Government of **Western Australia**
Department of **Health**

DRAFT

Your guide to advance care planning in Western Australia

A workbook to help you plan for your future care

Suggested citation

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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.

Interpreting service

Please ask for an interpreter if you need help to speak to a health service in your language.

Contents

This Workbook is an introduction to advance care planning. It includes activities to guide you through the advance care planning process.

My future care

What is advance care planning?

Many of us want to have a say in what type of care we receive in our lives, particularly at times when we are unwell and may be unable to communicate our wishes.

Advance care planning involves talking about your values, beliefs and preferences with your loved ones and those involved in your care.

Definition of advance care planning

A voluntary process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions.

Source: National Framework for Advance Care Planning

Advance care planning:

- is a voluntary process
- is focused on what is most important to you
- is respectful of your beliefs, values and culture
- is best started when you are feeling well and able to make decisions
- can involve as many, or as few, people as you choose
- works best when you are open about what is important to you – even though for some people this can be challenging
- is a flexible ongoing process that allows you to make and change decisions as your situation, health or lifestyle changes.

Why is advance care planning important?

Advance care planning can help you:

- think through and plan what you want for your future and share this plan with others
- describe your beliefs, values and preferences so that your future health and personal care can be given with this in mind
- take comfort in knowing that someone else knows your wishes just in case a time comes when you are no longer able to tell people what is important to you.

Advance care planning can also be helpful for families and health professionals:

- **Families of people who take part in advance care planning say they feel less anxious, depressed and stressed and are more pleased with care received.**
- **For healthcare professionals and organisations, it lessens unneeded hospital stays and unwanted treatments.**

How can advance care planning help me?

Starting advance care planning is a personal decision. It can be useful to start by thinking about how advance care planning could help you. Here are some examples based on what other people have found useful.

Figure 1. Examples of how advance care planning has helped people

Do any of these situations apply to you?

I'm healthy, in my 20s and have a young family.

Sharing what is important to me may help my health professionals or family make decisions about my care if something unexpected happens in future.

I'm 61, have no children and my partner is a lot older than me.

I have my finances in order but who will look after me if I become unwell? It would be helpful to talk to others about where I want to live and what will be important to me if my health deteriorates.

I have just been diagnosed with a life-limiting condition.

Talking with my loved ones and health professionals about what might happen as my condition progresses may help me and them understand the care I do or do not want in future.

I will soon be moving to a residential care facility.

I want to make decisions about where I want to live, and who I want around me when I move. I might start with talking to my GP about my future care and treatment needs and see what support is available to me.

Activity 1. What is your current situation in life?

Use the space below to write down your thoughts on your current situation in life (for example your age, health and family situation):

What is involved in advance care planning?

Advance care planning involves four main elements:

- think
- talk
- write
- share.

These elements are described in the picture below.

The Workbook includes various activities to help you work through these elements.

Figure 2: Advance care planning model

1. Think

What matters most to me now? What will matter most to me if I become less well in future?

Your advance care planning process will be guided by you. A good place to start is to think about your values, beliefs and preferences. This may help you to work out what matters most to you in relation to your health and personal care.

Helpful resources:

- Visit the **My Values** website
- Call Palliative Care WA 1300 551 704 (Monday to Thursday)
  - General queries and support on advance care planning
  - Find out about free advance care planning community workshops
  - Receive a set of What Matters Most cards
- Call Palliative Care Helpline 1800 573 299
  (9am to 5pm every day of the year)
  - Information, resources and support on any issues to do with advance care planning, palliative care and grief and loss

Activity 2: Values, beliefs and preferences

The following questions may help you think about your values, beliefs and preferences. There are no wrong answers to these questions.

What does 'living well' mean to you?

- ☐ Spending time with family and friends
- ☐ Living independently
- ☐ Being able to visit my home town, country of origin, or spending time on country
- ☐ Being able to care for myself (e.g. showering, going to the toilet, feeding myself)
- ☐ Keeping active (e.g. playing sport, walking, swimming, gardening)
- ☐ Enjoying recreational activities, hobbies and interests (e.g. music, travel, volunteering)

- [ ] Practising religious, cultural and/or spiritual activities (e.g. prayer, attending religious services)
- [ ] Living according to my cultural and religious values (e.g. eating halal foods)
- [ ] Working in a paid or unpaid job
- [ ] Other (use the space below to write down other things that are important)

Your life

What are the most important things to you in life?
(e.g. family, financial security, health, travel)

Do you have any worries about your future?

