Equitable access to Advance Care Planning for people living with sensory loss in Western Australia

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Palliative Care
Western Australia
Living, dying & grieving well

WA Primary Health Alliance
Better health, together

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An Australian Government Initiative

Acknowledgement

We wish to acknowledge and appreciate the contributions of past and present Australian Deaf and deafblind community members in preserving their rich heritage, culture and language; Auslan.

Funding

This project has been developed through a collaboration between Palliative Care WA (PCWA) and WA Primary Health Alliance (WAPHA)

This activity is supported by funding from WA Primary Health Alliance through the Australian Government's PHN Program

Committee Members

- Lenka Psar-McCabe-Palliative Care WA
- Julia Kennington-Palliative Care WA
- Tish Morrison-WAPHA
- Emily White-WAPHA
- Hannah McPierzie-Senses WA, lived experience
- Karen Wickham-Deafblind WA
- Linda De Rosario-Vital Interpreting
- Nicole Deprazer-WA Department of Health
- Professor Davina Porock-Edith Cowan University
- Marie Ware-Lived experience

Why?

Recognition of need from lived and clinical experience

Terminology

Any reference to the d/Deaf or deafblind community is not to suggest that every d/Deaf or deafblind person will have the same experience. Each person has their own unique story, and any recommendations made will require individualisation.

Project Aim

To improve access for individuals with hearing-related sensory loss to information which support Advance Care Planning (ACP) and palliative care in Western Australia (WA).

Project overview

DESKTOP REVIEW

FOCUS GROUPS

DEVELOPMENT OF RESOURCES

FOCUS GROUP TESTING

Focus Groups

Four focus groups with key stakeholders:

1. Auslan Interpreter workforce
2. d/Deaf and deafblind participants
3. Acquired hearing loss due to ageing
4. Review of resources

Focus Group 1-Key Learnings

An ACP visual resource in Auslan

Professional development session

Support for interpreters to understand the nature of the booking

Education and support opportunities for Deaf Support Officers

Interpretation is somewhat dependent on the interpreter’s understanding of information

No set glossary of terms that can be developed from English into Auslan

Focus Group 2-Key Learnings

Large blocks of text very difficult to read and understand

Preference for plain English and Auslan

Of the current resources available, Easy Read guide most accessible.

Pace is important, not too fast

Colour choices need to be considered

Focus Group 2-Key Learnings

Preference for videos

Videos require black background and black clothing to easily visualise hands

Full screen view of interpreter, not just in the corner of the screen

Captions (not auto-captions and preferably two lines at a time)

Braille translation requires short summaries

Focus Group 2-Key Learnings

Layout is very important for people with visual impairment

Questions should be written left to right and answers on the next line

One on one assistance required if severe visual impairment

Peripheral vision loss makes watching videos difficult

For those with dual sensory loss very difficult to look at a picture in a video and listen to an explanation at the same time

Focus Group 2-Other Considerations

Accessing an interpreter requires using up NDIS funding

Not everyone fluent in Auslan

Focus Group 2-Key Learnings

“It’s a big dream. I wish we could have a d/Deaf and deafblind friendly book. A book that we can give to these professionals to say, this is what we need. This is what we are. This is who we are. This is how we are. Just so we can give it to this particular professional and say, read this before you come and talk to me, find out how you can talk to me”

Focus Group 3-Key Learnings

- Distrust of information on the internet.
- Concise information be made available in doctors’ surgeries, libraries, and 55+ centres.
- Workshops to guide people on how to fill out the forms.
- ACP documentation could be done through routine health assessments with GPs.
- Use of subtitles during presentations.
- Use of a microphone to enable speech to be heard clearly. Recognition that accents can be tricky and that hearing aids can be challenging.

Key Findings Summary

Preference for provision of information in plain English, short, Easy Read documents and Auslan videos developed with consideration of layout, pace, colour contrast and captions. Auslan videos required to be specific for use in WA.

Key Actions

- Develop Auslan videos explaining ACP, palliative care and each component of ACP e.g. AHD/EPG for use in Western Australian context with accompanying short guides.
- Develop professional development session/s in conjunction with Australian Sign Language Interpreters and Translators Association (ASLITA) to provide knowledge and understanding of palliative care and ACP concepts to the Auslan Interpreter industry.

