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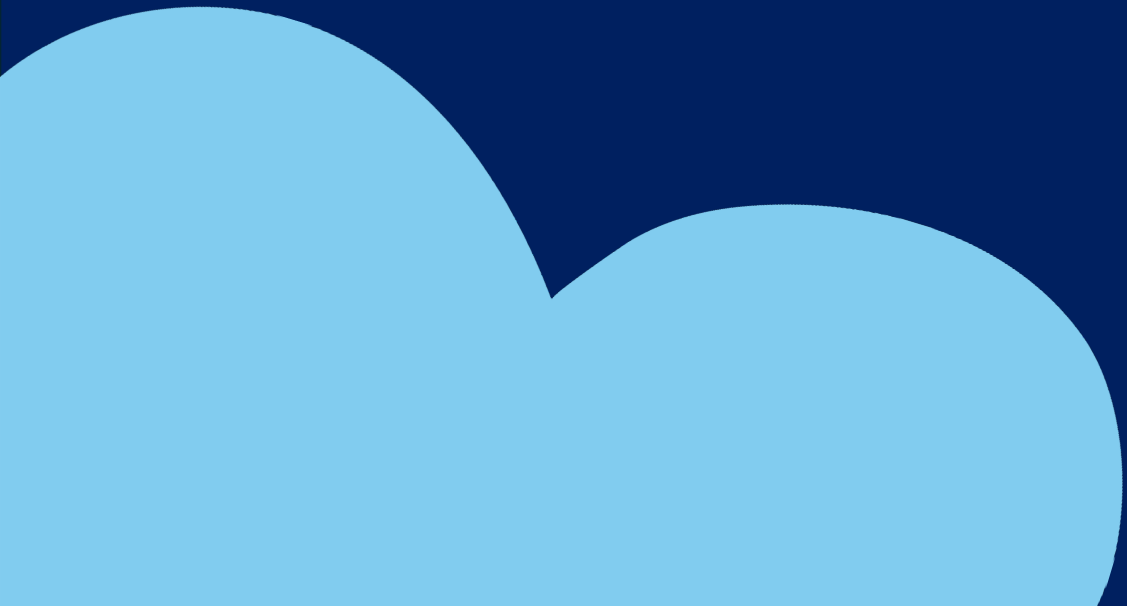
DESKTOP REVIEW

Access to Advance Care Planning and Palliative Care Resources for Individuals with Hearing-related Sensory Loss



Contents

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1 Summary of opportunities

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 Deaf and 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.

2 Purpose and scope

2.1 Purposes of this document

This document is part of a wider project to improve the access of individuals with hearing-related sensory loss to services which support advanced care planning (ACP) and palliative care in Western Australia.

This document will identify in the academic research literature, for individuals with hearing loss:

- challenges faced as they interact with care planning and palliative care services
- suggested strategies for improving access to and delivery of services.

This document reports the results of a desktop review of currently available information resources on 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.

2.2 Scope and limitations of this document

This review has been undertaken as a result of a project headed by Palliative Care WA (PCWA) that is supported by funding from the WA Primary Health Alliance (WAPHA). The focus of this report is to explore 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.

It is not in the scope of this report to explore cultural, health system or economic differences which, undoubtedly, will be factors affecting the detail of research findings in, for example, the literature review. Readers are encouraged to go to the list of references for details.

For clarity it is important to note that deafness, deafblindness and hearing loss occur across a spectrum, where the causes, severity and impacts to lifestyle and daily living because of hearing loss or impairment will affect each person differently (Hodge, 2024). As such, no single definition will resonate with every individual who has some form of hearing loss, deafness, or deafblindness.

Deafness and Deafblindness cultural groups carry many of the hallmarks of other cultural or linguistic groups, including colloquialisms, dialects, grammaticalisation, and cultural traditions (Johnston et al., 2015). As a broad survey, this report does not attempt to address the specific nuances of these communities in Western Australia relative to populations in the academic literature or in other states of Australia. In terms of the review of current resources, we acknowledge there may be knowledge and educational resources in the Deafness and Deafblindness communities which, as hearing individuals, we have overlooked.

2.3 Terminology

Throughout this report, there will be occasional reference to deafness and deafblindness as a disability, condition, or impairment that influences an individual's daily living to varying degrees. In some cases, this is unavoidable for the purposes of categorisation, and found in the legislation, policy, health and statistics. This is simply how deafness has been — and continues to be — defined (Australian Government Department of Health and Aged Care, 2014; World Health Organization, 2021).

Appendix – The glossary provides a list of common terms, abbreviations and simplified definitions. However, for this report, more detailed explanations of deafness and ACP are helpful and follow.

2.3.1 What is deafness

The World Health Organization (WHO) defines hearing loss as a form of sensory loss/impairment which leaves an individual unable to hear as well as a person deemed to have 'normal hearing', where normal hearing is categorised by hearing thresholds of 20 decibels (dB) or better in both ears (World Health Organization, 2021). This definition can be further categorised into what is known as 'hard of hearing' (HoH), which generally ranges between mild to severe hearing loss and affects one or both ears, and deafness, which is often taken to mean profound hearing loss that allows for little to no hearing. The WHO also further expands into what it defines as 'disabling hearing loss', classified as hearing loss greater than 35 dB in the better hearing ear (World Health Organization, 2021). This loss of hearing can be present congenitally, or develop in the early postnatal, pre-lingual phase of childhood. Hearing loss develops across the ageing process, often as a result of damage to the eardrum over time or other diseases that affect the sensory organs of the ear (Lin & Albert, 2014).

In the field of sensory impairment research, the condition of deafblindness is generally defined as an individual having a sensory impairment to both hearing and sight. Specifically, a person is considered to have deafblindness when their hearing loss is greater than 35 dB in their better-hearing ear, and their reduction in vision is equivalent to 20/60 acuity or less (Fellinger et al., 2009). As with deafness, deafblindness also exists across a spectrum, with differential classification, and differences in the needs of the individual and their unique challenges. Typically, there are three classifications of deafblindness: those with congenital or early postnatal hearing and vision impairments (typically in the pre-lingual phase); those with congenital sensory impairment to either vision or hearing, who then acquire sensory impairment to the other sensory input in later adulthood; and individuals who develop sensory impairment to both hearing and vision in post-lingual adulthood (Dyke, 2013).