Your current health

Does your health affect your day-to-day life or stop you doing things you like to do? If so, how?

Your future health

If you become unwell / more unwell in future, what worries you most about what might happen? (e.g. being in pain, not being able to make decisions, not being able to care for yourself)

Managing your future health

If you become unwell / more unwell in future, what will be important to you? Think about:

- Who you would like around you
- Which people know enough about you to make decisions for / with you
- Where you would like to receive your care
- What would give you comfort (e.g. having pain managed, practicing cultural and religious traditions, music, objects of significance such as favourite photos)

Remember that you can review and change any of your choices and documents to suit changes in your personal situation, health or lifestyle.

2. Talk

Talking about advance care planning is a way of letting your loved ones and those involved in your care know what you do and do not want to happen with your future health and care. A close or loving relationship does not always mean someone knows what is important to you. Having a conversation can be very important.

Who can I talk to about advance care planning?

You might want to discuss what is important for you with people you trust. This may include:

- family
- friends
- carer(s)
- enduring guardian (if appointed)
- GP or another member of your healthcare team.

What are some things to talk about?

You may want to share your values, beliefs or preferences for when you are unwell as a way of letting people know what it is important to you. Here are some conversation starters that can help you when talking to others.

About me	Being able to ..... is the most important thing to me.	For me, a life worth living is where I	..... is important for me to live well.
About life	What does a good day look like to you?	What's in your bucket list?	What do you value most in life?
About choices	I was thinking about what happened to ..... and it made me realise that	If ..... happened to me, I would want	I would want ..... to make medical decisions on my behalf if I was unable to.

Source: **Advance Care Planning Australia**

Talking with people close to you about what might happen if you become unwell in future may not be easy. You may feel uncomfortable sharing your wishes. Your family and friends may also feel nervous or upset talking about a time in future when you may be unwell.

Take your time - remember that advance care planning is an ongoing conversation and you do not need to talk about everything at once.

Some people also find that family and friends have their own opinions about what you should include in an advance care plan. While it may be helpful to hear what other people think, remember that you should decide what is best for you.

Refer to the **Where to get help** section for a list of services who you can talk to about advance care planning.

Other useful resources

- Advice on **starting the conversation** from Advance Care Planning Australia
- **Dementia Australia Start2talk**

Activity 3: Talking

Start by thinking about who you want to talk to about your future health care. People you want to talk to:

When might be a good time to have a conversation? You might want to think about the right time (e.g. this year, before your next specialist appointment, before your next birthday). It may also be helpful to think about where you would like to have the conversation (e.g. by phone, over dinner, while out walking).

Conversation starters you might use:

Opportunity	Example
Financial planning around retirement	"As we get closer to retirement, maybe we should start thinking about how we are going to spend our money and where we want to live. It might be a good idea for us to make a plan in case one or both of us becomes unable to make important decisions in future."
Medical check-ups	"I'm seeing my GP next week for my yearly check-up. There are a few things I want to discuss with the doctor. I know that in future I may need to make some decisions about my healthcare. It would be good to talk to you about this as well as the GP."

Opportunity	Example
Death of a friend or relative	"After seeing (our family member / friend)'s experience as he reached the end of his life, it has made me think about the sort of care I'd like in future. Can we spend some time talking about this? Perhaps we could write down some thoughts about what's important to us and then chat about it." "I felt really comforted that (our family member / friend)'s wishes about how she wanted to die were listened to by the family and her doctors. It's made me think about what's important to me and I'd like to know what's important for you. Can we have a chat about this? Maybe we could write a few things down so we know what will be important for us when we reach that point in future".
Movies or news items in the media	"It was so sad to see what that person went through at the end of her life because nobody knew what she would have wanted. I'd hate that to happen to us so can we have a conversation about what would be important to us?"

What are the top three things you would like to cover during this conversation?

