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

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Health professional guide for advance care planning

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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.

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How and when to use this Guide

The **Health professional guide for advance care planning** (the Guide) focuses on the role of health professionals in the advance care planning conversation(s) and process.

The Guide will help health professionals to familiarise themselves with advance care planning. The Guide can be revisited for further information prior to commencing, or during, the advance care planning process with people and their families.

There are existing resources that provide useful information on advance care planning. The aim of this Guide is to complement this by providing an overview of the health professional role in advance care planning and linking to existing resources for more details and guidance.

Below is a brief description of each section in the Guide.

What is advance care planning

This section provides a definition of advance care planning and introduces the model that describes the elements of the advance care planning process.

1. Think

How health professionals can encourage people to consider advance care planning.

2. Talk

How to support people to have advance care planning conversations.

3. Write

Descriptions of the range of advance care planning documents and ways to make values and preferences known.

4. Share

How to encourage people to share their advance care planning documents and health professional responsibilities to record advance care planning discussions.

Responsibilities and liabilities in advance care planning

Practical advice on how advance care planning decisions impact on the provision of medical treatment.

Reflections: Case studies to reflect on the learnings from the Guide

A series of questions for health professionals to reflect on their understanding of the information contained within the Guide.

Where to get help

A list of organisations that can be contacted for support on advance care planning, medical and legal advice.

Glossary

A list of advance care planning terms.

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What is advance care planning

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

Why should I support people through advance care planning?

Obligations and legislative requirements

The National Quality Standards for aged care, general practice and health services as well as the National Code of Conduct for health care workers all provide obligations for health professionals and care workers regarding advance care planning. From a legislative perspective, health professionals also have a number of responsibilities in terms of providing care in accordance with *Advance Health Directives and Enduring Power of Guardianship as outlined by the Guardianship and Administration Act 1990*.

Benefits of advance care planning

In addition to these obligations, there are a number of benefits of advance care planning for the person, their family, carers, health professionals and organisations that provide further justification as to why it should be a routine part of care. Benefits include:

- It helps to ensure people receive care that is consistent with their beliefs, values, needs and preferences.
- It improves end-of-life care, and person and family satisfaction with care provided.
- Families of people who have taken part in advance care planning experience less anxiety, depression and stress and are more satisfied with care received.
- For healthcare professionals and organisations, it reduces non-beneficial transfers to acute care and unwanted interventions.

WA Health has developed a set of principles to promote a consistent and common understanding of the key elements of the advance care planning process.

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Principles of advance care planning

Advance care planning:

- is voluntary, person-centred, and focused on empowering the person to have choice and control over their future medical treatment decisions
- is an ongoing process which the person can engage in at any point in time, and requires regular review allowing the person to make and change decisions as their preferences change
- can be undertaken at any age and ideally commences before a person is unwell
- is inclusive and can involve as many, or as few, people from the person's network that they choose to have involved i.e. such as family, carers, friends or health professionals
- should be undertaken in a way that is respectful of the whole person, holistic in approach and considers a range of health care needs, not just medical treatments
- should be a culturally safe process in which the person's personal and cultural attitudes towards health and lifestyle choices and interventions are acknowledged and respected
- focuses on the person's values, priorities and preferences and encompasses more than the completion of advance care planning documents
- may involve many, and sometimes challenging, reflections and discussions which may need to be facilitated to ensure the person understands all their options when it comes to planning for their future care
- needs to follow an ethical process and support the person's right to meaningfully participate in decision making to the greatest extent possible.

What is my role in advance care planning?

As a health professional you have an important role in initiating conversations and supporting people through the process of advance care planning. You need to have the capability to facilitate these conversations effectively.

Figure 1 outlines the four elements of the advance care planning process and is a useful tool you can use to educate individuals about advance care planning. Figure 2 outlines your role, as a health professional, in each element of the process.

More information

- **Advance Care Planning Australia Video: Understanding ACP**
- **My Values**

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Figure 1: Advance care planning model

