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PCWA/WAPHA SENSORY LOSS PROJECT

Final project report

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Introduction

The Sensory Loss Project is a partnership project between Palliative Care WA and WA Primary Health Alliance. It explores the health literacy for Advance Care Planning (ACP) and palliative care of people with sensory loss in WA, and aims to build additional resources and capacity and capability of the Auslan sector to support informed decision making for future care planning and palliative care awareness.

To guide the project, a Sensory Loss Project Steering Committee was formed and included:

- Lenka Psar McCabe – Palliative Care WA
- Julia Kennington – Palliative Care WA
- Tish Morrison – WAPHA
- Emily White – WAPHA
- Karen Wickham-Grey – Deafblind WA
- Hannah McPierzie – Senses WA and lived experience
- Linda de Rozario – Vital Interpreting
- Dr Sophie Fletcher – Silverchain group
- Nicole Deprazer – WA Department of Health
- Professor Davina Porock – Edith Cowan University
- Marie Ware – lived experience

A Working Group comprising Julia Kennington, Hannah McPierzie and Dr Sophie Fletcher was also established. Deaf Consultant Nishma D'Agostino was also engaged to consult on language and cultural appropriateness of developed resources.

Four focus groups were held with key stakeholders. They were:

1. Auslan interpreter industry on 20 September 2024
2. Auslan users including Deaf and Deafblind participants on 9 October 2024
3. Non-Auslan users including participants with acquired hearing loss due to ageing on 1 Nov 2024.
4. Auslan and non-Auslan users including D/deaf and D/deafblind participants to review project resources on 16 July 2025.

The findings and recommendations of these focus groups are listed under separate outcomes below.

Project outcomes

OUTCOME 1

Sensory Loss Desktop Review

The Sensory Loss Desktop Review was developed through a collaboration between Palliative Care WA and WA Primary Health Alliance, with funding support from WA Primary Health Alliance through the Australian Government's PHN Program.

The desktop review identified in the academic research literature and available information and resources for individuals with hearing loss, the challenges faced as they interact with care planning and palliative care services and suggested strategies for improving access to and delivery of services.

This document reported the results of a desktop review of currently available information resources on advance care planning and palliative care services in Western Australia. The resources were reviewed for suitability for individuals who are D/deaf, D/deafblind or Hard of Hearing.

The review explored the current health literacy and access to ACP, palliative care, death and dying, grief and loss, and bereavement resources for individuals with sensory loss, specifically, individuals who are D/deaf, D/deafblind or profoundly hard of hearing (HoH) that relate to outcomes in Western Australia. The research extended beyond Western Australia and included a review of resources in other states of Australia and other countries. In this report, there is sufficient analysis and synthesis, we believe, to efficiently inform policy and practice in Western Australia.

The summary of opportunities identified in the report are:

1. Ensure that any resources created for use by the D/deaf and D/deafblind communities are done so with input and advocacy on behalf of said communities, including Deaf and Deafblind consultants who can speak to the cultural appropriateness and applicability of these resources.
2. Develop, or repurpose an existing informational material assessment tool, tailored to the unique communication needs of the D/deaf, and D/deafblind communities, as a way of allowing relevant organisations to quickly and accurately measure whether ACP and palliative care resources are appropriate and accessible for individuals with sensory loss.
3. Reduce reliance on lengthy, written English guides and phone-based helplines as primary forms of information provision. Instead, provide easily accessible and appropriate alternatives for D/deaf and D/deafblind individuals, namely, Western Australian Auslan translated videos and easy-read versions for all guides and informational materials.
4. Increase awareness and availability of training programs for health care providers on specific needs or and communication with individuals with sensory loss. Likewise increase the training programs for Auslan translators to become familiar and comfortable with the content of interactions relating to advance care planning, palliative care, death and dying, and end-of-life care.
5. Increase awareness and familiarity by including advance care planning and palliative care content on websites designed specifically for the D/deaf and D/deafblind communities. Encourage conversations on death and dying, palliative care, advance care planning at community meetings for example running a Death Café at the DBWA Drop-In Centre.
6. Adapt and develop Palliative Care WA Advance care planning workshops specifically for Auslan interpreters, the Hard of Hearing, and the D/deaf or D/deafblind communities.
7. Provide Auslan translations for all WA Department of Health informational videos including the guides to completing the Advance Health Directive document.
8. Research and development are needed to
 - a. Understand the needs of individuals with sensory loss in relation to advance care planning, palliative and end-of-life care
 - b. Develop best-practice methods for communicating multiple modalities of information with D/deafblind individuals
 - c. Create a death literacy tool for the D/deaf and D/deafblind communities' deviating the pre-existing WA model of 'death literacy' which has the potential to be seen as ableist;

skewing negatively against D/deaf and D/deafblind individuals who may be incapable of performing tasks but may be no less 'death literate' because of this.