1. _____

2. _____

3. _____

Remember that you can review and change any of your choices and documents to suit changes in your personal situation, health or lifestyle.

3. Write

Once you have thought about what is important to you and talked with others, it is a good idea to write down what you decide.

There are several different documents used for advance care planning in WA. Some are legal documents (i.e. Advance Health Directive and Enduring Power of Guardianship). Others are more informal (i.e. My Values and Preferences Form: Planning for my future care).

Some documents are written by you and others are completed by others on your behalf.

You do not have to use any of these documents, but they can be helpful in different situations. Thinking about what is important to you will help you decide which one(s) could be useful for you.

Advance care planning and other related documents

To help you understand when you might use different documents for advance care planning, you can think of them in the following way:

Documents related to your health and care

- Values and Preferences Form: Planning for my future care
- Advance Health Directive
- Enduring Power of Guardianship
- Organ and tissue donation

Documents related to estate and financial matters

- Making a Will
- Enduring Power of Attorney

Documents that may be completed by others on your behalf

- Goals of Patient Care
- Advance Care Plan for someone with insufficient decision-making capacity

Each of these documents is described on the following pages.

Documents related to your health and care

Values and Preferences Form: Planning for my future care

Thumbnail of doc that link to online version (when available)

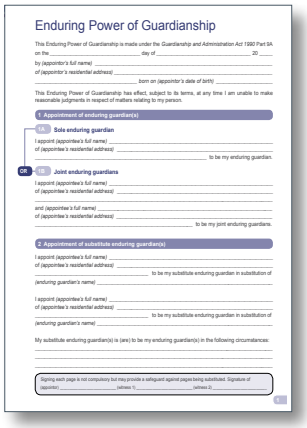
Type of document: Informal

What it is: A record of your advance care planning discussions.

Why it is useful: To let people know your values, preferences and wishes. Your wishes may not necessarily be health related but will guide treating health professionals, enduring guardian(s) and/ or family as to how you wish to be treated including any special preferences, requests or messages.

What is included: Questions are the same as the 'Values' section of the Advance Health Directive (see below). If you are not yet ready to complete a full Advance Health Directive with formal witnessing and signing requirements, you may like to start with completing this Form.

Enduring Power of Guardianship (also called an EPG)


Enduring Power of Guardianship

This Enduring Power of Guardianship is made under the Guardianship and Administration Act 1990 Part 9A

on the _____ day of _____ 20 ____

by (appointor's full name) _____

of (appointor's residential address) _____

_____ born on (appointor's date of birth) _____

This Enduring Power of Guardianship has effect, subject to its terms, at any time I am unable to make reasonable judgments in respect of matters relating to my person.

1. Appointment of enduring guardian(s)

1A Sole enduring guardian

I appoint (appointee's full name) _____

of (appointee's residential address) _____

_____ to be my enduring guardian.

OR 1B Joint enduring guardians

I appoint (appointee's full name) _____

of (appointee's residential address) _____

_____

and (appointee's full name) _____

of (appointee's residential address) _____

_____ to be my joint enduring guardians.

2. Appointment of substitute enduring guardian(s)

I appoint (appointee's full name) _____

of (appointee's residential address) _____

_____ to be my substitute enduring guardian in substitution of

(enduring guardian's name) _____

I appoint (appointee's full name) _____

of (appointee's residential address) _____ to be my substitute enduring guardian in substitution of

(enduring guardian's name) _____

My substitute enduring guardian(s) is (are) to be my enduring guardian(s) in the following circumstances:

_____

_____

_____

Signing each page is not compulsory but may provide a safeguard against pages being substituted. Signature of (appointor) _____ (witness 1) _____ (witness 2) _____

Type of document: Legal

What it is: A legal document that authorises a person to make important personal, lifestyle and treatment decisions on your behalf. You can choose the person who undertakes this role. This person is known as an enduring guardian or Health and lifestyle decision maker.

