Chief Medical Officer

Telephone: (08) 9222 2300
Email: acp@health.wa.gov.au
Website: www.healthywa.wa.gov.au/advancecareplanning
Postal Address: PO Box 8172, Perth Business Centre, PERTH WA 6849

(The above internet address includes access to a self-directed eLearning resource)

Enduring Power of Guardianship

Office of the Public Advocate

Telephone: 1300 858 455; TTY: 1300 859 955
Email: opa@justice.wa.gov.au
Website: www.publicadvocate.wa.gov.au
Postal Address: PO Box 6293, EAST PERTH WA 6892

Enduring Power of Attorney

Office of the Public Advocate

Telephone: 1300 858 455; TTY: 1300 859 955
Email: opa@justice.wa.gov.au
Website: www.publicadvocate.wa.gov.au
Postal Address: PO Box 6293, EAST PERTH WA 6892

Will

Office of the Public Trustee

Telephone:
1300 746 116 (Wills, Deceased Estates and EPA)
1300 746 212 (Administration and Represented Persons)
Email: public.trustee@justice.wa.gov.au
Website: www.publictrustee.wa.gov.au

Glossary

In this guide, the following words have the following meanings:

Advance Care Planning

Advance Care Planning is an ongoing discussion between a patient and their carers, family and health professionals about the patient's values, beliefs, treatment and care options. It focuses in particular on the patient's wishes for their future treatment and care should they no longer be able to make or communicate their decisions at the time they are needed.

Full legal capacity

The capacity to make a formal agreement and to understand the implications of statements contained in that agreement.

Health professional

Any person who practises a discipline or profession in the health area that involves the application of a body of learning, including a person belonging to a profession specifically defined by legislation.

Life sustaining measure

Medical, surgical or nursing procedure that replaces a vital bodily function that is incapable of working independently. Includes assisted ventilation and cardiopulmonary resuscitation.

Living will

The term 'living will' is an expression sometimes used to describe a record in which a person communicates their views regarding their anticipated future healthcare decisions.

Palliative care

Palliative care means a medical, surgical or nursing procedure directed at relieving a person's pain, discomfort or distress but is not a life sustaining measure.

Terminal illness

An illness or condition that is likely to result in death. The terminal phase of a terminal illness means the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).

Treatment

Any medical, surgical or dental treatment or other health care, including a life sustaining measure or palliative care.

Treatment decision

A decision to consent or refuse consent to the commencement or continuation of any treatment of the person.

Notes

Notes

Notes

Notes

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Affix patient ID label here

My Advance Care Plan

Last name: ____

First name: ______________________________ Date of birth _____ /_____ /_____

Address: ____

My Advance Care Plan is a record of your advance care planning discussion and a way of informing those who are caring for you of your wishes. Your wishes may not necessarily be health related but will guide your treating health professionals, Enduring Guardian and or family as to how you wish to be treated including any special requests or messages.

Please note: Should you wish to make legally binding treatment decisions, it is recommended that you record these decisions in an Advance Health Directive. You may also wish to give consideration to appointing an Enduring Guardian to make personal, lifestyle and treatment decisions on your behalf. See the Guide for further detail.

I have given a copy of my Advance Care Plan to:

Full name	Telephone	Mobile	Relationship to me

MR00H.01 MY ADVANCE CARE PLAN

Affix patient ID label here

I have completed one or more of the following:

Advance Health Directive

Yes/No (please circle)

I have stored a copy at: ______________________________

A copy can also be obtained from:

Name: ______________________________

Telephone: ______________________________

Enduring Power of Guardianship

Yes/No (please circle)

I have stored a copy at: ______________________________

A copy can also be obtained from:

Name: ______________________________

Telephone: ______________________________

Enduring Power of Attorney

Yes/No (please circle)

I have stored a copy at: ______________________________

A copy can also be obtained from:

Name: ______________________________

Telephone: ______________________________

Will

Yes/No (please circle)

I have stored a copy at: ______________________________

A copy can also be obtained from:

Name: ______________________________

Telephone: ______________________________

Affix patient ID label here

Wishes for my future care

These are my wishes, in relation to my future care.
Please refer to the Advance Care Planning Guide for Patients.

Other outcomes of the Advance Care Planning conversation:

For example, you may have considered completing other relevant legal documents such as an Advance Health Directive or Enduring Power of Guardianship or you may have decided to become an organ donor.

Outcome	Description

Affix patient ID label here

If I have lost capacity or am approaching end of life, where practical and appropriate, I would prefer to be cared for:

Initial the option you prefer:

- [ ] In my usual home: ______________________________
- [ ] At a family member's home: ______________________________
- [ ] At a hospice or palliative care unit
- [ ] In hospital
- [ ] On country (for Aboriginal and Torres Strait Islanders)
- [ ] At another place: ______________________________

I would like to leave the following message(s)

For example: I am a carer for my partner/family member or I would like the following person to care for my pet, or I would like a particular song played or I would like a particular complementary therapy to be used or I would like my family to respect my wishes to be an organ donor etc.

____

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____

____

Signed: ______________________________ Date: _______ /_______ /_______

This document can be made available in alternative formats on request for a person with a disability.

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