Professional development workshop

“I learnt a lot and it was very clearly presented. The information was specific and made complex things easy to understand. Very important that interpreters understand so they can interpret accurately.”

Resources-Quick Guide

Elderly man and woman smiling and having a cup of tea in a garden

WHAT IS AN **ENDURING POWER OF GUARDIANSHIP?**

Quick Guide

In WA, an Enduring Power of Guardianship (EPG) is a legal document.

It means you pick someone you trust to make lifestyle and treatment choices for you for a time when you can't make these choices for yourself (for example, if you have a brain injury or are unconscious).

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Middle aged man and woman embracing and smiling in a country area

You can choose one, or two people jointly, as your Enduring Guardian and you can choose one or two people to be back-up decision makers if you want to.

It should be someone you trust to make the best choices for you and who will follow your instructions. You should talk to the person you choose so that they understand your choices.

They make choices about lifestyle such as:

- where you live
- what services you can use
- what medical and personal care you have.

When making choices for you, the Enduring Guardian should think about what you want and your health problems, the risks, as well as the good things about any treatments.

Where can you get help?

You can get support with Enduring Power of Guardianship by speaking to your GP or a member of your medical team.

You can also contact:

Palliative Care WA
☎ **1300 551 704**
✉ **info@palliativecarewa.asn.au**

You can access EPA kits from
www.publicadvocate.wa.gov.au
☎ **1300 858 455**
✉ **opa@justice.wa.gov.au.**

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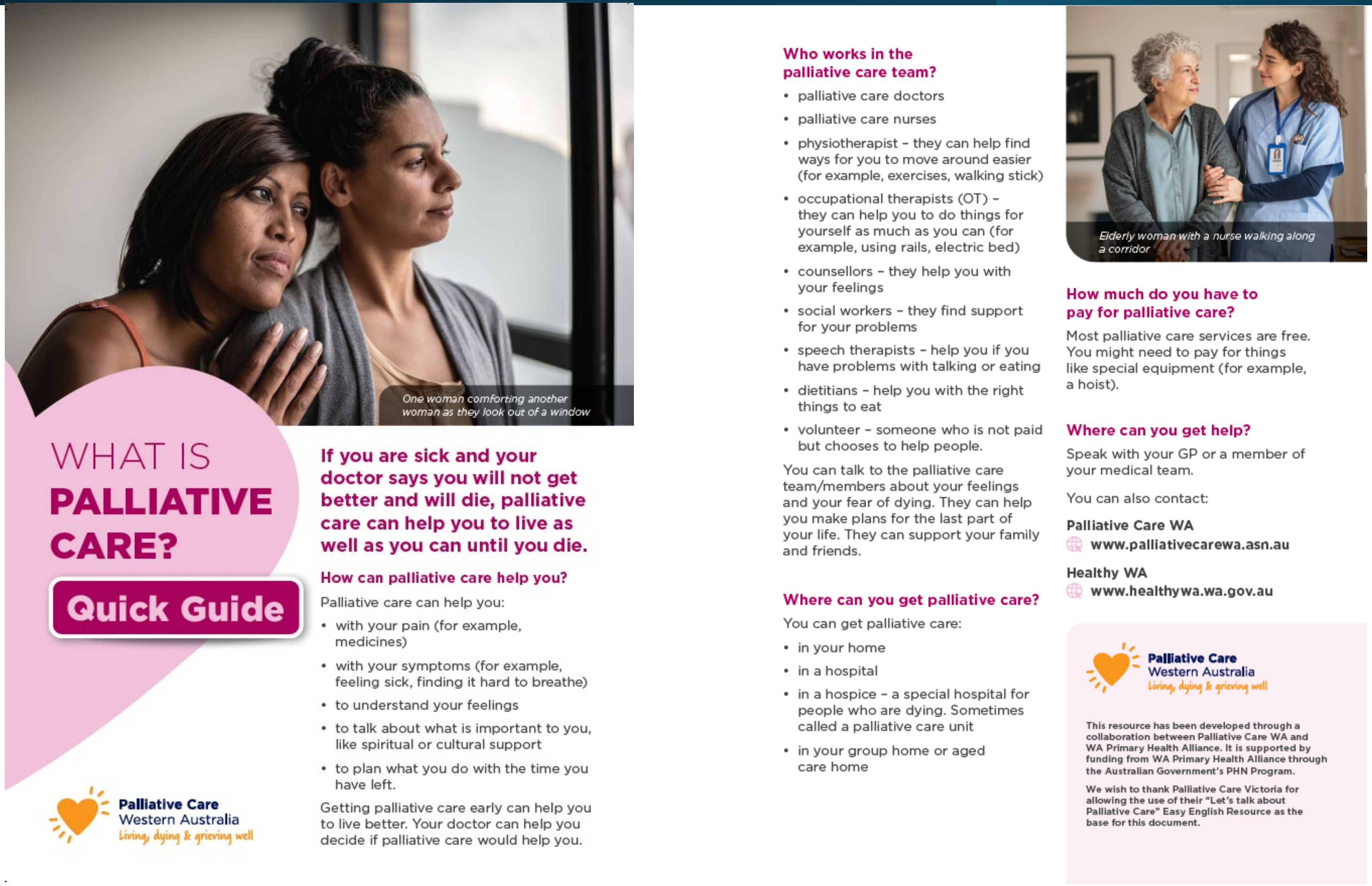
Resources-Quick Guide