Note: It is a personal choice by an individual as to whether they associate as part of the culturally Deaf or Deafblind communities.

2.3.2 What is Advance Care Planning

Advance Care Planning (ACP) is best described as the process of an individual contemplating their preferences about their health care, medical treatment options and financial decision making, and then ideally expressing those preferences in a document. This responds to the risk they may one day lose their legal, decision-making capacity or ability to meaningfully communicate future decisions about their healthcare or medical treatments (Blake et al., 2018). These decisions can range from choices about the type of treatments a person will or won’t tolerate, including the acceptance or refusal of life-sustaining measures (e.g. cardiopulmonary resuscitation, assisted ventilation, etc.), to preferences about where a person would like to live or be cared for as they approach their end of life. In Western Australia specifically, the WA Department of Health (2022) website describes ACP as:

> ‘… a voluntary process of planning for future health and personal care where your values, beliefs, and preferences are made known to guide decision-making at a future time when you cannot make or communicate your decisions’.

ACP is grounded in respect for a person’s individual views and preferences in relation to their health and medical treatment options (Blake et al., 2018).

3 Population perspective

Hearing loss affects an estimated 1.5 billion individuals globally, potentially growing to 2.5 billion by 2050 (World Health Organization, 2021). Furthermore, at the global level, unaddressed hearing loss has been shown as the third largest cause of years lived with disability.

3.1 Australian Census data

In Australia, based on self-reported data from the Australian Bureau of Statistics in 2015, more than 3 million Australians (14% of the then national population) had at least one long-term hearing disorder, with approximately 230,000 of these individuals being West Australians (Australian Bureau of Statistics, 2016). A more recent estimate also puts the total number of Australians living with a hearing impairment closer to 3.6 million (Australian Government of Department of Health and Aged Care, 2024). For Australian Aboriginal and Torres Strait Islander populations these proportions are markedly and worryingly higher than the national average. In 2018-19, there were 290,400 Indigenous Australians aged 7 and over with some form of measured hearing loss in one or both ears (43% of the then national Indigenous population), and this proportion was higher in remote areas (59%) than non-remote areas (39%) (Australian Bureau of Statistics, 2019).

Almost half of the population who identify as having some form of long-term hearing disorder are categorised in the ‘over 75’ age bracket (Australian Bureau of Statistics, 2021). The number of individuals with long-term hearing disorders is expected to double to an estimated 7.8 million individuals by 2060 (Australian Government Department of Health and Aged Care, 2024).

More than 16,000 individuals across Australia use Auslan in the home, with Western Australian Auslan users making up 1,767 of this total number (Australian Bureau of Statistics, 2021). This data shows a significant increase of approximately 60% in recorded Auslan users Australia-wide as compared with the previous 2015 Census data. This increase is in keeping with the steady rise in the number of recorded Auslan users following each Census since it was first measured as a statistic in 2001 (n=5,306). The most recent increase could also be attributed to lobbying efforts from Deaf Australia, which saw ‘Auslan’ included as an example language prompt. That is, when asking if a person uses a language other than English at home — the example prompt under ‘other language’ now reads: *‘If other, for example, Auslan, please write here’* (Deaf Connect, 2022).

3.2 Hearing loss and general health

There are numerous examples in prior literature that speak to potential negative health outcomes that are associated with deafness and deafblindness. At a broad, overall level, several studies explore links between hearing impairment and increases in risk of morbidity; some being mediated through more specific factors such as cardiovascular or walking disability mortality rates, while others focus on all-cause mortality. What this research shows is that even after adjusting for numerous, potentially exacerbating factors such as demographic characteristics and the presence of co-morbidities, a statistical association can be observed between the presence of hearing impairment and increased mortality rates (Genther et al., 2015; Karpa et al., 2010; Lin et al., 2019). This is further exacerbated when looking specifically at D/deafblind population samples, where further increased mortality rates are found as compared to single sensory impaired individuals (Schneider et al., 2011).

Additional research has investigated how communication challenges and limited access to appropriate and timely health resources can be directly linked to negative health outcomes for D/deaf and D/deafblind individuals. One study conducted in France found that Deaf individuals were more likely to have a cancer diagnosed at an advanced stage, and in almost all situations diagnosis occurred at a stage later than that of the general population sample (Druel et al., 2018). Druel et al (2018) attributed this outcome to a potential combination of factors, including challenges in communication and the reduced medical knowledge of Deaf individuals.

These challenges were also seen to lead to confusing and sometimes distressing situations in which a decontextualised diagnosis or the diagnostic process itself (such as invasive screening methods) may be misunderstood by a Deaf individual. This is largely in keeping with findings that show imbalances to health care access, economic resources, communication standards and health education are all contributing factors to avoidance of and dissatisfaction with healthcare outcomes amongst D/deaf communities, which then translates to avoidance of healthcare settings, the potential for untreated or undiagnosed conditions, reduced quality of life, and higher mortality rates (Payami, 2021). Naturally, this is of particular importance when we are dealing with discussions of palliative care and ACP, as untreated or late-diagnosed health conditions can potentially leave individuals in a position where their illness progresses before they have a chance to make their treatment and healthcare preferences known.

For D/deafblind populations, with data from 36 countries, a report (World Federation of the Deafblind, 2023) found children aged 2 to 4 years with deafblindness were:

- 20% more likely to have acute respiratory infection
- 48% more likely to have diarrhoea
- 22% more likely to experience wasting
- 24% more likely to have stunted growth compared to children without disabilities
- while also being no more likely to have access to quality health insurance compared with non-deafblind cohorts.

There is also an ever-growing base of research into the potentially negative psychological health implications that exist for all D/deaf and D/deafblind individuals. Due to the isolating nature of sensory loss and impairments, links have been made to experiences such as loneliness, social isolation, and depression (Bott & Saunders, 2021; Patel et al., 2021). This theme of loneliness and social isolation is a common one that is often observed throughout much of the research into negative health and well-being implications specific to D/deaf and D/deafblind communities. These increased tendencies for depression amongst sensory impaired populations has also been shown to exist after controlling for additional factors such as age, gender, education, and more (Wallhagen et al., 1996).