Thank you to Philip Bafile, PCWA, for authoring the desktop review and to Professor Davina Porock, Dr Pelden Chejor, and Gordon Hobday from Edith Cowan University for assistance with the review of academic literature and editing the report for the Sensory Loss Project.

The full report will be available on the PCWA website.

OUTCOME 2

Focus Group 1: Auslan Interpreter Industry

Focus Group 1 was conducted on 20 September 2024 with participants from the Auslan interpreter workforce to identify gaps, appropriate interpretation and the needs of the interpreting workforce to effectively interpret information regarding ACP and palliative care.

This group was asked to complete the standard Death Literacy Index (DLI) tool which demonstrated that 80 per cent of the focus group had limited understanding regarding dying at home, ACP, navigating the health care system for a dying person, navigating funeral services, palliative care, accessing palliative support or caring for someone at end of life.

Recommendations

- An Auslan-based ACP visual resource for Auslan users be developed in consultation with the Deaf and Deafblind community. This resource should be developed using Deaf Interpreters to provide best Auslan interpretation for the community. This resource would then be used by the Auslan interpreting industry as a learning tool for background preparation prior to an interpretation within an ACP context. It was recommended that videos be developed on palliative care and ACP concepts.
- It was recommended that professional development session/s be developed 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, current Deaf Support Officers and communication guides. This was seen as an opportunity for collaboration and understanding of best practice within the industry regarding Auslan interpretation within a palliative care and ACP context. [Participants in the focus group advised that a set glossary of terms from English into Auslan cannot be developed as the interpretation is expressed in concepts that may be expressed in many ways. The interpretation is somewhat dependant on the interpreter's understanding of what is to be interpreted and the breakdown of the concepts and meaning].
- Education and support opportunities for current Deaf Support Officers, who are supporting community members with health and government interactions to develop knowledge, understanding and confidence in supporting community members to complete their ACP documentation should be explored.
- A story board resource depicting ACP progression should be developed to assist with understanding.
- Further support needed for interpreters to understand the nature of the booking to support the interpreter's choice if they don't feel they can cope with the nature of the topic to be discussed or feel ill-equipped to manage the booking relating to palliative care or ACP.
- Presentations or information sharing to be in-person and face-to-face. They should include simple slide presentations, white on dark background, paced delivery with simplified information and the opportunity for individuals to ask questions and create conversation at their own pace of understanding.

Based on these recommendations a professional development session was held on 15 March 2025 with WA members of the Auslan Interpreter Industry and current Auslan interpreter students invited to attend. The professional development session focused on advance care planning, palliative care and end of life choices.

The DLI was not repeated with Focus Group 1 following the professional development session as the initial focus group participants were not available to attend the professional development session. A series of evaluative questions were asked following the professional development session, where all participants stated the session was useful to them and they would recommend a professional development session or refresher training session be held for the interpreter industry on a yearly basis. A total of 83 per cent, or 10 out of 12, participants said that their confidence in interpreting for a client for ACP or palliative care conversations had increased through the session.

OUTCOME 3

Focus Group 2: Auslan users including Deaf and Deafblind participants

Focus Group 2 was held on 9 October 2024 with participants who are Auslan users, including members of the Deaf and Deafblind communities. This group was complex in nature due to the diversity of participants sensory loss, communication needs, negative lived experiences regarding palliative care and the use of interpreters.

Participants provided feedback on current WA Advance Care Planning resources and provided strategies and recommendations on how to better present information for their community. A review of the current DLI Tool was conducted by the Steering Committee members and found not to be fit for purpose for the Deaf and Deafblind community due to difficulty with translation to Auslan and reduced English literacy and comprehension levels.

Recommendations

Written resources

- Review current WA Health and Office of the Public Advocate resources, including Guide to Advance Care Planning in Western Australia, A Guide to Making an Advance Health Directive in Western Australia, Enduring Power of Guardianship, Enduring Power of Attorney EPA with a view to providing an easy-read version with simple step-by-step instructions, simplified language and minimal blocks of text. Information should be broken down into smaller portions.
- Feedback to WA Health regarding the format of the AHD document with questions on the side causing some confusion.

Video resources

- Create a series of Auslan-specific videos with the interpreter large in the screen and not just in the corner. Interpreter to have black clothing with a black background.
- Minimise English content as much as possible.
- Provide information on the video in dot points with main information and then have an interpreter explain the dot point further.
- Short summaries following each section.
- Slow the pace of the video to include gaps for processing and absorption of information.
- Recognition that people reading sign can't watch an interpreter and follow an image at the same time. Slow pace and focus moving from when the interpreter is signing to when a demonstration is happening in the image.
- Include translated captions from the Auslan interpretation imbedded into the video not relying on auto translation from English. Captions should be in large font and dialogue should not

overlap image movement so that people can focus on one section at a time. Two lines of captions at a time.

