



Supporting Advance Care Planning



Our Vision

All people live with a sense of purpose, a sense of belonging and a sense of wellbeing.



Our Mission

Identitywa works in partnership with individuals and families to build a community where people with disability enjoy a fulfilled life.

We support individuals to achieve their goals, whatever they may be. We offer families the support they need.



Our Values

Above all else, we make a commitment to act.

We will look for the opportunities rather than seeing the barriers.

Our approach will be objective, transparent and fair. We will always be honest and open and no matter how challenging, we will endeavour to see it through to the end.

Contents

Introduction	pg3
Important Information	pg4
Completing Your Advance Care Plan	pg6
If you cannot make decisions	pg10
Decision making	pg12
What do these principles mean	pg14
Helpful Contacts	pg17
Definitions	pg18

Introduction

Advance care planning is a process of an individual making decisions about their health and medical care in the event that they are not able to make decisions in the final stages of their life.

An Advance Care Plan (ACP) is recommended to be written in consultation with people who are close to the individual such as family members, friends and trained Identitywa staff.

An ACP is a valuable point of reference which promotes a person's choice and dignity in decisions made with regard to their personal and medical preferences.

A well documented ACP clearly defines an individuals' wishes and choices, therefore ensuring they are understood and respected. It is integral in assisting Identitywa staff to support individuals.

Identitywa is committed to working closely with the people we support and their families to ensure they receive the best possible support and care throughout their life.

Planning ahead can provide individuals and families with confidence in knowing the person's wishes and choices have been formally documented.

Identitywa, as one of Western Australia's leading disability support providers, is well placed to assist individuals and families to complete their ACP.

Important Information for you

1 What is this handbook for?

This advance care planning handbook is intended to assist you when you are having conversations with the people close to you about your values, wishes and preferences.

Whilst these can be difficult conversations, Identitywa staff are available to support you through each step of the way in the development of your ACP.

2 What is an Advance Care Plan?

An ACP is a plan you make for your treatment and care during the final stages of your life.

Your ACP should consider your values, wishes and preferences with regard to the activities you enjoy, personal care and more advanced medical care. It should also outline who you would like to care and support you, and to visit you at the end of your life.

3 Talk to people you care about

It is important to ensure the people you care about, and those close to you, are aware that you have ACP which includes your decisions.

By planning in advance you have the time to consider various situations and possible implications. We encourage you to consult people close to you to discuss your wishes and ultimately your decisions. They could be your family, friends, doctor or other health care professionals - people you feel comfortable with and trust.

Life style and personal care information you might include in your plan:

- Personal messages to family and friends.
- Who you would like to visit you?
- How you might like religious or spiritual beliefs reflected in your care?

Medical care information to include in your plan may include:

- Would you like to be cared for at home or in a hospital?
- Who you would like to visit/be with you at the end of your life?
- The treatment preferences which are acceptable to you?

It is important also to outline things in your ACP that you **do not** want. It can be of great comfort and reassurance for people knowing that you have a well thought out ACP.

4 Talk to your doctor

Once you have had a discussion with those close to you, it is time to talk to your doctor and tell him/her your wishes.

Your doctor can help you to understand the state of your current health and what treatment or care you might need in the future. If you do not already know, or are unsure, it may be a good time to ask your doctor just what your illness means.

Things to think about:

- How will your illness affect you?
- What will be the effects of any potential treatment?
- What palliative care options will be available to you?

Discuss with your doctor treatment options and the decisions you have made about your future medical care. It is recommended that you take someone along with you for support.

Completing your Advance Care Plan

Your ACP is made up of two (2) parts. It outlines your preferences for how you want to be treated by doctors, nurses and other health professionals and Identitywa support workers.

Part A: Conversation Tool

Part A of your ACP is a conversation tool used to explore your attitudes, values and wishes around the end of life.

For example, it asks what activities you like to do. It also asks you to nominate your Decision Maker and list emergency contacts.

Part B: Medical Considerations

Part B of your ACP asks you to think about, and outline, medical treatment preferences that are acceptable or not acceptable to you.

We recommend you discuss/consider all the various options and choices of treatment available to you with your doctor, and the choices you have in the event you are faced with a diminished quality of life.

It is advised that you take someone with you to these discussions. This could be your Decision Maker, an Identitywa Team Leader, a Clinical Nurse or all of these people. It is important that you feel comfortable with the person/s who are supporting you.