In an editorial commenting on research that had been done exploring associations of hearing loss and dementia, Lin and Albert (2014) detail how decreased social engagement could influence the mechanistic pathways resulting in poorer cognitive functioning. They also explain how increased cognitive load produced by reduced hearing may produce potentially detrimental effects to cortical reorganisation and brain morphometry. If there is indeed a quantifiable link between deafness and hearing loss and increased likelihood of dementia, then this could have very significant effects on the areas of ACP in Western Australia, where dementia (and the rights of those with ‘limited decision-making capacity’) is still being debated, specifically as to what access a person with cognitive decline or impairment should have to anticipatory decision making processes such as ACP (Blake et al., 2018).

Research has also been conducted into how any potential increases in social isolation may also impact a D/deaf individual’s interaction with the healthcare system, as post-lingually deafened adults have been observed to be at a higher likelihood to seek medical treatment and access healthcare services in general as compared to this more culturally isolated cohort of pre-lingually (often congenitally) D/deaf individuals, potentially due to mistrust in the systems available or a lack of confidence in engaging with them (Barnett & Franks, 2002).

4 Literature review

Identified in the academic research literature for individuals with hearing loss were the:

- challenges faced as they interact with care planning and palliative care services
- suggested strategies for improving access to and delivery of services.

4.1 Method

A search strategy was developed with the help of a subject librarian for this review, following the Joanna Briggs Institute (JBI) methodology for systematic reviews (Aromataris & Munn, 2020). A combination of keywords such as “deaf”, “hard of hearing”, “hearing impair*”, “hearing loss*”, “hearing disorder*”, “deafblind”, “deafblindness`”, “advance care*”, “end of life*”, “advance health directive*”, “advance decision*”, “advance healthcare plan*”, “palliative care”, “end of life care”, “hospice care” and relevant MeSH terms were used to search the databases such as MEDLINE, CINAHL Ultimate, and PsycINFO. Following the search, all identified citations were screened by titles and abstracts and eligible full-text articles relevant for this review were included for data extraction and synthesis. We extracted data related to 12 study details (author, publication year), study aim, study design, study participants, and key findings and this is presented in Appendix – Systematic review.

Given the purpose and scope of this report, these 12 sharply focussed studies were supplemented with other research to situate their findings within the broader context of a health system and giving information to people with hearing loss.

4.2 Definitions, naming conventions of D/deafness and D/deafblindness

As discussed previously, both deafness and hearing loss occur across a spectrum. The table below summarises the different terminology based on WHO (World Health Organization, 2021) definitions unless otherwise noted.

Terminology	**Explanation**
‘normal hearing’	Hearing thresholds of 20 decibels (dB) or better in both ears
‘hard of hearing’ (HoH)	Ranges between mild to severe hearing loss and affects one or both ears, and deafness, which is often taken to mean profound hearing loss that allows for little to no hearing.
‘disabling hearing loss’	hearing loss greater than 35 dB in the better hearing ear.
‘deafblindness’	Sensory impairment to both hearing and sight. Specifically, when the person’s hearing loss is greater than 35 dB in their better-hearing ear, and their reduction in vision is equivalent to 20/60 acuity or lesser (Fellinger et al., 2009).

‘Deaf’	Individuals who are born with congenital deafness tend to identify as culturally Deaf (signified with a capital D). A congenitally deaf child born to hearing parents (which research indicates will be true for ~95% of deaf children) will often grow up unable to as effectively learn the language that their household speaks, leading to both cultural and practical feelings and experiences of isolation (Allen et al., 2002).
‘Auslan”	In Australia, the sign language that has been developed by the Deaf community is Auslan (Hodge, 2024).
‘Deafblind’ or deafBlind’	Cultural group , the use of one naming convention over the other is a deliberate choice to represent members of both the Deaf (Blind) and deaf (blind) communities who make the conscious, personal decision to label themselves either within or outside of these distinct populations – (McIlroy & Storbeck, 2011).

Note: Loss of hearing can be present congenitally, or develop in the early postnatal, pre-lingual phase of childhood. We also often see hearing loss develop across the ageing process, often as a result of damage to the eardrum over time or other diseases that affect the sensory organs of the ear (Lin & Albert, 2014).

4.3 Literature review findings: Challenges

Studies have focused on three cohorts of individuals:

- people living with hearing-related sensory loss
- their family members and caregivers
- health care providers.

The experiences of each of these cohorts is instructive because what is striking is the similarity. Likewise, many reported experiences related to health settings in general are instructive with respect to palliative and end-of-life care. All these experiences point to a set of issues shared across cohorts and health settings and therefore suggest common strategies.

In summary, in the relationship between health service providers, families and people with hearing loss, each cohort suffers and is frustrated by the poor communication.

4.3.1 People living with hearing-related sensory loss

People living with hearing-related sensory loss or Deaf individuals reported barriers to end-of-life care, including challenges in communicating with healthcare providers and understanding medical information (Cerilli et al., 2023; Franchi, 2011). As a result, people living with hearing impairments felt isolated and frustrated from being misunderstood (Smith et al., 2016; Wallhagen et al., 2019).

Some individuals feel that healthcare practitioners do not adequately respect their intelligence, often mistaking sign language syntax and grammar for lack of knowledge or ‘stupidity’ (Iezzoni et al., 2004). Much of the research finds that D/deaf individuals would prefer that interactions in healthcare settings feature an interpreter, but there can be a wide variation in the knowledge base of interpreters around areas of health and palliative care, which can lead to miscommunication, unnecessary confusion, fatigue, and inconsistent outcomes (Franchi, 2011; Major et al., 2012).

4.3.2 Family members and/or caregivers

Family members take the responsibility of ensuring their loved ones' needs are met and preferences respected (Kehl & Gartner, 2010), including the advance care planning for their loved ones living with hearing impairments (Cerilli et al., 2023). Like the communication challenges faced by people living with hearing impairments, family members reported difficulties in communicating with healthcare providers and understanding medical information and care instructions (Maddalena et al., 2012). They also share the experiences of emotional burden from caring for their loved ones with hearing impairments, particularly during the end-of-life care (Franchi et al., 2011).

4.3.3 Healthcare providers

Healthcare providers reported that the communication failures at multiple points impacted the delivery of hospice and palliative care for people living with hearing impairments. For example: 1) not getting the needed information from the people living with hearing impairments; and 2) family members/caregivers and people living with hearing impairments misunderstanding care instructions. (Wallhagen et al., 2019).