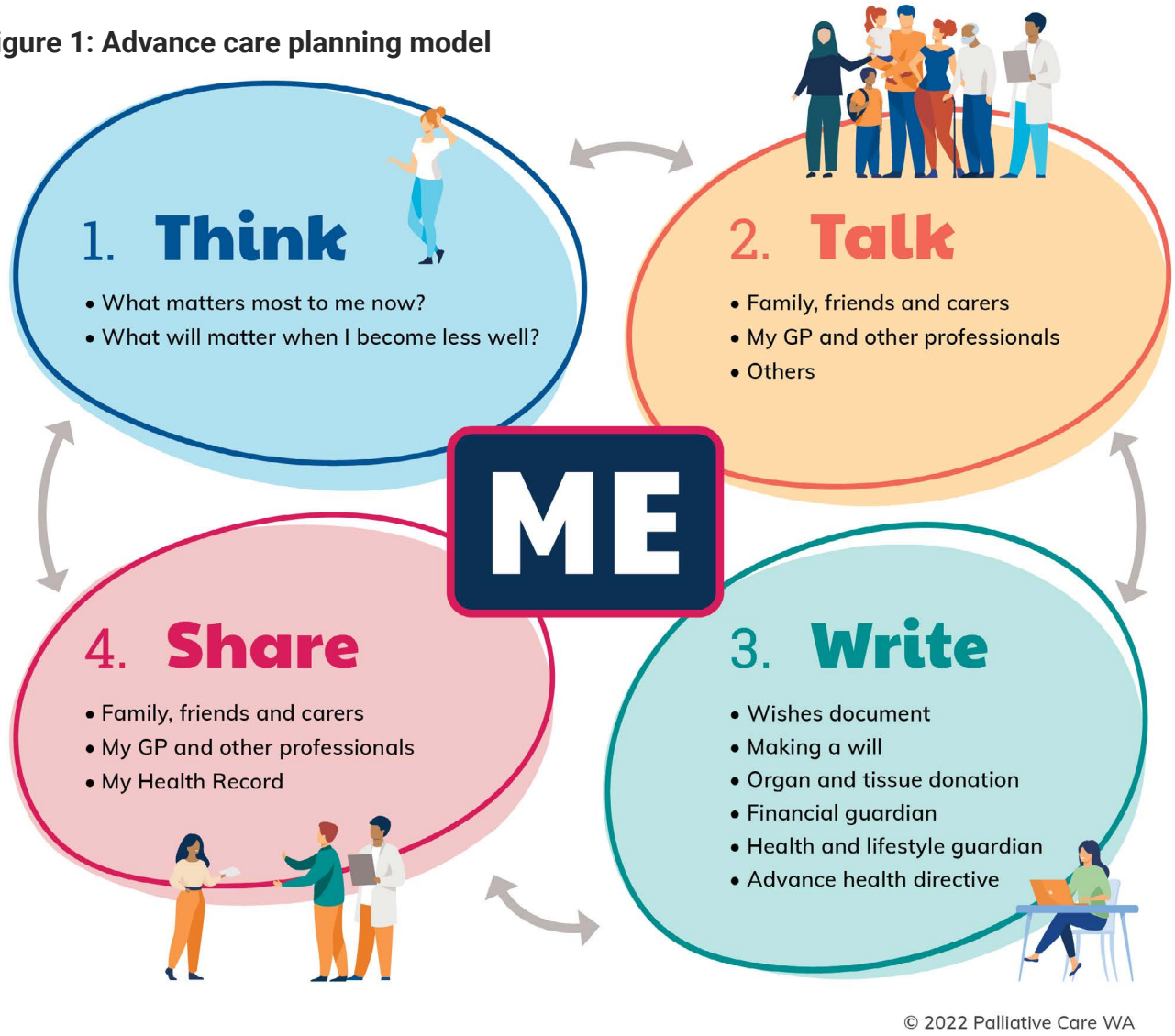

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Figure 2. The role of health professionals in advance care planning

1. Think

Encourage the person to consider ACP by:

- Learning about ACP
- Understanding triggers for ACP
- Raising the topic of ACP.

2. Talk

Support the person to talk about ACP by:

- Actively listening and responding positively
- Considering conversation starters
- Planning time to continue the conversation.

4. Share

Ensure appropriate sharing and storing ACP documents by:

- Advising the person on sharing with all those involved in their care.
- Following organisational policies on recording ACP discussions and documents.
- Ensure all documents are uploaded onto My Health Record.

3. Write

Support the person to make their wishes known in writing by:

- Understanding ACP documents
- Supporting the completion of ACP documents, including Advance Health Directives.

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1. Think

How should I respond when someone approaches me with an interest in advance care planning?

- Be open to engage in advance care planning conversations and look for opportunities to discuss
- Acknowledge and validate the importance of the conversation
- Encourage the person to also talk with their family and friends
- Provide or direct them to reliable, easy to read information (e.g. **Your guide to advance care planning in WA: A workbook to help you plan for your future care** (in draft))

URL to be updated

- Acknowledge and respect the person's own beliefs and values (be aware of and keep free from own bias)
- Consider learning about advance care planning through relevant **training and resources**
- Recognise advance care planning is an ongoing, evolving process and plan time to continue the conversations in the future.

Advance care planning is **voluntary** and people should not feel pressured to participate in discussions or write advance care planning documents.

How can I encourage the person to participate in advance care planning?

Advance care planning conversations should be routine and occur as part of a person's ongoing health care plan.

Advance care planning is more effective when introduced early as part of ongoing care rather than as a result of health decline or crisis.

Consider the person's condition and what might be appropriate opportunities or important situations to start or revisit advance care planning.

Triggers for advance care planning conversations can include:

- when a person or family member asks about current or future treatment goals
- at scheduled health assessments (i.e. a 75+years health assessment, GP Management Plans and Team Care Arrangements, chronic disease management consultations)
- when an older person receives their annual flu vaccination
- when there is a diagnosis of a chronic or life limiting illness
- when there is a diagnosis of a metastatic malignancy or end organ failure indicating a poor prognosis
- when there is a diagnosis of early dementia, a neurodegenerative disease or a disease which could result in loss of capacity
- when someone is applying for assistance with care (i.e. Aged Care Assessment Teams (ACAT) assessment or applying for the National Disability Insurance Scheme (NDIS))
- if you would not be surprised if the person died within twelve months
- if there are changes in care arrangements (e.g. admission to a residential aged care facility).

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Examples of comments which may suggest interest in ACP

"How will I know when the time comes to stop this treatment/medication?

"Just keep me comfortable."

"What is going to happen to me in the future?"

"Is there any hope of recovery?"

"If I'm always going to feel like this, I don't want to go on."

"Do you think palliative care might help my mother/father?"

A useful tool may be the **Supportive & Palliative Care Indicators Tool (SPICT™)** which can help identify people with deteriorating health due to advanced conditions or a serious illness, and can prompt the need for holistic assessment and future care planning. There is also the SPICT-4ALL which aims to make it easier for everyone to recognise and talk about signs that a person's overall health may be declining so that those people and their carers get better coordinated care and support whether they are at home, living in a care home or in hospital.

General practices are uniquely placed to support patients with advance care planning because of the enduring and trusted relationships that exist between general practitioners and their patient. There are no Medicare Benefits Schedule (MBS) items specifically for advance care planning, however there are **MBS items that may support advance care planning in general practice**.

If the person is not interested in advance care planning discussions, ensure they are aware that they can revisit the topic at any time in the future. Offer to provide written information for the person to take away if they are receptive.

What skills do I need to encourage the person to participate in advance care planning?

Any health professional with good communication skills can raise or positively respond to queries of advance care planning and encourage the person to begin the process. Regardless of the health professional's role, effective communication skills are necessary including:

- non-biased and non-judgemental approach
- active listening
- attending and reflecting
- use of clarifying questions
- summarising.

This approach is likely to encourage individuals to take time to reflect and make considered and informed decisions which are reflective of their views, values and preferences. For further information on communication skills in advance care planning and end-of-life discussions, refer to the **Communication Skills Education Videos for Health Professionals** produced by Cancer Council WA, Palliative and Supportive Care Education (PaSCE).

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People should feel empowered to continue the advance care planning process and be provided with further information to reflect on and explore such as:

- Your guide to advance care planning in WA: A workbook to help you plan for your future care (in draft)
- **My Values**
- Palliative Care WA (1300 551 704):
  - For general advice
  - **To attend a community workshop**
  - Receive a set of PCWA What Matters Most Cards.

More information

- **Advance Care Planning Australia Video: Starting a conversation with patients**
- **Advance Care Planning Australia Video: ACP as a part of routine care**
- **Communication Skills Education Videos for Health Professionals produced by PaSCE**

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2. Talk

How can I support the person to begin talking about advance care planning?