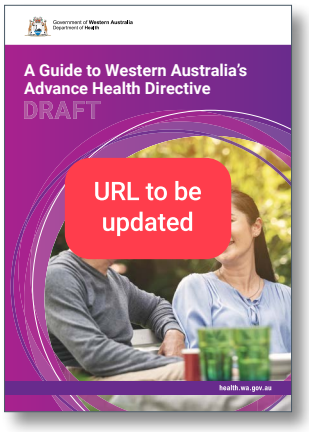
When it is used: An Enduring Power of Guardianship is only used if you become unable to make decisions or tell people what you want.

What is included: An enduring guardian could be authorised to make decisions about things such as:

- where you live
- the support services you have access to
- the treatment(s) you receive.

An enduring guardian cannot make property or financial decisions on your behalf.

Advance Health Directive (also called an AHD)



Type of document: Legal

What it is: A record of your decisions about the treatment you want or do not want to receive if you become unwell or injured and are unable to make or communicate decisions. If this happens, your Advance Health Directive becomes your 'voice'.

When it is used: An Advance Health Directive is only used if you become unable to make or communicate decisions or tell people what you want. It can only be used if the information in it is relevant to the treatment / care you require.

What is included: You decide what decisions and what treatments you want to include. The term 'treatment' includes medical, surgical and dental treatments. It also includes palliative care and measures such as life-support and resuscitation.

Tip: You can have both an Advance Health Directive and an Enduring Power of Guardianship.

Organ and tissue donation

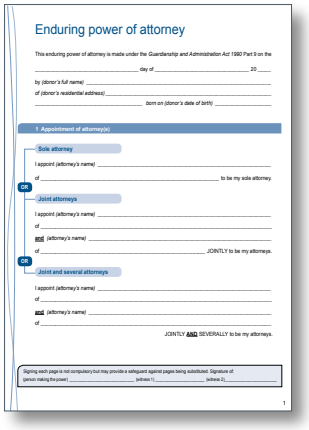
People can register to donate organs and tissue when they die. It is important they talk to family, as relatives will be asked to agree. Organ and tissue donation can only formally be registered at **Donate Life**.

Documents related to estate and financial matters

Making a Will

A Will is a written, legal document that says what a person wants to do with their money and belongings when they die. Visit the **Public Trustee** for more information.

Enduring Power of Attorney (also referred to as EPA or Financial decision maker)



Type of document: Legal

What it is: An agreement that enables a person to appoint a trusted person or people to make financial and property decisions on their behalf.

When it is used: Can only be used by a person older than 18 years. An Enduring Power of Attorney can only be made when a person is still able to make and communicate their own decisions.

Documents that may be completed by others on your behalf:

Goals of Patient Care (GoPC)

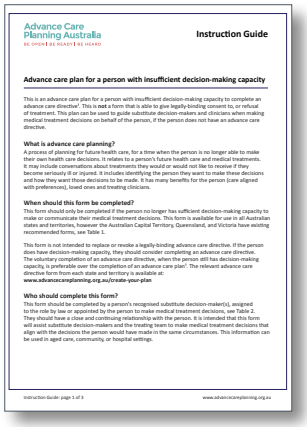
Type of document: Clinical

What it is: A document written by a health professional to record information about the decisions you and your healthcare team have made about the treatment and care that is most appropriate for you based on your health and what is important for you.

When it is used: A Goals of Patient Care document is written by a health professional after a 'goals of care' discussion between you, your doctor / other members of your healthcare team and your family or carer(s).

What is in it: You and the members of your healthcare team decide what goes into your Goals of Patient Care document. The document records which treatments will be used if you become very unwell and are unable to make or communicate decisions

Advance Care Plan for someone with insufficient decision-making capacity


Advance Care Planning Australia

Instruction Guide

Advance care plan for a person with insufficient decision-making capacity

This is an advance care plan for a person with insufficient decision-making capacity to complete an advance care directive[1]. This is **not** a form that is able to give legally-binding consent to, or refusal of treatment. This plan can be used to guide substitute decision-makers and clinicians when making medical treatment decisions on behalf of the person, if the person does not have an advance care directive.

What is advance care planning?

A process of planning for future health care, for a time when the person is no longer able to make their own health care decisions. It relates to a person's future health care and medical treatments. It may include conversations about treatments they would or would not like to receive if they become seriously ill or injured. It includes identifying the person they want to make these decisions and how they want those decisions to be made. It has many benefits for the person (care aligned with preferences), loved ones and treating clinicians.