Having someone with you at these meetings can help in several ways:

- They can be your support if the conversation is upsetting.
- They can be a second 'set of ears' to ensure that what is being discussed is not forgotten.
- They can assist you when it comes to planning your preferred treatment and care.

When you have made your final decisions, it is helpful to have assistance from your Decision Maker, an Identitywa Team Leader or a Clinical Nurse to record them in preparation for your ACP.

Your ACP can be done in parts, or as a whole, and can be reviewed as often as required. At the minimum, your ACP will be reviewed annually in conjunction with your Identitywa Individual Plan.

Filling in *Part A* of your ACP

1. Start with a discussion with people you trust. This conversation can take place anytime, however, it needs to be recorded following the format of an ACP.
Please see Appendix 1 and 2.
2. Your Identitywa Team Leader or Clinical Nurse can assist you by writing down your decisions and preferences as you go through the questions.
3. Upon completing *Part A*, your Team Leader or Clinical Nurse will make a copy of your ACP for you to keep, a copy will be placed in your individual file and the ACP will also be filed electronically in Identitywa's records management system.

Filling in *Part B* of your ACP

1. We encourage you to look through the questions included in *Part B* before going to your doctor so that you are aware of the treatment and care options that are available to you.
2. We can assist you to make an appointment to see your doctor. *Part B* of your ACP should be taken to your appointment. Your doctor can sit with you and discuss treatment options so this important section of your ACP can be completed.
3. The doctor may issue a letter outlining your medical preferences which can be attached to your ACP .

If you cannot make decisions

The Guardianship and Administration Act 1990 recognises that people who are not capable of making reasoned decisions for themselves may need additional support and assistance. This Act enables you to choose a substitute decision maker who will make decisions in the best interests around your care and medical treatment.

A decision-making disability may affect a person's ability to manage various aspects of their lives. In this situation, support is often given by people who are already involved in a person's life, such as family, friends and service providers.

If you are unable to choose a decision maker, the State Administrative Tribunal may appoint a guardian for a person with a decision-making disability. This allows a guardian to be appointed as a substitute decision maker.

Who is the Decision Maker?

You can choose anyone over the age of 18 years to be your decision maker, however, choosing the *right* person is really important. Your Decision Maker is required to act in your best interest and make the same decision they believe you would have made.

They should therefore be someone who you trust to listen carefully to your wishes for future medical treatment and to faithfully represent you when you can no longer speak for yourself. He or she may be faced with situations which require them to make difficult decisions. It is important that you feel totally confident that they will be able to do this on your behalf - following the directions outlined in your ACP.

What is involved in decision making?

The responsibility of your Decision Maker is to:

1. Understand their rights and responsibility
2. Give consent to:
 - What treatment you may receive
 - What the risks of this treatment are, and any other available treatments options
 - Say no to the treatment on your behalf

How is a decision maker established in an emergency?

If you do not have a nominated decision maker in an emergency, health professionals will use the chart below to determine a decision maker in regard to your urgent medical care.