If a person wants to have an advance care planning conversation, it is important health professionals are supportive when the topic is raised. It is also important to normalise these conversations so they become a consistent part of care.

In some instances, you may need to initiate the conversation. Examples of conversation starters may include, but are not limited to:

For healthy person	If you became unwell and were unable to make or communicate your own decisions, who would you want to make decisions on your behalf? Do you know what you would want them to say?
	I try to talk to all my patients about what they would want if they become more unwell. Have you ever thought about this?
	I am pleased to see you recovering from your recent illness. If you became very sick again, have you thought about the treatment that you would want or not want?
For someone with life-limiting illness	This is a long-term condition and there are going to be periods when you are well and periods when you will not be so well. Would you like to discuss how we should approach your care during the times when you are not well? What's important to you? Who would you like me to involve?
Someone with expected deterioration or impending death	We've discussed what I think is likely to happen in the future. I'd like to know more about how you think we should approach your care from here. What's important to you? Who would you like me to involve? Have you been thinking much about what happens?

Advance Care Planning Australia have further **conversation starters** as well as a list of **COVID-19 related conversations starters**.

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Before you begin the discussion, consider…

Things to consider when having advance care planning conversations include:

- Is the environment private and comfortable with no or minimal interruptions?
- Who should be present?
- Does the person and/or carer/family have the decision-making capacity to participate in the discussion?
- Is all relevant clinical information available (review files/notes)?
- Are there any cultural or religious needs to consider?

During the discussion…

Explain what advance care planning is and outline some of the reasons the person, their families and carers may want to have the discussions. Some things the person may want to take some time to consider are:

- their current health
- any current health problems
- concerns or worries about their future health care
- any family history of diseases
- their fears e.g. pain, losing ability to think, losing ability to communicate, being dependent on their loved ones, being removed from life support too soon
- any other concerns or worries.

Check if the person already has an advance care planning document (i.e. Advance Health Directive and/or Enduring Power of Guardianship) and if so, consider if it needs to be reviewed.

Health professionals can use the resource '***Your Guide to Advance Care Planning in WA***' *(in draft)* as a resource to facilitate advance care planning discussions as it walks people through the type of things they should consider about their health, values, preferences and future care.

When finishing up discussions…

Always review and summarise with the person and any others present and clarify any inconsistencies or misunderstandings. Arrange further meetings or offer your contact details for future reference.

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What skills do I need to effectively facilitate ongoing conversations throughout the advance care planning process?

Many health professionals already have developed skills, the confidence and expert knowledge and are able to spend the time to have in depth advance care planning conversations and support the person through the advance care planning journey. Others may need more training and support. For some health professionals, it may be beyond their scope of practice to play this role and health professionals need to understand their own capability and recognise when to refer people on for more support.

For further information on communication skills in advance care planning and end-of-life discussions, refer to the **Communication Skills Education Videos for Health Professionals** produced by Cancer Council WA, Palliative and Supportive Care Education (PaSCE).

Where can I refer people for support with advance care planning?

Refer to the '**Where to get help**' section for a list of services who can talk to individuals or health professionals about advance care planning.

More information

- **Advance Care Planning Australia Video: A nurse introduces ACP to her patient**
- **Advance Care Planning Australia Video: A doctor discusses ACP**
- **Advance Care Planning Australia Video: Revisiting your advance care plan**
- **Advance Care Planning Australia Video: Changing priorities and ACP**
- **Communication Skills Education Videos for Health Professionals produced by PaSCE.**

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3. Write

How can I support the person to make their wishes known in writing?

Once the person has considered their values, beliefs and preferences for future treatment it is recommended they put these in writing. Health professionals can help to:

- discuss the options in terms of different advance care planning documents - noting those tools which are statutory and which are not
- support the person to complete their advance care planning documents
- encourage the person to document medical treatment decisions in their own words
- provide advice and guidance about treatment decisions to consider and the potential outcome of their choices
- refer to their organisational guidance for clarification of their role in this step.

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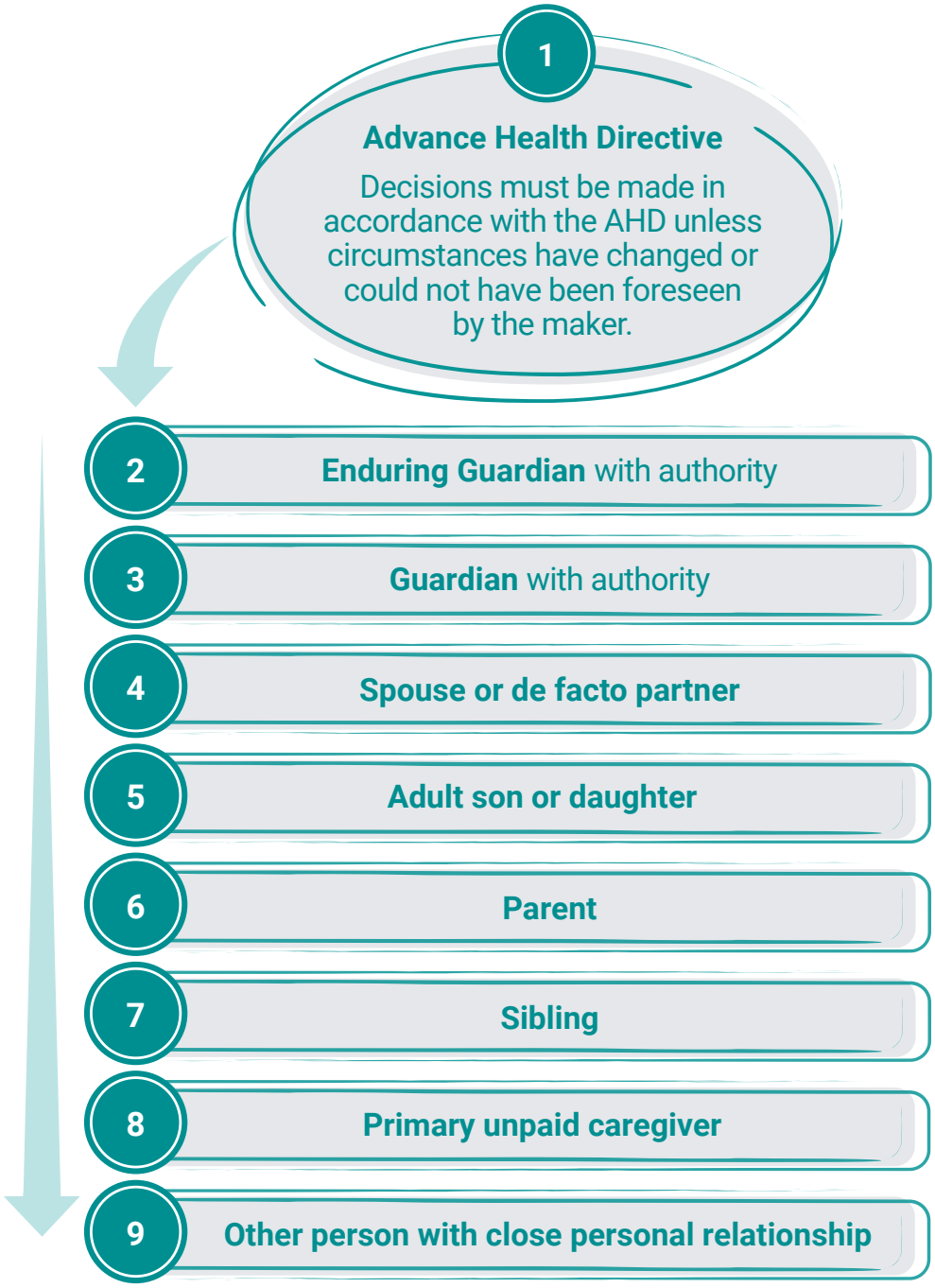
When assisting people to decide which advance care planning documentation is right for them, it is useful to inform people of the **Hierarchy of treatment decision makers**. This explains the order of decision-makers that health professionals must follow when seeking a treatment decision for a person who lacks the capacity to make their own judgements. Advance Health Directives are at the top of the hierarchy.