Broadly, training for healthcare practitioners in working respectfully and successfully with D/deaf individuals is lacking (Ludlow et al., 2018; Smith et al., 2016). While there may be exceptions to this based on location or differing healthcare models. Any specific training in this regard appears to be left for an individual health practitioner or worker to seek out for themselves, and if present, it does not form much more than a cursory portion of formal training and education.

4.3.4 The shared frustration: health settings in general

In the relationship between service providers, families and people with hearing loss, each cohort suffers and is frustrated by poor communication.

Incorrect screening of hearing-related sensory loss led to inappropriate meeting conditions and at times this devolved into healthcare workers shouting into the hearing-impaired patient’s ear to communicate (Smith et al., 2015). Indeed, this combination of poor screening methods for individuals who are HoH, coupled with a lack of specialised training to raise awareness and teach effective communication techniques for working with D/deaf individuals often leads to the use of non-recommended communication techniques being employed, such as speaking into a person’s ear, using written notes to communicate, or directing conversations to a family member or caregiver in lieu of speaking directly to the patient (Smith et al., 2016). Other studies show that some in the health profession seem to be unaware that Deaf and Deafblind individuals, particularly those who are pre-lingually deaf, do not engage with the English language in the same way as a hearing person, with sign language often being their primary language (Kehl & Gartner, 2010; Lee et al., 2021). Furthermore, even if a D/deaf individual's English literacy is at a level that allows them to have medical conversations via methods of written communication, this is often a slow and fatiguing process for all parties.

4.3.5 The shared frustration: palliative care

People living with hearing-related impairments reported limited knowledge about ACP, receiving information on advanced care from their families, peers and media (Cerilli et al., 2023). Barriers to accessing quality end-of-life care, including less frequent hospice care, and fewer discussions about care preferences were also reported (Carpenter et al., 2020).

Research into the experiences of the D/deaf community with ACP, while limited, have determined that additional barriers present for a D/deaf individual are likely to result in lower numbers of ACP document completion (Cerilli et al., 2023). These can include, but are not limited to, language and communication barriers, D/deaf and D/deafblind individuals having limited English proficiency, and a lack of trust in the medical model. Further research into how the challenges present for individuals with sensory loss affects their willingness and ability to participate in the process of ACP is likely needed to understand how best to improve these processes.

There is similarly limited research into the specific experiences and preferences of D/deaf and D/deafblind individuals regarding palliative care treatment preferences and end-of-life decisions. One British study found that HoH individuals were almost twice as likely as Deaf sign language users to have discussed their end-of-life wishes, and there was a wide difference in preference for where an individual would like to die, with 72% of sign language users stating a preference for dying at home, and 75% of HoH individuals preferring hospice as their preferred place to die (Jobling, 2016). It is worth noting the very limited sample size of this study (n=31), however, this does provide a rationale for further research into this area.

In palliative care settings, this can be particularly troublesome, as improper communication methods have been cited as leading to unnuanced, decontextualised, and potentially distressing summaries of a patient's condition, their treatment options, and prognosis (Smith et al., 2015). Another consideration specific to the context of end-of-life situations or palliative care settings can be that the development of general fatigue or disabling factors that may not impact a hearing individual's ability to communicate — such as limitations of the upper limbs or the development of arthritis in older adults — can be extremely debilitating to a Deaf individual's ability to communicate (Kehl & Gartner, 2010).

Franchi (2011) explored the experience of D/deaf and hard of hearing individuals in participating in end-of-life communication, and the effects their sensory loss had on the grieving and bereavement experience. A common theme that emerged amongst the participants was a feeling of exclusion, often feeling that a lack of effective communication methods or a lack of understanding by palliative and healthcare professionals as to the unique communication challenges facing D/deaf individuals, led to them being excluded from the decision-making or grieving processes. Many participants also explained that in the absence of interpreters or health workers who could adequately communicate with a D/deaf person, conversations would often take place around a dying individual's bed that a D/deaf person was completely excluded from, and it would be left for the family to recount to them what was said after the fact. This is particularly troublesome as it can lead to exacerbation of a sense of cultural exclusion present from birth for much of the congenitally Deaf community, who must often face feelings of being separated by language even within their family groups (Allen et al., 2002).

One qualitative analysis detailing how a Deaf individual was without an interpreter as a loved one was entering palliative care. Not being familiar with the phrase ‘palliative care’, the individual was unsure what was happening, where their loved one was being taken, and for what purpose (Maddalena et al., 2012). Lack of available interpreters during these stressful and confusing times is a serious, and all too common problem amongst D/deaf and D/deafblind research participants (Cerilli et al., 2023; Jobling, 2016). Furthermore, if support is ever available in this area (i.e. specialised bereavement support for D/deaf individuals), often other concessions must be made. Furthermore, as Auslan is considered a language of limited diffusion — due to the relatively small population of Auslan users spread across a geographically large distance — and has no traditional written format, the spread and accessibility of healthcare information amongst Auslan users is particularly challenging (Allen et al., 2002; Major et al., 2012).

While much of what is discussed above largely concerns the difficulties present in face-to-face communication settings, just as important are the issues that face D/deaf and D/deafblind communities around access to quality written or online information, be it web-based or in the form of educational videos, pamphlets, brochures, or other medical literature. This is something that varies on an individual level, although prior analysis has found that on average Deaf, and particularly Deafblind, individuals demonstrate lower levels of English literacy as compared with hearing populations, creating one obvious barrier to engagement with this medium (Maddalena et al., 2012; Napier & Kidd, 2013; Payami, 2021).

4.4 Literature review findings: Opportunities

Researchers find effective alleviation of communication challenges for D/deaf and D/deafblind populations consistently leads to improved health outcomes, which can be particularly crucial in palliative care settings, where a high priority is placed on the management of pain, stress, and additional symptoms (Blustein et al., 2018; Smith et al., 2016).

- More research in understanding and addressing the needs of individuals with hearing impairments (Carpenter et al., 2020; Shaw, 2015)
    - Including family members in research to better understand their perspectives and challenges in the care for people living with hearing impairments (Cerilli et al., 2023; Kehl & Gartner, 2010).
- Research into best-practice methods for communicating multiple modalities of information with D/deafblind populations. This seems an area of relative infancy (Roy et al., 2021), though some methods, as follows, are preferred.
    - Preferred methods can include: repetition of information, slowed speech, clear pronunciation which aids in the process of lip-reading, speaking directly to the individual with the sensory impairment and not an interpreter/caregiver who may also be present, providing information that is presented in a legibly written format or that is supplemented by printed resources, and the use of purposeful body language (Ludlow et al., 2018).