One woman comforting another woman as they look out of a window

WHAT IS **PALLIATIVE CARE?**

Quick Guide

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If you are sick and your doctor says you will not get better and will die, palliative care can help you to live as well as you can until you die.

How can palliative care help you?

Palliative care can help you:

- with your pain (for example, medicines)
- with your symptoms (for example, feeling sick, finding it hard to breathe)
- to understand your feelings
- to talk about what is important to you, like spiritual or cultural support
- to plan what you do with the time you have left.

Getting palliative care early can help you to live better. Your doctor can help you decide if palliative care would help you.

Who works in the palliative care team?

- palliative care doctors
- palliative care nurses
- physiotherapist – they can help find ways for you to move around easier (for example, exercises, walking stick)
- occupational therapists (OT) – they can help you to do things for yourself as much as you can (for example, using rails, electric bed)
- counsellors – they help you with your feelings
- social workers – they find support for your problems
- speech therapists – help you if you have problems with talking or eating
- dietitians – help you with the right things to eat
- volunteer – someone who is not paid but chooses to help people.

You can talk to the palliative care team/members about your feelings and your fear of dying. They can help you make plans for the last part of your life. They can support your family and friends.

Where can you get palliative care?

You can get palliative care:

- in your home
- in a hospital
- in a hospice – a special hospital for people who are dying. Sometimes called a palliative care unit
- in your group home or aged care home

Elderly woman with a nurse walking along a corridor

How much do you have to pay for palliative care?

Most palliative care services are free. You might need to pay for things like special equipment (for example, a hoist).

Where can you get help?

Speak with your GP or a member of your medical team.

You can also contact:

Palliative Care WA
www.palliativecarewa.asn.au

Healthy WA
www.healthywa.wa.gov.au

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We wish to thank Palliative Care Victoria for allowing the use of their "Let's talk about Palliative Care" Easy English Resource as the base for this document.

Resources-Quick Guide

Woman writing and sitting at table with another woman and man

WHAT IS **ADVANCE CARE PLANNING?**

Quick Guide

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This is talking about your future decisions.

You might want to have a say in the health and personal care you get in the future.

But it might be hard to do this if you are unwell or cannot communicate what you want.

Advance Care Planning is when you think about what health and personal care you want in the future, then put those decisions in writing.

You can change your mind at any time.

Woman and man smiling and filling forms at a kitchen table

It is important to do this planning when:

- you feel healthy
- and can make your own choices.

Advance Care Planning can help you to:

- feel less stressed
- spend less time in hospital
- explain the care that you want
- name people you trust to make decisions if you cannot.

Thinking about Advance Care Planning

Take time to think about what is important to you now and the things you want and do not want for your future when you are unwell. For example, who do you want to make decisions for you if you cannot? What medical treatment you want or do not want (for example, Cardiopulmonary Resuscitation (CPR), antibiotics, blood transfusion) and how you want people to look after you.