Figure 3. 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.



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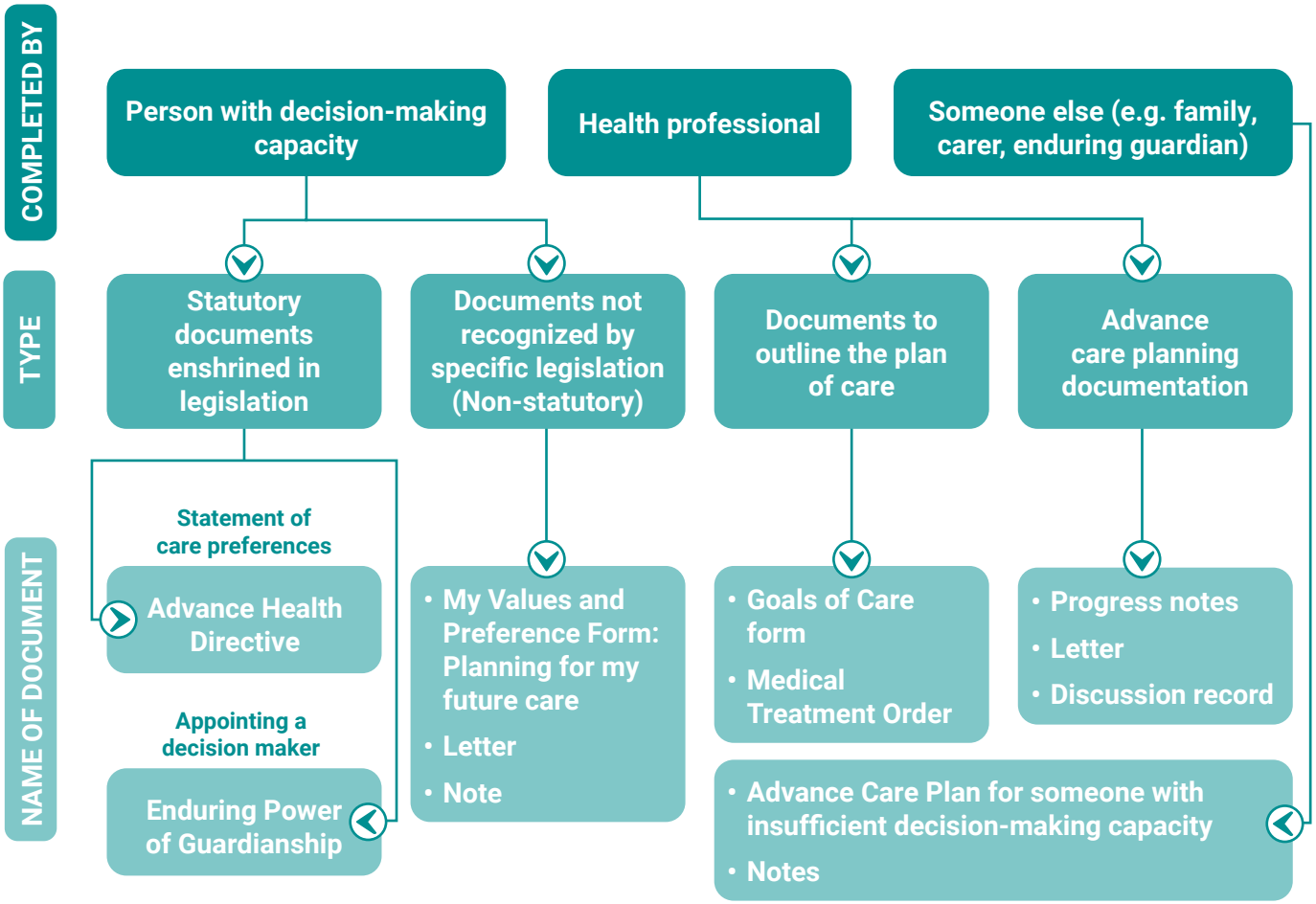
The Advance Health Directive and other advance care planning documents are discussed below. Encourage the person to consider which document(s) are right for them.

The '**Where to get help**' section in the Guide lists some services to support people with completing advance care planning documents.

Advance care planning and other related documents

The flowchart below provides an overview of the types of advance care planning documents that can be used in WA and whether they are statutory or non-statutory. (Statutory = refers to a document recognised under legislation)

Figure 4. Advance care planning documentation flow chart for WA



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Documents regarding health and care

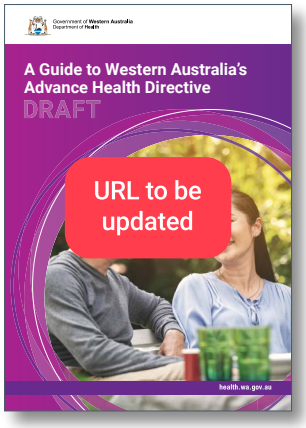
My Values and Preference Form: Planning for my future care

Thumbnail of doc that link to online version

This is a record of a person's advance care planning discussions and a way of informing those who are caring for them of their values and wishes. Their wishes may not necessarily be health related but will guide treating health professionals, enduring guardian(s) and/or family as to how they wish to be treated including any special preferences, requests or messages. This document is non-statutory legally binding.