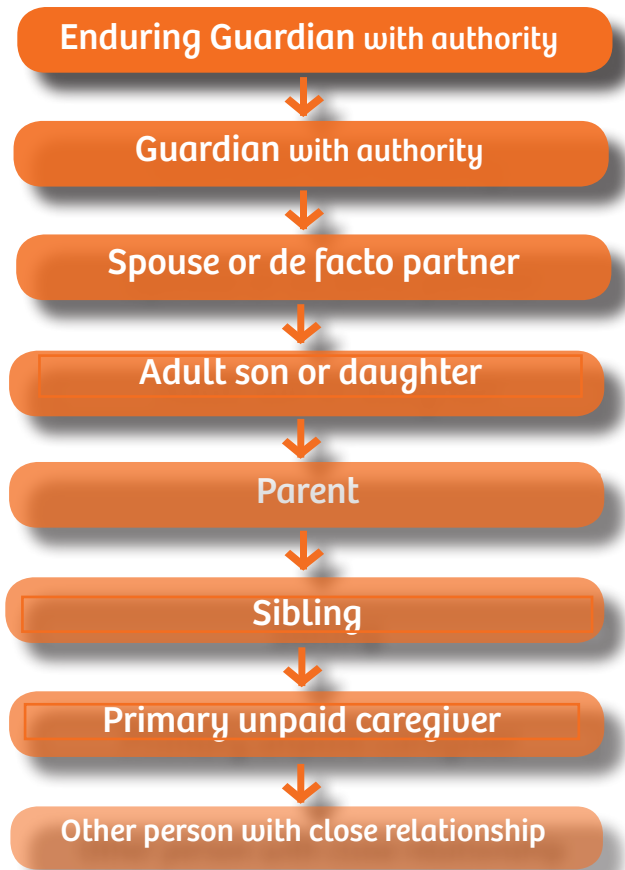


Fig. 1 List of persons of Guardianship and Administration Act 1990 summarised as a hierarchy of decision makers, Office of Public Advocate.

Decision making

Involving your Decision Maker in your ACP can prepare them for their future role in your care and treatment and give them the confidence to carry out your wishes. Below are a few principles you, your family or friends and Decision Maker can use when assisting you to make decisions in your ACP.

- 1. Assume I can**
We assume everyone has the capacity to make decisions, unless proven otherwise.
- 2. One decision at a time**
Capacity is decision specific.
- 3. Understand the right assistance for me**
Support to make decisions needs to reflect good assistance for each person uniquely.
- 4. Understand me and my preferences**
Everyone demonstrates preferences and these can be used as the building blocks of decisions.
- 5. It's up to me**
People have the right to make unwise decisions.
- 6. Support me to experience choice**
People have the right to learn from experience.
- 7. I can change my mind**
People have the right to change their minds.
- 8. Have you explored all options to assist me?**
Every effort should be made to support people make their decisions.
- 9. Involve me in decisions about my life**
Everyone has the right to be involved in decision making including substitute decision making.
- 10. I have the right people supporting me and my decisions**
Supported decision making relies on integral assistance.



Fig. 2 WA's Individualised Services (WAIS) Supported Decision Making principles.

Conclusion

You always have the right to change your ACP. It may need to be reviewed in response to changes in your general health or medical condition.

If you have further questions or wish to discuss any aspects of advance care planning please contact us. ACP forms are available at our Head Office or can be emailed.

Contact details

To contact Identitywa Team Leaders, Clinical Nurse and Managers:
Call 9474 3303 | **Email** admin@identitywa.com.au

Definitions

Advance care planning

Advance care planning (ACP) is an ongoing discussion between a person, their loved ones, carers and their health care professional(s), about their values, beliefs, and treatment and care options. In particular, their wishes for future care should they no longer be able to communicate their decisions at the time they are needed.

Advance Care Plan

An Advance Care Plan is a document consisting of two parts Part A: *Conversation Tool* and Part B: *Medical Considerations* used by Identitywa to document the above plan.

Health care professional

A health care professional is any qualified and registered doctor, nurse, allied health or dental professional who provides your medical and clinical treatment and care. This includes: chiropractor, dentist (including dental therapist, dental hygienist and dental prosthetist), medical practitioner, medical radiation technologist, midwife, nurse, occupational therapist, optometrist, osteopath, pharmaceutical chemist, physiotherapist, podiatrist and psychologist.

Palliative care

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

Treatment

Treatment means any medical, surgical or dental treatment or other health care, including a life-sustaining measure and palliative care.

Treatment decision

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

Urgent treatment

Urgent treatment means treatment that in the opinion of the health professional, is needed to save the life of the person, to prevent serious damage to the person's health or to prevent the person suffering or continuing to suffer significant pain or distress.

Where the person needs urgent treatment the Guardianship and Administration Act 1990 allows for the urgent treatment to be provided without the need for a health professional to obtain a treatment decision if the health professional believes it is not practicable to obtain that decision.

Helpful contacts

Listed below are organisation who can also assist in advance care planning.

Cancer Council WA

T (08) 9212 4333
W www.cancerwa.asn.au

Carers WA

T 1300 227 377
E info@carerswa.asn.au
W www.carerswa.asn.au

Palliative Care WA

T 1300 551 704
E pcwainc@palliativecarewa.asn.au
W www.palliativecarewa.asn.au

Office of Public Advocate

T 1300 858 455 or (08) 9278 7300
E apa@justice.wa.gov.au
W www.publicadvocate.wa.gov.au





**A Catholic outreach supporting people
with disability and their families.**

Contact Us

T (08) 9474 3303 | F (08) 9474 3315

E admin@identitywa.com.au

www.identitywa.com.au