Talking about your choices

Talk to your family, friends, doctor, lawyer and support people about what is important to you. They can help you when you cannot tell people what you need or want.

You can talk to your doctor if you want to know more about your health. They can tell you about the type of help you might need.

Writing your documents

It is important to write down the choices you have made. People can read your choices and know what help you want.

It is important that you pick the right document to write down your choices. You can get someone to help you understand the different documents, for example, a doctor, a lawyer, a community health nurse, family member, friend, or support person. Different people can help with different questions and advice.

Types of documents to use:

Values and Preferences Form: Planning for my future care

This document can be helpful to record what is important to you.

This can help to guide family members, care givers and doctors or nurses to understand the things that are important to you.

It does not have decisions about medical care.

Advance Health Directive (AHD)

This is a legal and binding document where you write down the type of medical treatment you want or do not want (for example, CPR, antibiotics, blood transfusion).

The instructions that you put in your AHD are only used if you cannot make or communicate choices for yourself.

Doctors and nurses must follow these decisions.

Enduring Power of Guardianship (EPG)

This is a legal and binding document where you pick someone else to make medical and lifestyle choices for you only when you cannot.

They make choices about lifestyle such as:

- where you live
- what services you can use
- what medical and personal care you can have.

Enduring Power of Attorney (EPA)

It is also important to think about your financial decisions when thinking about what you want for the future.

This is a legal and binding document where you pick someone else to make money and property choices for you when you cannot.

It does not include anything about medical care.

Sharing your documents

You should pick a safe place to keep your document. Tell your family, friends, support people, and doctors where to find it.

You can save it in your My Health Record. This is a record on a government internet site where your medical information is kept.

You can also give a copy of your documents to people you trust:

- family
- friends
- carers and support people
- doctors
- lawyer.

Resources-Quick Guide

Male doctor talks to a male patient in bed while his wife looks on

WHAT IS AN **ADVANCE HEALTH DIRECTIVE?**

Quick Guide

An Advance Health Directive (AHD) is a legal and binding document. Doctors must follow the choices you have made in this document.

It is a legal record of your decisions about the medical treatments you do or do not want to receive if you become unwell or injured in the future and are unable to make or communicate decisions yourself.

An AHD is only used if you are unable to make or communicate your decisions at a time when you require treatment. It can only be made by a person older than 18 years old who is able to make and communicate their own decisions at the time of making the document.

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The AHD has six parts:

- one is for your personal details (for example, name, address, date of birth)
- part two is about your past or current health (for example heart disease, diabetes)
- part three is about your values and choices about your care (for example, where you want to be cared for, who you want to care for you)
- part four is about your treatment decisions for the future (for example, Cardiopulmonary resuscitation (CPR), antibiotics, receiving blood)
- part five is about people who helped you complete the form (for example, brother, friend)
- and part six is about your signature and witnessing requirements.

It is always best to get advice from your doctor when completing an AHD.

Once you have completed an AHD, you should share this document with your doctor. You may also choose to share your AHD with close family or friends if you want to. This will help them know what you would want for your future care.

You can also save your document in your My Health Record. This is a record on a government internet site where information about your medical care is kept, and it means that doctors can get quick access to the document when needed.

A grandmother, mother and teenage daughter holding hands sit together on sofa

Where can you get help?

You can get support with your AHD by speaking to your GP or a member of your medical team.

You can also contact:

WA Department of Health ACP Information Line
☎ **9222 2300**
✉ **ACP@health.wa.gov.au**