The questions within this form are the same as the 'Values' section of the Advance Health Directive. If people are not yet ready to complete a full Advance Health Directive with formal witnessing and signing requirements, they may like to start with this Form.

Advance Health Directive



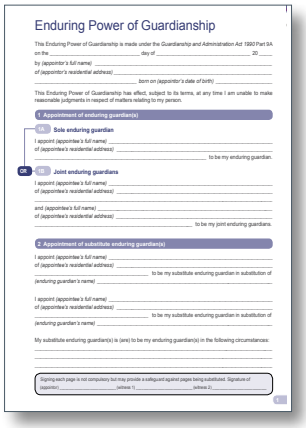
An Advance Health Directive (AHD) is a legal document completed by a competent adult with which contains decisions regarding future medical treatment. It specifies the treatment(s) for which consent is provided, refused or withdrawn under specific circumstances and only comes into effect if the person becomes incapable of making or communicating their decisions.

The term 'treatment' includes medical, surgical and dental treatments, including palliative care and life-sustaining measures.

An AHD would come into effect only if it applied to the treatment the person required and only if the person was unable to make reasoned judgements about a treatment decision at the time that the treatment was required.

Health professionals should be familiar with the **Advance Health Directive Guide** (link to be added) for instructions on how to complete an AHD.

Enduring Power of Guardianship


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 to _____ witness 2 _____

An **Enduring Power of Guardianship** (commonly referred to as EPG) is a legal document in which a person nominates an Enduring Guardian to make personal, lifestyle and treatment decisions on their behalf in the event that they are unable to make reasonable judgments about these matters in the future. An EPG is different from an Enduring Power of Attorney (EPA), which relates to financial and property matters.

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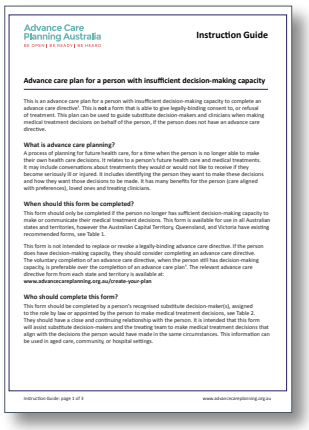
Advance Care Plan for someone with insufficient decision-making capacity


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 3 www.advancecareplanning.org.au

This is an advance care plan which should only be used when a person no longer has sufficient decision-making capacity to complete an Advance Health Directive. 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 Health Directive. It can be completed by a person's recognised substitute decision-maker(s) and they should have a close and continuing relationship with the person.

Organ and tissue donation

People can register to donate organs and tissue when they die. It's important they talk to family, as relatives will be asked to agree. Organ and tissue donation should be formally registered at **Donate Life** as it cant be formally registered using advance care planning documents.

Documents not related to health but may be considered at the time of advance care planning:

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. See the **Public Trustee** for more information.

Enduring Power of Attorney (EPA)

An enduring power of attorney is a legal agreement that enables a person to appoint a trusted person - or people - to make financial and property decisions on their behalf.
An enduring power of attorney is an agreement made by choice that can be executed by anyone over the age of 18, with capacity.

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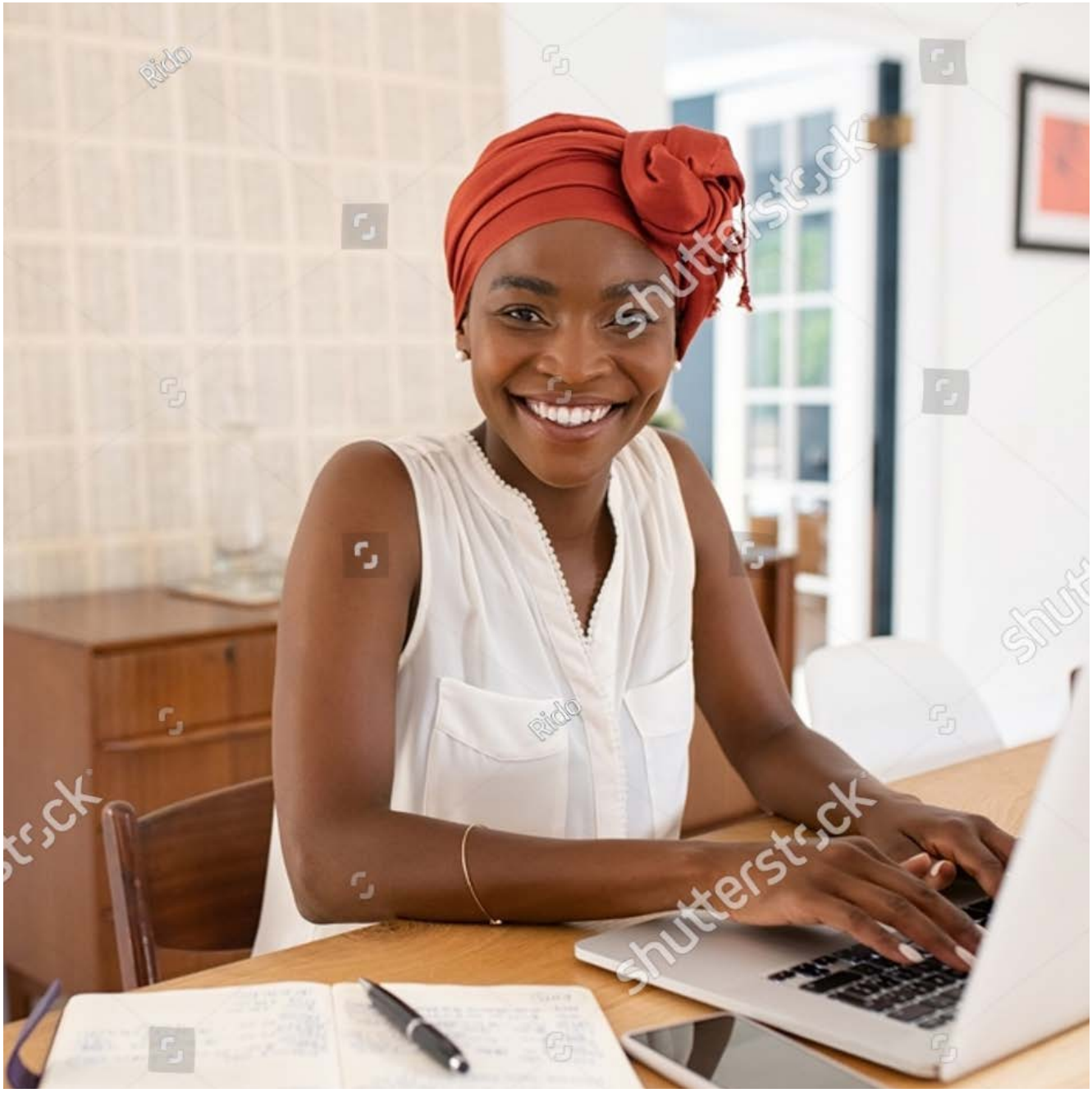
Documents initiated by health professionals