  - The use of hearing aids, audio-visual aids, and other assistive technologies improved communication and care for people living with hearing impairments (Coyle et al., 2002; Hughes et al., 2023).
  - D/deaf and D/deafblind study participants prefer text that is bulleted, carefully worded, succinct, and accompanied by pictures (Napier & Kidd, 2013).
  - However, for D/deafblind participants often even written aids are of limited, to no use, depending on the type and severity of their deafblindness.
  - Aids to native sign language users simply would not be of much use to a HoH individual who does not sign.
  - During a routine doctor's appointment, an individual who is HoH but *not* completely deaf can benefit greatly from various strategies that improve audibility, such as auditory aids, a reduction in background and environmental noise, and clear, concise, well projected communication from the health care professionals (Ludlow et al., 2018; Pryce & Gooberman-Hill, 2011).
- Policy changes to improve access to quality end-of-life care (Wallhagen et al., 2019).
  - Support families in caregiving roles (Maddalena et al., 2012).
- Increase training and awareness programs for healthcare providers on the specific needs of individuals living with hearing impairments (Smith et al., 2016).
  - Provide communication strategies to improve effective communication and/or interaction with people living with hearing impairments (Olson & McKeich, 2017; Ricky & Englih, 2016).
  - Understanding the emotional stress faced by people living with hearing impairments and their families and/or caregivers (Maddalena et al., 2012).

5 Desktop review of resources in Western Australia

This section details the findings of a desktop review of primary resources which provide information about ACP and palliative care available to D/deaf, D/deafblind, or profoundly HoH service users in Western Australia. Resources discussed are:

- websites
- paper-based resources
- videos
- support for interpreters
- community organisations.

5.1 Method

5.1.1 Identification

Resources were found via the following methods.

- Conventional search engines, using combinations of terms such as *deaf, deafblind, Auslan, Western Australia, advanced care planning, palliative care, help, guide*.
- Citations in print.
- Knowledge of various individuals who work in palliative care, Auslan interpretation, and D/deafblind advocacy, some of whom form the steering committee for this project.
- The review includes the most reliable sources were preferred, such as the WA Department of Health, relevant peak bodies, and some of the more prominent organisations associated with the areas of palliative care, ACP, and D/deaf or D/deafblind advocacy.

Resources from Western Australia are given preference. However, selected resources from outside of Western Australia are included if they were instructive, could be useful or adapted to the WA models for ACP and palliative care.

As a result, this is not a complete list of every available resource an individual with sensory loss would be able to find. However, it addresses the main resources and efficiently indicates opportunities for improvement.

5.1.2 Assessment of accessibility and applicability

The desktop review assessed whether:

- the resources are available in an Auslan translated format
- to what extent they adhere to accessibility standards
- if the resources cater to various levels of English and health literacy (e.g. easy read formats).

The review relied on pre-existing accessibility measures such as:

- the W3C Web Content Accessibility Guidelines (WCAG) 2.2 (Web Accessibility Initiative 2024)
- the Patient Educational Materials Assessment Tool (PEMAT; Shoemaker et al., 2014)
- the International Federation of Library Association and Institutions' (IFLA) guidelines for easy-read materials (Nomura et al., 2010).

5.2 Websites

No single specific website was located which covered information on palliative care and/or ACP in Western Australia that was also primarily tailored to, or intended for use by, individuals with hearing-related sensory loss. That is, no website met the ideal of presenting all of the following:

- both English and Auslan formats
- easy-read or plain-English options
- embedded text-to-speech and contrast options
- advice and information on palliative care and ACP specific to D/deaf or D/deafblind individuals.

A D/deaf or D/deafblind person would not be precluded from using any of the reviewed websites, but their access will depend on their individual English and health literacy. This mirrors a prevailing theme of our literature review: D/deaf and D/deafblind communities must adapt and make concessions to hearing culture, rather than hearing culture adapting to theirs, as is the case with other cultures with languages other than English.

Below are listed the main websites, explaining their accessibility options, as well as some of the precluding factors which may make navigation of these websites difficult for a D/deaf or D/deafblind individual.

5.2.1 Websites: WA government: HealthyWA

https://www.healthywa.wa.gov.au/

The HealthyWA Website is the primary source of public, consumer-friendly information provided by the WA Department of Health. The HealthyWA website makes note that it has been created to adhere to the WCAG 2.0 AA rating (Web Accessibility Initiative 2024) and lists additional accessibility goals that it has set out to achieve

Featured throughout the site were dedicated webpages for ACP, palliative care, AHDs, and more. Information was presented primarily in concise bullet-points. Use of an active voice for information delivery was employed, and webpages were mostly free of jargon – all qualities that are cited as being helpful for increasing patient accessibility (Shoemaker et al., 2014).

No Auslan-translated information was available on these pages, and Auslan was not a listed option under the 'ACP translated resources' section of the website.

While no embedded text-to-speech reader or contrast options were present on the ACP, AHD, and palliative care pages, the Authors tested the built-in 'reader view' functions on two internet browsers (Mozilla Firefox v128.0 and Microsoft Edge v126.0.2592.113) and the screen reader program NonVisual Desktop Access (NVDA v2024.2). Most tested pages on the HealthyWA website were functional in 'reader view', allowing for text-to-speech options and changes to text size and contrast options (both of which we felt made readability difficult in their default size and colour-scheme).

However, the FAQ and 'additional resources' sections of the webpages, located within embedded drop-down menus, could not be interacted with while in 'reader view'.

Additionally, while the current iteration of the HealthyWA website did not feature embedded videos on any of the pages mentioned, the use of 'reader view' eliminated the ability to see embedded videos, which could be problematic if Auslan translated information were to be added without a built-in text-to-speech system also being implemented

Browser-based 'zoom-in' functionality was working fully. Links to additional printed and published forms/materials were featured throughout the website, as well as links to external informational videos – these resources are covered in the relevant sections of this resource review.

5.2.2 Websites: WA government – Department of Health

https://www.health.wa.gov.au/

The information on this website is tailored to health professionals rather than consumers or general community members. However, this intention would be unclear to many individuals interacting with this website for the first time, particularly if they had limited health literacy.