Healthy WA
🌐 **www.healthywa.wa.gov.au**

Palliative Care WA
☎ **1300 551 704**
✉ **info@palliativecarewa.asn.au**

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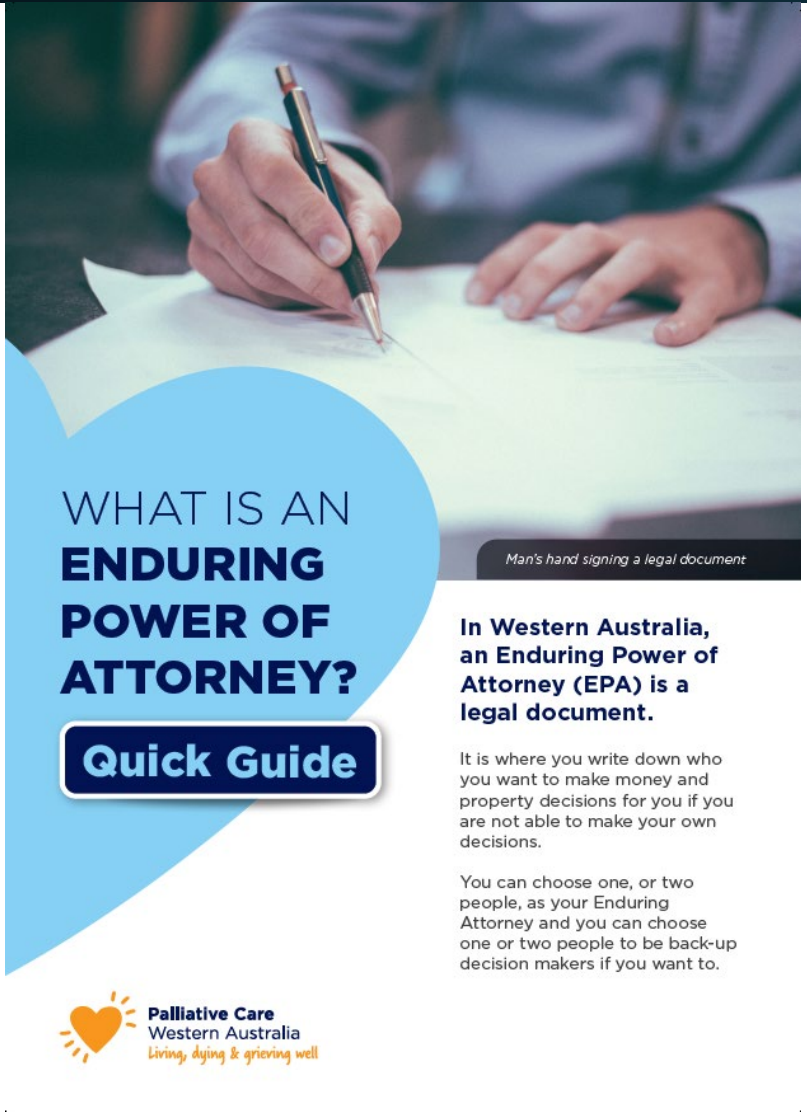
Resources-Quick Guide



WHAT IS AN

ENDURING POWER OF ATTORNEY?

Quick Guide

Man's hand signing a legal document

In Western Australia, an Enduring Power of Attorney (EPA) is a legal document.

It is where you write down who you want to make money and property decisions for you if you are not able to make your own decisions.

You can choose one, or two people, as your Enduring Attorney and you can choose one or two people to be back-up decision makers if you want to.

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Smiling older couple with their adult daughter

You should choose people you trust and who will make the best decisions for you and follow your instructions. This may be a family member, a friend or other person.

It is important to know that you do not need to choose a family member if you do not want to.

An EPA is only for decisions about money and property. It does not include decisions about medical treatment and care.

You get to choose when an EPA can start. It can start at two different times.

1. as soon as the document is signed, or
2. only after a person can no longer make their own decisions and the State Administrative Tribunal confirms this in writing.

The EPA ends when the person who has made it dies.

If you own a home or land, it is good to have two copies of your EPA made so you can give one to the Landgate office and keep one yourself.

Where can you get help?

You can get help with an Enduring Power of Attorney by contacting:

Palliative Care WA

☎ **1300 551 704**
✉ **info@palliativecarewa.asn.au**

You can also speak to a lawyer.