Goals of Patient Care

The Goals of Patient Care process uses a clinical document written by the healthcare team to record information about the shared-decisions that have been made following the goals of care discussions between a person, their doctor or health care team and their family or carer(s). It is used during an admission to hospital or other care facility. It helps to determine which treatments would be useful for a person, if there was deterioration in their condition.

Goals of Patient Care documents are not the same as advance care planning documents for legal purposes. If a person has an advance care planning document, such as an Advance Health Directive, they should make sure their healthcare team are aware and have a copy in their medical records. A Goals of Patient Care document is still relevant and should align with a person's advance care planning document.



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4. Share

What advice can I provide the person regarding sharing and storing their advance care planning documents?

Inform people to keep the original copies in a safe place and encourage and help people to register with **My Health record** and **upload their advance care planning documents**.

Encourage people to share their advance care planning documents with as many of the following people they feel comfortable with:

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

An AHD Alert Card or a **Medic Alert** can also be considered.

Individuals should be advised to write a list of all the people who have a current copy of their advance care planning documents should they wish to revoke or update them in the future.

What are my responsibilities to record advance care planning discussions?

Health professionals should refer to their relevant organisational guidance and practice for instruction on recording advance care planning discussions and documents. For health professionals within WA Health, refer to relevant statewide policies for the storage of advance care planning documents: **WA Clinical Alert (MedAlert) Policy**.

General advice for health professionals includes:

- Placing written documentation in the person's file in a consistent and accessible section.
- Recording details of all individuals present during discussions as well as others consulted in relation to this.
- Recording details of topics discussed, including feedback from the person regarding what they consider acceptable treatment, along with specifics of any treatment decisions e.g. circumstances for cessation of treatments.
- Documenting the presence of advance care planning documents including Advance Health Directives and Enduring Power of Guardianship in the person's medical file.
- Ensuring copies of the advance care planning discussion are included in handover documents if/when the person is transferred to another care setting.

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Responsibilities and liabilities in advance care planning

The Guide has outlined the role health professionals play in supporting people to think and talk about advance care planning, to write and record their values, preferences and treatment decisions and to share the outcomes with those close to the person and involved in their care.

Health professionals should also be clear about their responsibilities and the liabilities when enacting advance care planning documents. It should be noted that the role of health professionals will vary between settings.

Law and policy in WA

In order to understand responsibilities and liabilities, an understanding of the following is required:

- **Guardianship and Administration Act**
  Enables individuals to complete an Advance Health Directive and/or appoint an Enduring Guardian by completing an Enduring Power of Guardianship. The Act also outlines the **Hierarchy of treatment decision makers** which explains the order of decision-makers that health professionals must follow when seeking a treatment decision for a person who lacks the capacity to make their own judgements.
- **Criminal Code**
  Provides legal protection to health professionals who follow a valid AHD or EPG.
- **Legislative protection from Criminal Prosecution**
  Providing that health professionals act in good faith, they are protected, if treatment is withheld or withdrawn in accordance with an AHD or a decision of an Enduring Guardian, even when death ensues.
- **Civil Liability Act**
  Clarifies the definition of a health professional.
- **Common Law**
  Under common law a person can also prepare a directive to express their future treatment wishes. A common law directive has no prescribed format, however has legal standing under common law and health professionals must comply with a valid common law directive as they would an AHD.
- **Mental Health Act**
  If a voluntary mental health patient has made an AHD at a time when they had full legal capacity and they subsequently lose capacity, their AHD will be respected in the same manner as any other patient who has made a valid AHD and subsequently loses capacity. An involuntary mental health patient, who holds a valid AHD, can be given treatment without consent, if the patient's' Psychiatrist believes it to be in the patient's best interest.

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Key responsibilities across the advance care planning process

- Recognise opportunities to have advance care planning discussions
- Identify the existence of advance care planning documents
    - This can be done by asking the person at the earliest possible time or checking patient records
- Follow organisational procedure on the storage of advance care planning documents if/when presented by a patient
- Enact and follow the treatment decisions outlined within valid Advance Health Directives when a person loses capacity
- Reviewing advance care planning documents every 2 years or when there are major changes to a person's condition of health.

Seeking clarification

It is very important to remember: A valid AHD, EPG or common law directive is a legal document which must be followed by all health professionals.

Health professionals should understand what an AHD can and cannot be used for. For instance, an AHD cannot be used to:

- Require unlawful medical interventions such as euthanasia. An AHD cannot require or authorise a health professional to take active steps to unnaturally end life
- Require specific interventions if they are not clinically indicated
- Request treatment which is considered to be medically futile
- Record wishes about organ and tissue donation. An AHD is ineffective after death.

If a health professional has concerns in relation to the validity of an AHD or EPG, it is recommended they discuss their concerns with the person (if they have capacity). If they do not have capacity, then the health professional should:

- follow their organisation's internal process for resolution of such concerns
- lodge concerns with State Administrative Tribunal (SAT).

The SAT is the organisation responsible for resolving concerns/conflicts in relation to either an AHD/ EPG and can be contacted any time.

A health professional cannot choose to ignore an AHD or EPG, but they can report their concerns to the SAT.

If a patient's family object to an AHD they have the right to lodge their concerns with the SAT.

There are some circumstances which may affect the operations of AHDs. Refer to the Act. If there is any doubt about whether and AHD applies in any given situation, it may be necessary to obtain direction from the SAT.