The website adheres to the State Government's own Web Content Accessibility Guidelines. No embedded text-to-speech or contrast options were available, and all embedded videos featured English subtitles, but no Auslan translations. Default text size appeared somewhat small but was fully compatible with all browser-based zoom functionality.

The website was fully functional with NVDA screen reader software.

This website features information dedicated to both palliative care and ACP (as well as related pages such as information on advance health directives). This website would not be intended as a primary source of information for a D/deaf or D/deafblind community member, however, it was the top result for a web-based search of 'Advance Care Planning Western Australia'.

There was repeated mention of the role of health professionals on the website, and the embedded resources are tailored toward this cohort as well. As a result, the website has repeated use of what could be considered medical and legislative jargon, though we contend that this fits with the purpose and intended audience. The website includes links to external resources and webpages, including the more consumer-friendly HealthyWA website, though we suggest that this link could be more prominently displayed. The website adheres to the State Government's own Web Content Accessibility Guidelines. No embedded text-to-speech or contrast options were available, and all embedded videos featured English subtitles, and no Auslan translations. Default text size appeared somewhat small but was fully compatible with all browser-based zoom functionality. The website was fully functional with NVDA screen reader software.

- Websites: WA government: For the HealthWA website, include Auslan among the listed options under the 'ACP translated resources' section.
- On the WA Department of Health website make clear it is intended for use by health or government professionals.

- On the WA Department of Health website, make the link to the more consumer-friendly HealthyWA website more prominent.

5.2.3 Websites: Non-government services

A selection of additional websites associated with ACP and palliative care are listed more briefly below, as most contain information that is already present in the WA government websites, and none of which indicated, to the best of our knowledge, that they were created for a primarily D/deaf or D/deafblind cohort. We will not list all accessibility standards and options present on the following websites unless there are aspects worth noting. All websites were functional with NVDA screen reader software.

- **Palliative Care WA** – PCWA is the peak body for palliative care information in WA. Information contained on the website regarding palliative care and ACP was largely in keeping with the information provided by HealthyWA. There were additional links to ACP and palliative care services, as well as published materials, which are detailed in the relevant proceeding sections of this review.

- **MyValues** – This website features an interactive, online questionnaire for helping individuals to think about their values and preferences. It can be a helpful resource or initial first step for individuals who are not clear about their values and preferences around future health care, medical treatments, advance care planning, and palliative care. Completion of the questionnaire allows a person to receive a saveable, printable copy that will have a list of value statements that reflect the answers they gave, and this can also be uploaded to an individual's health record.

  Silverchain – While information targeted towards consumers about palliative care and ACP is somewhat limited on the Silverchain website, they are the primary at-home specialist palliative care service provider for WA. As such their website could be a source of information that an individual seeks out or comes across during cursory searching for information into palliative care. Furthermore, as mentioned in our literature review, preliminary research has indicated that Deaf individuals may be more likely to desire at-home end-of-life care as compared to HoH individuals (Jobling, 2016).

- **PalliAGED** – PalliAGED was one of the few websites the Authors discovered that had collated available resources for Auslan users regarding the areas of palliative care and ACP. They featured links to externally hosted video materials created by NSW Health which are discussed below in the videos section.

5.2.4 Websites: Non-government services: Opportunities

Subject to a fuller and more rigorous assessment, given the work already done on the PalliAGED website to collate available resources for Auslan users regarding the areas of palliative care and ACP, other sites could provide a link to it.

5.3 Websites: Hearing loss community

The following websites are specifically for D/deaf and D/deafblind communities. While these websites have more accessibility options and Auslan translated information, we could find no specific information about palliative care or ACP on any of these websites.

- **Deaf Connect** – Listed as the largest whole-of-life service provider for D/deaf, D/deafblind and hard of hearing individuals in Australia, the Deaf Connect website has limited information specific to palliative care and ACP
    - Section of the website include 'Information Service', 'Community Access', and 'Community Engagement', all of which could introduce and link to resources for ACP and palliative care.
    - Their 'Ageing Well' service is an approved provider of at home care for D/deaf, D/deafblind and HoH individuals over the age of 65, and as the service is person-centred and designed to be tailored to a service-user's specific needs, it is possible that help could be provided for the ACP process.

- **Deaf Australia** – Deaf Australia is the peak Deaf-led advocacy and information organisation representing all Deaf, Deafblind, hard-of-hearing Australians. Their website features an eLearning platform which contains self-paced online courses aimed at improving self-advocacy for D/deaf, D/deafblind and HoH individuals. We identify this platform as an exemplar of more long-form Auslan translated information. It shows how information about palliative care and ACP for the D/deaf and D/deafblind communities could be presented.

- **Deafblind Information Australia** – This website provides individuals with D/deafblindness or dual sensory loss a directory of information about both deafblindness and living with deafblindness. They also feature a service-finder function which provides information on various services Australia wide that provide support with D/deafblindness, as well as a list of D/deafblind support groups. The site's excellent suite of embedded accessibility options was among the best across any of the resources we saw in conducting this desk review, including built-in font size and contrast options, as well as Auslan translated information.

5.3.1 Websites: Hearing loss community: Opportunities

Each website provides a potential avenue for disseminating ACP and palliative care information.

- Deaf Connect as a whole-of-life service provider, and the information sections of its website.
- Deaf Australia with an exemplar eLearning platform.
- Deafblind Information service-finder function and exemplar web accessibility options.

5.4 Paper based

Below we detail a list of the main paper-based materials for information on palliative care and ACP in Western Australia. These include relevant ACP forms , guides for how to complete these documents, and a selection of some of the educational material on ACP, palliative care, and related healthcare subjects. This list is not an exhaustive collection of *every* resource relevant to this topic, as many of the resources identified during our desk review featured similar information and were no more or less accessible for D/deaf and D/deafblind populations.

These documents were written in English and, had they been translated to Auslan, would have been placed in the ‘Video Resources’ section of this review. However, we were unable to find any of the resources listed below in an Auslan format. Unless otherwise mentioned, these resources were all available in an online format as well as a printable pdf format. The online versions of these documents were all functional with NVDA screen reader software.

5.4.1 Advance Health Directive

The Advance Health Directive is the State Government of Western Australia’s official statutory document allowing individuals over the age of 18 with full legal capacity to make medical treatment decisions in advance. Recent changes to the document have improved consumer access and reduced barriers to completing the form.