You can access EPA kits from

🌐 **www.publicadvocate.wa.gov.au**
☎ **1300 858 455**
✉ **opa@justice.wa.gov.au**

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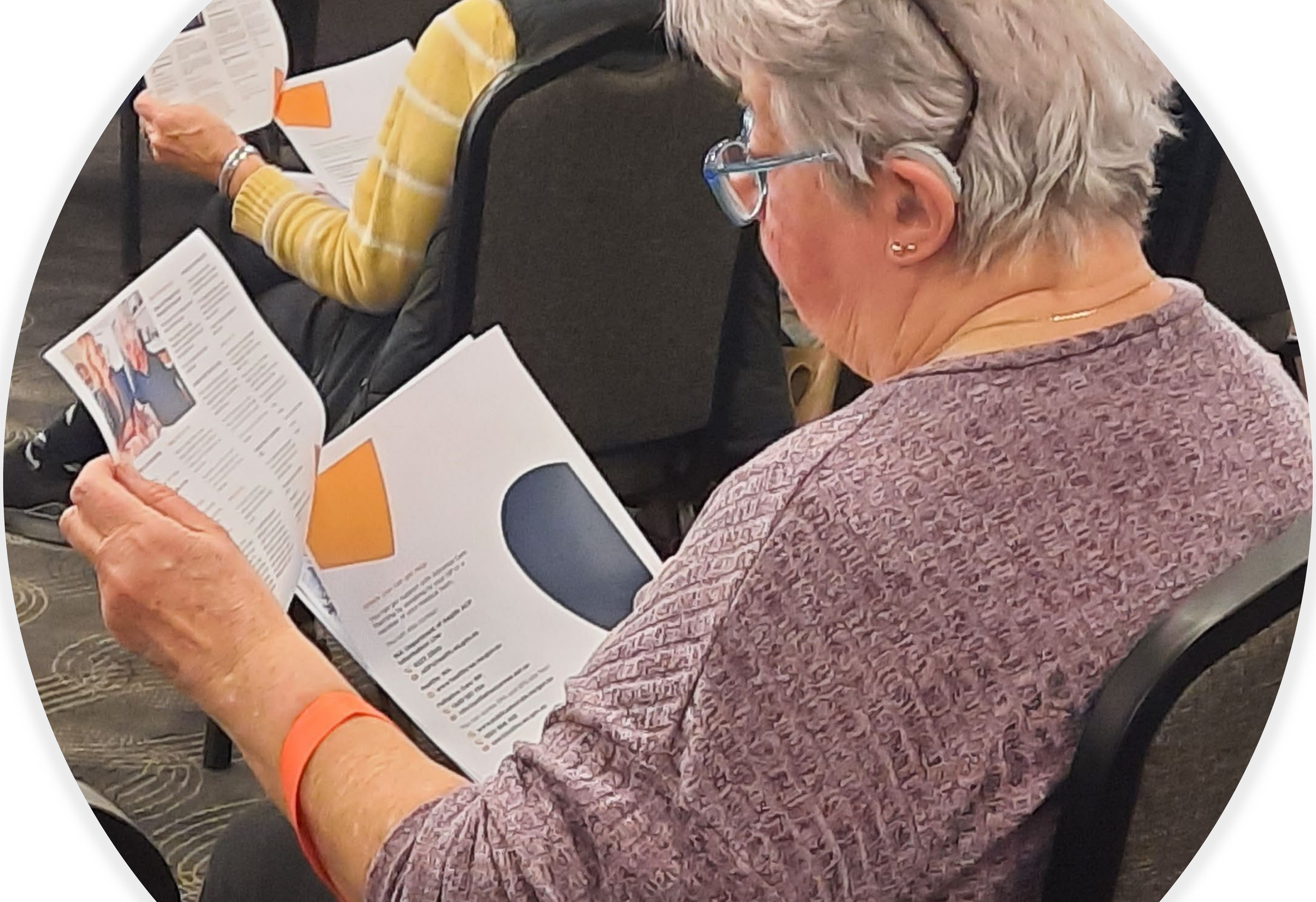
Resources-Auslan videos



Enhanced Collaboration

Further to the outcomes listed above, the Sensory Loss Project has also led to increased engagement and relationship building with key stakeholders in the d/Deaf and deafblind sector in WA, including Deafblind WA and the Auslan interpreter industry.

Palliative Care WA (PCWA) Webpage

Links to all the project resources, including videos and quick guides, plus a link to the full desktop review and final report can be found at:

https://palliativecarewa.asn.au/working-with-the-sector/sensory-loss-project/