When should this form be completed?

This form should only be completed if the person no longer has sufficient decision-making capacity to make or communicate their medical treatment decisions. This form is available for use in all Australian states and territories, however the Australian Capital Territory, Queensland, and Victoria have existing recommended forms, see Table 1.

This form is not intended to replace or revoke a legally-binding advance care directive. If the person does have decision-making capacity, they should consider completing an advance care directive. The voluntary completion of an advance care directive, when the person still has decision-making capacity, is preferable over the completion of an advance care plan[2]. The relevant advance care directive form from each state and territory is available at: **www.advancecareplanning.org.au/create-your-plan**

Who should complete this form?

This form should be completed by a person's recognised substitute decision-maker(s), assigned to the role by law or appointed by the person to make medical treatment decisions, see Table 2. They should have a close and continuing relationship with the person. It is intended that this form will assist substitute decision-makers and the treating team to make medical treatment decisions that align with the decisions the person would have made in the same circumstances. This information can be used in aged care, community, or hospital settings.

Instruction Guide: page 1 of 8

www.advancecareplanning.org.au

Type of document: Informal

What it is: An advance care plan used to guide health professionals, enduring guardians and close family and friends when making medical treatment decisions on behalf of a person who does not have an Advance Health Directive.

When it is used: This document can only be used when a person is no longer able to make their own decisions. It can be completed by a recognised substitute decision-maker(s) who has a close and continuing relationship with the person receiving care.

What is in it: This form allows you to provide information about the values and preferences relating to future medical treatment for a person who has lost the capacity to make their own decisions. The information provided in this form should be guided by the person's past choices and decisions, and any known values and preferences. This form cannot be used to give legal consent to, or refusal of treatment.

Who will make decisions for you if you cannot make your own?

Health professionals must follow a certain order when seeking a decision about treatment for a person who is unable to make decisions or tell people what they want.

This is called the **Hierarchy of treatment decision makers**.

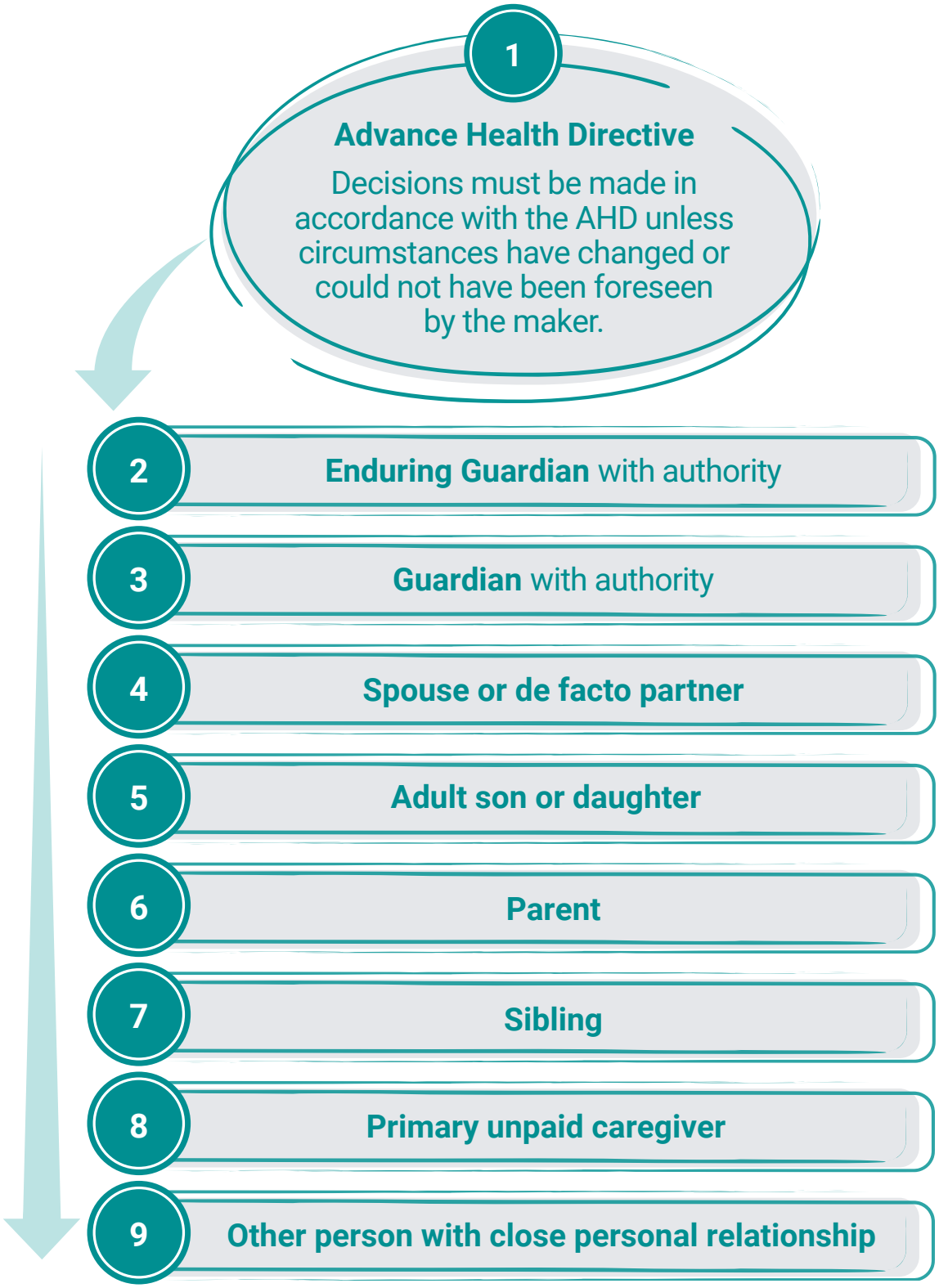
It is important you understand who may be making decisions for you and this may help you decide which advance care planning documents you need.