Our literature review explains in more detail some of the potential difficulties that may be present for D/deaf and D/deafblind individuals in engaging with a document such as this. The form must, as a legislated requirement, be completed in English, though the AHD itself directs individuals who speak languages other than English to the National Accreditation Authority for Translators and Interpreters (NAATI) if they need the document translated or interpreted for them.

The AHD is available in a fillable pdf format, allowing an individual to complete it on their computer if they prefer. The AHD also includes provisions allowing an individual to use a marksman clause in the event they are unable to sign their name.

5.4.2 A Guide to Making an Advance Health Directive in Western Australia

This is the WA State Government Department of Health’s comprehensive guide for completing an AHD. It contains information about AHDs, a step-by-step guide for completing an AHD yourself, a section answering frequently asked questions, a glossary of terms, and an example of a completed AHD.

The length of the guide (59 pages when including the example AHD) and the density of the information provided could be prohibiting factors for individuals with limited English and/or health literacy.

As with the AHD itself, the guide directs individuals who speak languages other than English to various services that can provide translation and interpreting. The guide mentions it can be made available in alternative formats, upon request.

5.4.3 Enduring Power of Guardianship (and Attached Guide)

An EPG (Enduring Power of Guardianship) allows an individual to appoint another person to make personal, lifestyle, treatment and medical research decisions on their behalf, in the event they lose their legal decision-making capacity or are unable to make those decisions themselves.

EPGs are provided by the State Government of Western Australia's Department of Justice, and the guide is produced by the Office of the Public Advocate. The form itself is much shorter than the AHD, although it could be seen as more intensive with frequent use of jargon. A provision is included for the use of a marksman and read over clause which could be employed by a person who has limited English literacy or trouble writing. The guide attached to the EPG form is 45 pages and provides information for both the appointer and the appointee of the EPG.

The guide explains the process of completing the form and general information about EPGs, primarily presented in the form of questions and answers. The guide suggests that an individual with limited English capacity seek the help of an interpreter in completing the document. No specific information is provided in the guide or on the EPG itself for interpreting services. No mention of translated versions of these forms was found or alternative formats being available.

5.4.4 Values and Preferences Form

This is a document allowing an individual to state their values, preferences, and wishes in relation to future healthcare, lifestyle, and medical treatments. It can help guide health practitioners, doctors, family, guardians, and other loved ones about treatment decisions in the absence of an AHD.

While not legally binding under any specific statute, it may be recognised in some cases as a common law directive. The questions in this document are largely the same as the 'values and preferences' section found in an AHD.

The form is available in a fillable pdf format, and the document can be made available in alternative formats upon request. The short FAQ at the beginning of the values and preferences form guides individuals with limited English capacity to NAATI translating services.

5.4.5 'Your Guide to Advance Care Planning in Western Australia' Workbook

This document provides in-depth information about ACP, including what ACP is and the associated benefits. Much of the document is interactive, asking individuals to go through 'think, talk, write, share' activities of the WA ACP model to help them consider ACP as it relates to them. The workbook is available in a fillable pdf format and can also be made available in alternative formats upon request. The inside cover of the workbook guides individuals with limited English capacity to a translation and interpreting services.

5.4.6 Advance Care Planning Brochure

This brochure is provided by the WA Department of Health. The brochure gives similar information to the ACP Workbook mentioned above, but in a more concise and simplified format. It explains what ACP is, some of the associated benefits, and details the 'think, talk, write, share' model of ACP promoted in WA. The same information is also presented as a more easy-to-print factsheet version for consumers. The brochure can be made available in alternative formats upon request.

5.4.7 Advance Care Planning Easy Read Workbook

This document is adapted from the Advance Care Planning Workbook mentioned above and has been rewritten in an easy read format. The most important information has been summarised in simplified English, with large print and accompanying pictures.

There are simplified, interactive activities included in the booklet, however the online version of the form was not a fillable pdf and so could not be interacted with via computer. This is a more accessible resource for individuals with limited English capacity.

The format of the booklet follows almost every recommended style guide for easy-read material creation. However, the document is almost four times longer than the recommended 20-page maximum for easy-read materials (Inclusion Australia 2023). The workbook mentions translation and interpreting services toward the back of the booklet.

5.4.8 'My Palliative Care' and 'Palliative Caring' Booklets

These two booklets created by Palliative Care WA with consultation from individuals and organisations in health, aged care, and palliative care sectors, provide information on many facets of palliative care.

'My Palliative Care' is tailored to individuals who want to know more about their own current or future palliative care. 'Palliative Caring' is for individuals who will be caring for a person receiving palliative care.

While comprehensive, the size of the booklets and density of information could make them quite inaccessible for anyone who had limited English or health literacy. Both booklets provide the contact details for translation and interpreting services toward the front of the document.

5.4.9 Paper-based: Opportunities

- The information in all paper-based resources could be translated into Auslan. If accurate information already exists in video resources (see below), target only the gaps.
- Make available 'easy to read' formatted versions of print-based resources.

5.5 Video Resources

In this section we detail the main video resources about palliative care and ACP. Our targets were 'primary' resources, guides, or other sources of information, as well as *any* resources on these topics that featured translation into Auslan, as this feature is currently missing from existing Western Australian resources. Considerations were the use of captions (preferably not auto generated as these are prone to errors), the simplicity and clarity of the videos, video length, and use of eye-catching presentation or visual aids.

5.5.1 WA Department of Health Informational Videos

This collection of videos listed as an Advance Care Planning Playlist, hosted externally on the WA Department of Health YouTube account, is featured prominently on HealthyWA webpages for ACP and AHDs via external links. There are 11 videos in total, 6 of which make up a 6-part guide to completing an AHD that goes over the individual sections of the AHD. The videos are all essentially concise adaptations of the WA Department of Health's guides and educational resources that we have mentioned in the preceding sections, including broad knowledges relating to ACP and palliative care, as well as more specific examples to increase understanding. This would make them excellent resources for D/deaf and D/deafblind individuals were they to feature Auslan translation either embedded into the video or were recreated as Auslan specific versions featuring the same information. The videos all feature subtitles, and many of the videos also employ the use of embedded text.