- Use of colour contrast in the images, particularly when there is movement in the image.
- Consider using actors to role play completing the form.

General comment recommendations

- Access to a content expert to provide one-to-one support to those who are not able to follow a video or the paperwork.
- Any information provided to community should be in small portions to allow the community to absorb and process information.
- Increase accessibility features on the Healthy WA website and fillable forms, for example, ability to increase font size in the document, change contrast, information in bullet points.
- Review current guidelines for health professionals regarding the interface between the health professional, people with sensory loss and their carers.

Issues identified for further consideration

- Codependent issues associated with access to support workers and interpreters. The time limitations and costs involved limiting use of current supports and communication aids required for daily living tasks. This limits the funding and support required to support understanding of written information on ACP and completion of documentation. Questions remain regarding how people with sensory loss are enabled to access information to support choice/end of life planning? What can NDIS participants access to provide supports for end-of-life planning.
- The options available for Braille accessible resources if needed.
- Examples of quality Auslan videos and user-friendly websites were provided for consideration. NDIS website accessibility functions and the you tube video *2021 Auslan – How do I complete the Census?*
- Exploration of the role of Artificial Intelligence in Auslan – developing technology and how it will impact Auslan communication.
- Review of PCWA current resources and services and how they support those with sensory loss, disability and complex needs.
- Questions were raised regarding Voluntary Assisted Dying (VAD) and demonstrated the need for community education of VAD.

OUTCOME 4

Focus Group 3: Non-Auslan users, including participants with acquired hearing loss due to ageing

Focus Group 3 was held on 16 November 2024 with participants who are non-Auslan users, including participants with acquired hearing loss due to ageing. Participants provided feedback on current WA Advance Care Planning resources.

Most participants described there being too much information which they said was somewhat overwhelming. They said they would prefer less information, in particular summaries of the information in concise language.

Recommendations

- That concise information be made available in doctor's surgeries, libraries, 55+ centres, and the Office of Senior's Interests.
- Workshops to guide people on how to fill out the forms with private areas available for people to complete the forms away from other people was a good idea.
- They thought ACP documentation should be done through routine health assessments with GPs.

- There was distrust of the internet and internet searching due to a fear of misinformation and concern about some acronyms being hard to understand, such as CPR.
- Presentations and workshops should be more accessible, for example, by considering the following:
 - for PowerPoint presentations, presenter should read through the information and speak to the audience
 - use of a microphone to enable speech to be heard clearly
 - include subtitles
 - recognise that accents can be tricky and that hearing aids can be difficult
 - try to avoid information overload
 - ensure that training videos are approved by Government.
- Presentations/workshops should be run in Seniors Week and Have a Go Week organised by Have a Go newspapers.
- Other ways to disseminate information should be via Caresearch website, My Aged Care, word of mouth and conversation with GPs to trigger services.

OUTCOME 5

Focus Group 4: Auslan and non-Auslan users including Deaf and Deafblind participants to review project resources

Focus Group 4 was held on 16 July 2025 with Auslan and non-Auslan users, including Deaf and Deafblind participants. Those attending the group focussed specifically on reviewing project resources (see detail about the resources in separate outcomes below).

Their comments were gratefully received. Following advice from Steering Committee and Working Group members with expertise in specific areas, several of the suggestions were applied, including:

- adding descriptions to the images in the quick guides
- refilming sections of the What is ACP? video to better explain the ACP process and its voluntary nature
- Reducing the run speed of the What is ACP? video
- relaying suggested changes to the WA Department of Health for the *Easy Read – ACP WA Health Department document*.

OUTCOME 6

Videos

Originally, the project considered adapting Auslan videos currently in use that were produced by Deaf Connect. However, these videos were reviewed and considered not suitable for use in WA due to differences in legislation and Auslan language dialect.

The project Steering Committee acknowledged the learnings from reviewing the Palliative Care Victoria videos and decided to create five WA videos that use the same topics in the Quick guides (see Outcome 7). As mentioned in Outcome 5, the WA videos were reviewed by a focus group and their feedback considered.

The videos comprise:

- What is Advance Care Planning?
- What is an Enduring Power of Attorney?

- What is an Enduring Power of Guardianship?
- What is Palliative Care?
- What is an Advance Health Directive?