For example:

- If you **have** an Advance Health Directive, then that will be used to guide treatment decisions for you.
- If you **do not have** an Advance Health Directive, then your enduring guardian would be asked to make treatment decisions on your behalf.
- If you **do not have** an Advance Health Directive or and enduring guardian, then your spouse or de facto partner would be asked to make treatment decisions on your behalf.

Hierarchy of treatment decision makers

Where an AHD does not exist or does not cover the treatment decision required, the health professional must obtain a decision for non-urgent treatment from the first person in the hierarchy who is 18 years of age or older, has full legal capacity and is willing and available to make a decision.

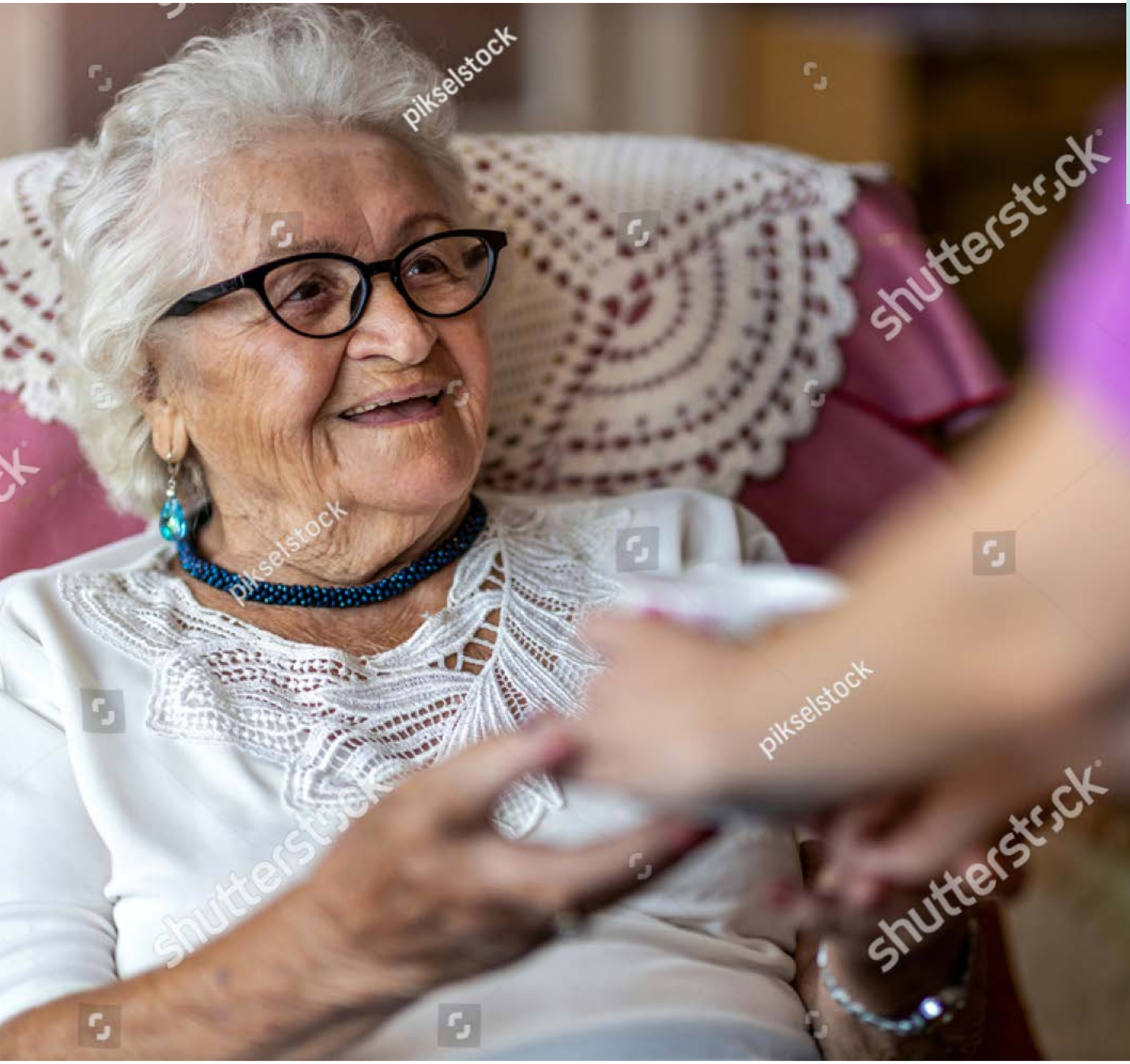


Tip

- Your answers to the activities in this Workbook may help you to fill in the required information in some advance care planning documents.
- The '**Where to get help**' section lists services to support you to complete advance care planning documents.

More Information

- The Office of the Public Advocate has more information **on who can make decisions for you if you cannot make your own.**



Activity 4: Is there an advance care planning document(s) that is right for me?

Your decision about which advance care planning documents, if any, are right for you starts with a question about whether you want to make a record of things that are important to you to guide your future treatment and care.

Can you relate to any of the following statements?

I have strong views on the treatment(s) I would / would not want to receive in future.

I could:

- make an Advance Health Directive to record my treatment decisions, and / or
- appoint an Enduring Guardian and share my preferences.

I have strong values and beliefs on the care I would / would not want to receive in future, but I am not ready to make decisions about specific treatments I do or don't want.

I could:

- complete a Values and Preferences Form, and / or
- appoint an Enduring Guardian who knows me well and I believe would make decisions on my behalf in the same way I would make.

I want to make sure my finances and assets are in order.

I could:

- make a Will, and / or
- appoint an Enduring Power of Attorney.

If you are still unsure whether any of these documents are right for you, you can:

- talk to friends or loved ones, or to health professionals involved in your care
- call Palliative Care WA **1300 551 704** (Monday to Thursday)
  - General queries and support on advance care planning
  - Find out about free advance care planning community workshops
  - Receive a set of What Matters Most cards
- call Palliative Care Helpline **1800 573 299**
  (9am to 5pm every day of the year)
  - Information, resources and support on any issues to do with advance care planning, palliative care and grief and loss
- seek specific advice from a relevant organisation (see **Where to get help**).

Remember that you can review and change any of your choices and documents to suit changes in your personal situation, health or lifestyle.

4. Share

Once you have written down your preferences and wishes, it is important that people close to you know where to find the information.