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For more information on responsibilities and liabilities

See Advance Care Planning Australia for further information on **ethics in advance care planning**.

See Department of Health WA website for **frequently asked questions on health professional responsibilities in advance care planning**.(add link)

URL to be updated

See Department of Health WA website for information on the **role of health professionals in relation to Advance Health Directives**. (add link)

See **QUT's End of Life Law in Australia** website provides accurate and practical information to assist you to navigate the challenging legal issues that can arise with end of life decision-making. It is a broad introduction to end of life laws in each Australian State and Territory to help you know the law, and your rights and duties.

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Reflections: Case studies to reflect on the learnings from the Guide

See Appendix 1 for the answers.

1. Advance care planning should only be done when the person is dying?
2. My patient has been diagnosed with dementia, should I consider bringing up advance care planning?
3. The Advance Health Directive and Enduring Power of Guardianship are formal tools which can be used within advance care planning?
4. Martin would like to ensure that he can donate his organs after his death? Can he identify this on his Advance Health Directive?

Case study - Diane

5. Diane, a 55 year old woman whose mother has just died after a period of prolonged suffering due to a protracted illness, would like to know how she can make sure that the same thing doesn't happen to her. In particular, she wants to make sure that if she was unable to communicate with her family that she would not be artificially kept alive. She wants to know how she can legally make sure her wishes will be followed. What is your advice?

Case study – Thomas

6. Thomas is a 50 year old gentleman with acute kidney failure. He receives dialysis several times per week and is no longer able to enjoy the various sports and activities of his youth. He is also aware that his life expectancy has been shortened by his medical condition. As a result he wishes to complete an Advance Health Directive to refuse resuscitation but this is at odds with his wife's cultural and religious beliefs. She would be his default substitute decision-maker and refuses to engage with the conversation; he is confident that she would not honour his wishes and would instruct medical staff to perform CPR if required. What is your advice?

Case study – Sam and Joan

Sam and his wife Joan have always been very open about the treatment preferences they would want at end-of-life. Sam has very strong opinions on artificial nutrition and stated in his AHD that should he one day be unable to feed himself, he refuses to receive any food or fluids including anyone feeding him or any artificial nutrition. Following a stroke, Sam is unconscious and unable to feed himself.

7. You are aware that not feeding Sam will eventually result in his death. Should you follow his treatment wishes, and if so, will you expose yourself to criminal liability?
8. Sam's daughter disagrees with the treatment decision contained in his AHD and says that is wrong not to feed her father. What should the health professional do? Sam's wife, doesn't wish to enter into the conflict.

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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)
Phone: **9222 2300**
Email: **ACP@health.wa.gov.au**

Palliative Care WA
General queries and support on advance care planning, register for free advance care planning community workshops, receive a set of What Matters Most cards
Phone: **1300 551 704** (Mon to Thurs)

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

Advance Care Planning Australia Free Support Service
General queries from health professionals, care workers, consumers and loved ones and support with completing advance care planning documents
Phone: **1300 208 582**
Online referral form: **www.advancecareplanning.org.au/about-us/referral**

Enduring Power 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**

General legal advice

Citizens Advice Bureau
Phone: **(08) 9221 5711**
Website: **www.cabwa.com.au**

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 (AWST)

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State Administrative Tribunal (SAT)

Applications for guardianship and administration, as well as applications regarding capacity and enduring guardians can be made at SAT: **www.sat.justice.wa.gov.au**
Tel: **1300 306 017**
Mon - Fri, 8:30am – 4.30pm

The Law Society of Western Australia

Phone: **(08) 9324 8652**
Find a Lawyer referral enquiry section: **www.lawsocietywa.asn.au/find-a-lawyer/**

Advice and support for staff at residential care facilities

Metropolitan Palliative Care Consultancy Service (MPaCCS)

A mobile specialist palliative care team that works collaboratively with General Practitioners and other health professionals to ensure superior outcomes.
Phone: **(08) 9217 1777**
Email: **MPaCCS@bethesda.org.au**
Website: **www.bethesda.org.au/facilities-services/mpaccs/**

Residential Care Line

Phone: **(08) 6457 3146**

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Glossary

Advance Care Directives

Advance Care Directives is as a catch-all term to refer to the instruments which are recognised in each Australian jurisdiction under advance care directive legislation or common law.

They are voluntary, person-led documents completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care.

They come into effect when an individual loses decision-making capacity. Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets.

Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory).

- *Common law (non-statutory) Advance Care Directive*: a structured document that is completed and signed by a competent adult and that is not a legislated statutory document. In Western Australia, this includes the *My Values and Preference Form: Planning for my future care*.
- *Statutory Advance Care Directive*: a signed document that complies with the requirements set out by a jurisdiction's legislation. In Western Australia, this includes an Advance Health Directive and Enduring Power of Guardianship which comply with the *Guardianship and Administration Act 1990*.

Advance Care Plan

Documents that capture a person's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).

An Advance Care Plan for a non-competent person is often very helpful in providing information for substitute decision-makers and health practitioners and may guide care decisions but are not legally binding.

An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment.

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.

Advance care planning documents

A catch all term to include documents that result from advance care planning. This includes Advance Health Directives, My Values and Preference Form and Enduring Power of Guardianship.

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Advance Health Directive

An Advance Health Directive (AHD) is a voluntary, person-led legal document completed by an adult with full legal capacity that focuses on an individual's values and preferences for future care decisions, including their preferred outcomes and care.

It specifies the treatment(s) for which consent is provided or refused under specific circumstances and only comes into effect if the person becomes incapable of communicating their wishes.

The term 'treatment' includes medical, surgical and dental treatments, including palliative care and life-sustaining measures.

An AHD would come into effect only if it applied to the treatment a person required and only if the person was unable to make reasoned judgements about a treatment decision at the time that the treatment was required. An AHD is one of the types of Advance Care Directives available in WA.

Capacity

The ability to make a decision for oneself.

Decision-making capacity can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made.

Capacity assessment does not assess whether the decision is considered "good" or "bad" by others such as health practitioners or family, but rather considers the person's ability to make a decision and comprehend its implications.

Generally, when a person has capacity to make a particular decision they can do all of the following:

- understand and believe the facts involved in making the decision
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- make their decision freely and voluntarily
- communicate their decision.

By default, people are assumed to have capacity, unless there is evidence to the contrary.