Links to the videos will be included on PCWA's website: <https://palliativecarewa.asn.au/working-with-the-sector/sensory-loss-project/>

OUTCOME 7

Quick guides

A series of five quick guides have been developed to accompany the Auslan videos. The content includes simplified and accessible information explaining the key components of ACP.

The project Steering Committee acknowledged the learnings from written guides and documents produced by Palliative Care Victoria and the WA Department of Health to create five quick guides that use the same titles as the videos (see Outcome 6). As mentioned in Outcome 5, the quick guides were reviewed by a focus group and their feedback considered.

The quick guides comprise:

- What is Advance Care Planning?
- What is an Enduring Power of Attorney?
- What is an Enduring Power of Guardianship?
- What is Palliative Care?
- What is an Advance Health Directive?

Links to the quick guides will be included on PCWA's website: <https://palliativecarewa.asn.au/working-with-the-sector/sensory-loss-project/>

OUTCOME 8

Enhanced stakeholder engagement

Further to the outcomes listed above, the Sensory Loss Project has also led to increased engagement and relationship building with key stakeholders in the Deaf and Deafblind sector in WA, including Deafblind WA and the Auslan interpreter industry. As a result, PCWA has delivered two information sessions on ACP and palliative care to Deafblind WA members. Deafblind WA has agreed to continue to offer these information sessions annually during National ACP Week and National Palliative Care Week and will include information on ACP and palliative care on their website.

Existing relationships with WAPHA and the WA Department of Health have also been enhanced through the project.

In addition, information gleaned from the focus groups will lead to better outcomes for community members. Some issues raised in the groups have been actioned, including:

- Liaison with WA Department of Health regarding potential changes in communication processes for people with sensory loss and interpreters
- Contact with WA Department of Health to raise the issue of interpreters having difficulty with lack of information sharing to prepare for the interpreting service. This issue is currently being investigated through the Cultural Diversity Unit at WA Department of Health.

- Issue identified with some documents created as 'My Hospital or My Health Passport' not providing an option to document sensory loss or communication needs. This has been raised with WA Department of Health Cultural Diversity Unit.

OUTCOME 9

Presentation at the international Advance Care Planning Conference 2025 in Brisbane in September 2025

Dr Sophie Fletcher, who was a member of the project steering committee, presented 'Equitable access to Advance Care Planning for people living with sensory loss in Western Australia' at the Advance Care Planning Conference 2025 in Brisbane in September 2025.

Dr Fletcher outlined the project's and explained that most people with sensory loss experience difficulties communicating with health professionals, resulting in exclusion from information required for decision-making around care. People who are deaf, deafblind or hard of hearing (HoH), and those identifying with the Deaf and Deafblind communities, have their own unique and individual needs which require consideration when developing accessible resources. This extends to access to information on ACP.

Dr Fletcher discussed how the project brought together key stakeholders to assess accessibility of current ACP information and documentation and plan for what is needed, held three focus groups: those with lived experience of deafness or deafblindness; those who are HoH; and Auslan interpreters.

She outlined participants' preference for text-based resources in plain English, using easy-read styles and videos using a full screen view of the Auslan interpreter and contrasting colours to ensure interpreters' hands can be seen clearly is essential, and with captions in two-line format.

Additionally, the presentation discussed:

- Auslan interpreters require knowledge and understanding of ACP concepts to assist with effective interpretation and communication. Increased awareness of the specific needs of this cohort and resources available can support health professionals to better prepare for interactions with D/deaf, D/deafblind and HoH patients.
- This work provides unique insights from people with lived experience of sensory loss who generously shared their concerns and previous experiences as well as their wishes, values and preferences for effective communication and accessible provision of information for ACP.
- Specific, tailored resources for the D/deaf and D/deafblind community and those who are HoH developed from this work to improve access to information and support completing ACP will be showcased in the presentation. Essential collaborations with organisations supporting people living with sensory loss have been formed with a plan to strengthen these relationships with annual events. Dissemination of resources to health professionals has been commenced and provision of education for the Auslan interpreter industry in WA has been undertaken.

OUTCOME 10

Dedicated webpage on PCWA website

All reports and resources created as part of this project are available through a dedicated webpage on the PCWA website. Please visit <https://palliativecarewa.asn.au/working-with-the-sector/sensory-loss-project/> for links to all the project resources, including videos and quick guides, plus a link to the full desktop review and final report. Links to other useful websites are also included.

ACCOMPANYING DOCUMENTS

Sensory Loss Project Desktop Review – see <https://palliativecarewa.asn.au/working-with-the-sector/sensory-loss-project/>

Presentation at the international Advance Care Planning Conference 2025 in Brisbane in September 2025 – see <https://palliativecarewa.asn.au/working-with-the-sector/sensory-loss-project/> (Available following presentation at the conference)