Where should I store my advance care planning documents?

If you have written an advance care planning document(s), you should keep the original in a safe place.

You can also store a copy online using **My Health record** (register and **upload your advance care planning document**).

Who should I share my advance care planning document(s) with?

You may choose to give a copy of your advance care planning document(s) with your:

- family, friends and carers
- enduring guardian (EPG)
- GP / local doctor
- specialist(s) or other health professionals
- residential aged care home
- local hospital.

Make a list of the people who have a copy of your current advance care planning document(s). This will be a good reminder of who to contact if you decide to change or revoke your document(s) in future. Use the checklist on the next page.

If you decide to make an Advance Health Directive you can carry:

- an **Advance Health Directive (AHD) alert card** in your purse or wallet - you can order an AHD alert card by contacting the Department of Health Advance Care Planning Line on (08) 9222 2300 or email **acp@health.wa.gov.au**.
- a **MedicAlert** bracelet.

Remember that you can review and change any of your choices and documents to suit changes in your personal situation, health or lifestyle.

Activity 5: Who has a copy of my advance care planning document(s)?

		They have a copy of my:				
Details		Values and Preferences Form	Advance Health Directive	Enduring Power of Guardianship	Enduring Power of Attorney	Will
Who else has a copy?						
My Family, friends and carers	Person 1	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
	Person 2	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
My enduring guardian(s)	Person 1	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
	Person 2	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
My Health professionals	GP	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
	Specialist/ health professional 1	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
	Specialist/ health professional 2	Name:				
		Contact details:				
		☐	☐	☐	☐	☐
	Residential aged care facility	Facilty name:				
		Contact details:				
		☐	☐	☐	☐	☐
	Local Hospital	Hospital name:				
		Contact details:				
		☐	☐	☐	☐	☐
Online versions						
My Health Record		☐	☐	☐	☐	☐
Other						
		☐	☐	☐	☐	☐
		☐	☐	☐	☐	☐

Checklist of where the original copy of my advance care planning document(s) is kept?

Document	Location of the original copy
My Values and Preferences Form	
Advance Health Directive	
Enduring Power of Guardianship (EPG)	
Enduring Power of Attorney (EPA)	
Will	

Where to get help

Advance care planning

WA Department of Health
(Advance Care Planning Information Line)

- General queries and to order advance care planning resources and documents (e.g. Advance Health Directives, Values and Preferences Form)
- Phone: **9222 2300**
- Email: **ACP@health.wa.gov.au**

Palliative Care WA

- General queries and support on advance care planning
- Find out about free advance care planning community workshops
- Receive a set of What Matters Most cards
- **1300 551 704** (Monday to Thursday)

Palliative Care Helpline

- Information, resources and support on any issues to do with advance care planning, palliative care and grief and loss
- **1800 573 299** (9am to 5pm every day of the year)

Advance Care Planning Australia (ACPA) Free Support Service

- General queries and support with completing advance care planning documents
- Phone: **1300 208 582**
- Online referral form: **www.advancecareplanning.org.au/about-us**

Medical advice

See your doctor.

Enduring Powers of Guardianship and Enduring Powers of Attorney

Office of the Public Advocate

- Enduring Powers of Guardianship and Enduring Powers of Attorney – for people with capacity
- Guardianship and Administration queries – for people who may lack capacity
- Phone: **1300 858 455** (local call rates from land line only).
- Email: **opa@justice.wa.gov.au**

Professional trustee and asset management services

Public Trustee

- Phone: **1300 746 116** (New enquiries and appointments)
- Phone: **1300 746 212** (Represented Persons)

General legal advice

The Law Society of Western Australia

- Phone: **(08) 9324 8652**
- Find a Lawyer referral enquiry section

Community Legal Centres

- Phone: **(08) 9221 9322**
- Website for locations and contact details: **www.communitylegalwa.org.au**

Legal Aid Western Australia

- Phone: **1300 650 579**
- Open Mon to Fri 9am to 4pm (Australian Western Standard Time).

Citizens Advice Bureau

- Phone: **(08) 9221 5711**
- Website: **www.cabwa.com.au**

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Government of **Western Australia**
Department of **Health**

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