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

Common law directive

An instruction or directive completed and signed by a competent adult and that is not considered a legislated statutory document as it does not comply with the requirements set out in the Guardianship and Administration Act 1990, and is therefore recognised instead by common law.

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Comprehensive care plan

(Including but not limited to: clinical care plans, clinical pathway, or medical order)

A document or electronic view which describes agreed goals of care, and outlines planned medical, nursing and allied health activities for a patient. Comprehensive care plans reflect shared decisions made with patients, carers and families about the tests, interventions, treatments and other activities needed to achieve the goals of care. The content of comprehensive care plans will depend on the setting and the service that is being provided and may be called different things in different health organisations. For example, a care or clinical pathway for a specific intervention may be considered a comprehensive care plan.

A comprehensive care plan is different to an Advance Health Directive. While an Advance Health Directive is completed by an individual and recognised within legislation, a comprehensive care plan is written by health professional together with the individual through shared decision-making (wherever possible). It is appropriate that comprehensive care plans be put in place whether or not the person has made an Advance Health Directive, but when there is an existing document that records directions about care, the comprehensive care plan complements, and therefore should be informed by, the person's documented preferences.

Competency

Competency is a legal term used to describe the mental ability required for an adult to perform a specific task. Competency is recognised in legislation and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an Advance Health Directive.

A person is deemed to be either competent or not competent – there are no shades of grey. Competency must be assumed unless there is evidence to suggest otherwise.

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/ fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end-of-life will be considered likely to die during the next 12 months.

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.

Enduring Power of Attorney (EPA)

An enduring power of attorney is a legal agreement that enables a person to appoint a trusted person - or people - to make financial and property decisions on their behalf. An enduring power of attorney is an agreement made by choice that can be executed by anyone over the age of 18, with capacity.

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Enduring Power of Guardianship (EPG) and enduring guardian

An Enduring Power of Guardianship is a legal document in which a person nominates an Enduring Guardian to make personal, lifestyle and treatment decisions on their behalf in the event that they are unable to make reasonable judgments about these matters in the future. An EPG is different from an Enduring Power of Attorney (EPA), which relates to financial and property matters.

Goals of care

Clinical and other goals or a patient's episode of care that are determined in the context of a shared decision-making process.

Goals of care may change over time, particularly as the patient enters the terminal phase and during end-of-life care.

Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient.

Non-medical goals of care articulated by the person may include returning home or reaching a particular milestone, such as participating in a family event.

Goals of care documents are different to Advance Health Directives. Goals of care are completed by medical practitioners but should align with the preferred health outcomes and treatment decisions made by the individual (to the capacity they have to participate in shared decision-making). The person may or may not have previously completed an Advance Health Directive. Where an Advance Health Directive has been completed, and the individual no longer has decision-making capacity, the goals of care should reflect the Advance Health Directive, and should include a discussion with the person's substitute decision-maker.

Guardian

A guardian is a person appointed by the State Administrative Tribunal to act on an individual's behalf. The State Administrative Tribunal determines which powers the guardian may exercise on the individual's behalf.

Healthcare professional

Any registered professional 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-limiting condition

A life limiting condition is a disease, condition or injury that is likely to result in death, but not restricted to the terminal stage when death is imminent.

Life-sustaining measures

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

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Palliative care

An approach that improves the quality of life of individuals, including their family/carer, facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.

Specialist palliative care

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end-of-life and palliative care and/ or to provide direct care to people with complex palliative care needs.

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.

Urgent treatment

Urgent treatment means treatment urgently needed by a patient:

- to save the patient's life
- to prevent serious damage to the patient's health
- to prevent the patient from suffering or continuing to suffer significant pain or distress.

It does not include sterilisation.

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Appendices

Appendix 1: Answers to reflections

1. False
2. Yes. It is vital that discussions with individuals living with dementia are started early to ensure that whilst they have mental capacity they can discuss how they would like the later stages of their condition managed.
3. True
4. No. Advance Health Directives are of no effect following death and therefore it cant be used to formally register interest in organ and tissue donation. Organ and tissue donation should be formally registered at **Donate Life**. It is also important for people to talk to family, as relatives will be asked to agree.
5. You can advise Diane of the legislation in Western Australia allowing her to make an Advance Health Directive in which she can state her medical treatment preferences in relation to being kept artificially alive. You should inform Diane that the Advance Health Directive is legal document and her preferred treatment decisions outlined within the document will be followed if she is unable to make or communicate her wishes at any time. Diane should also be counselled on treatment options, and encouraged to express her preferences to her family and medical specialists.
6. You can advise Thomas that the Advance Health Directive is a legal document that requires medical staff to follow his preferences. Once established he can give copies to his GP and hospital doctors and he can upload it to MyHealthRecord to ensure that doctors and nurses can access his decision. He could also start wearing a MedicAlert bracelet, which would not feature any explicit information about his AHD but would provide medical professionals with a phone number to call and confirm his resuscitation status in an emergency. Another alternative would be to advise Thomas that he could consider appointing an alternative substitute decision-maker if his wife is unable to honour his preferences.

   It would be worth counselling Thomas that making all these preparations without his wife's knowledge runs the risk of complications when the time comes, and of causing her additional stress and emotional upset. You may direct him to resources provided by Advance Care Planning Australia to help guide the conversation with her, or introduce a third party counsellor to help facilitate the situation.
7. Health professionals must follow the treatment decisions contained within a valid and operative AHD. In this circumstance the patient has given a specific treatment decision which meets the current circumstances so the health professionals should follow this. The amendments to the Criminal Code provide exemption from criminal responsibility for the administration in good faith of reasonable medical treatment (including palliative care) even when death ensues. Legislative protection from criminal responsibility have now been extended to the withdrawal and withholding of medical treatment where the non-provision or cessation of that treatment is done in good faith and is reasonable to all the circumstances of the case, even where death ensues.
8. It is important to listen and respond to the daughter's concerns. But medical practitioners should explain to the daughter that they are legally bound to the instructions in a valid and operative AHD. If conflict remains health professionals may consider referring the issue to the State Administrative Tribunal.

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- Advance Care Planning Australia. Factsheet for healthcare professionals. Austin Health, August 2018.
- Nous Group. National Framework for Advance Care Planning Documents. Department of Health Australia, May 2021.
- Palliative Care WA. Advance care planning introductory model. Perth, WA; Palliative Care WA ACP Consortium, 2021.

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

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