5.5.2 Murray PHN Videos

Murray Primary Health Network commissioned Deaf Hub Bendigo to translate informational videos in Auslan about palliative care and ACP. The videos cover the basic information about the topics and provide information that would be helpful for an individual who had little to no knowledge on the subjects.

Despite being commissioned by an organisation from outside of Western Australia, the videos provide information that is general in nature and do not feature any state specific details that would be confusing or irrelevant to an individual from WA.

Input from a WA Deaf consultant and/or interpreter would be required to speak to the presence of any State-specific dialect or differences in the language used that may make the videos inappropriate for a D/deaf or D/deafblind individual from WA. Short, informative videos such as these are exemplars for similar Auslan translations of WA palliative care and ACP resources.

5.5.3 NSW Health Videos

New South Wales Health Department created four videos which contain Auslan translations for information about ACP and palliative care. One video is about ACP, another on palliative care, another on palliative care services for children with a life-limiting illness, and a final video on palliative care volunteer support services. As with the Murray PHN videos mentioned above, the videos are both informative and not particularly long. However, this collection of videos is much more NSW-specific, referring to services, resources and statutory documents which would not be relevant to someone living outside of NSW. Indeed, they may be confusing to an individual from WA.

5.5.4 Deaf Australia Palliative Care Webinar

This video is an on-demand recording of a webinar hosted by Deaf Australia, featuring a specialist palliative care physician speaking about a number of topics and answering questions from audience participants relating to WA palliative care, ACP, and more. The entire webinar was translated into Auslan live, and participants ask several questions that are specific to the D/deaf experience as it relates to these subjects. This is an excellent resource for obtaining a broad understanding. However, the 1-hour video lacks bookmarks or sections, making it difficult to find specific answers to a question or learn about one topic of particular interest.

5.5.5 Video: Opportunities

- Advance Care Planning Playlist on WA Department of Health YouTube account to include Auslan versions.
- Use the Murray PHN videos as exemplars for specific WA Auslan video productions.
- Add bookmarks or sections to the existing Deaf Australia Palliative Care Webinar video.

5.6 Resources for Interpreters

The resources described below are either specifically targeted for Auslan interpreters to help them understand palliative care and/or ACP, or resources targeted for health professionals that could, in theory, be utilised by an interpreter in upskilling in the areas of healthcare. However, with healthcare education platforms not specifically designed for interpreters, differences in interpreter experience, style, and ability could result in differences in what is drawn from these learning opportunities and then disseminated into the field of practice. Professional moderation is available, as described below.

5.6.1 NAATI Certified Specialist Health Auslan Accreditation

This is a specialist accreditation that is offered by NAATI, the national standards and certifying body for Australian interpreters and translators. Interpreters who complete this course are qualified to work within a range of health care settings and competent at interpreting complex and specialised communication within those settings. The recertification process (occurring every 3 years) for this accreditation requires continued professional development. Several palliative care and ACP workshops currently offered within WA that could fulfill the requirements for these development points.

5.6.2 Palliative and Supportive Care Education (PaSCE) Workshops

Supported by the Cancer Council WA, this platform provides a variety of workshops, programs and scholarships aimed at educating volunteers, practitioners, and other relevant parties in the health care sector about topics relating to palliative care, ACP, and more. Education streams such as this are an example of professional development opportunities that could benefit interpreters who are either certified specialist health accredited or are simply interested in expanding their working knowledge of palliative care and health literacy.

5.6.3 2M Training academy and palliative upskilling course

Originally commissioned by Brisbane South PHN, this program ran through much of 2023 and was aimed at increasing translator and interpreter engagement and upskilling participants within areas of palliative care. While the in-person portion of the course was based outside of the state of WA, there was also an online webinar element to the course and the recordings of these webinars now exists on the 2M training academy website, where they can be accessed by Auslan interpreters Australia wide. One specific webinar titled ‘The Interpreter’s Voice in Palliative Care’ featured experiences and learnings from an Auslan Interpreter.

5.6.4 Resources for interpreters: Opportunities

- Integrate translator and interpreter engagement into distribution workflows for publications.
- Promote ACP and Palliative Care professional development opportunities among translators and interpreters.

5.7 Community organisations

The following are community resources highlighted as potential avenues for facilitating open discussion amongst a community of D/deaf or D/deafblind individuals. These resources are not currently operating in such a way where D/deaf and D/deafblind individuals can specifically gather to speak about ACP and palliative care, but they could be adapted for this purpose and so are included.

5.7.1 Deafblind WA ‘Connect’ Drop-In Centre

DBWA are a peer led and run organisation for individuals who are D/deafblind in Western Australia. Their fortnightly DBWA ‘Connect’ Drop-In Centre is highlighted as a potential avenue for facilitating discussion, providing support, and spreading awareness about palliative care and ACP that is specific to individuals with D/deafblindness or dual sensory loss. Community groups such as these could be an excellent avenue for spreading awareness, information, and resources on topics such as ACP and palliative care in an environment that is both comfortable and familiar.

5.7.2 Death Cafés

Death Cafés are group-directed, community engagement opportunities where individuals are encouraged to come together and speak in a welcoming, confidential, and respectful space about issues relating to death and dying, grief and loss, bereavement, and any additional topics relating to this area. There are resources available on the Death Café website allowing people to organise and host their own Death Café, and as such we identify that this format could be adapted by a D/deaf or D/deafblind cohort to facilitate a discussion that features or is conducted in Auslan and is more relevant to the D/deaf and D/deafblind experience.

5.7.3 Community organisations: Opportunities

- Engage community organisations in the development of resources.
- Integrate community engagement into distribution workflows for publications.

6 Conclusion and recommendations

Below are the recommendations for potential implementation of strategies or changes to current resources, based on the discovery and research conducted that has been outlined in the previous sections of the report.

As this report was one of the initial steps taken in the first phase of a much larger project, these recommendations are likely to change as PCWA continues to consult with members of the D/deaf and D/deafblind communities, Auslan interpreters, health professionals, and other relevant stakeholders. They should be viewed as starting points for future research and testing, rather than final recommendations and will be adapted following analysis of the findings of the Sensory Loss Project.

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 Deaf and 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
    d. Understand the needs of individuals with sensory loss in relation to advance care planning, palliative and end-of-life care
    e. Develop best-practice methods for communicating multiple modalities of information with D/deafblind individuals
    f. 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.

7 Appendix: Glossary

Below is a list of common terms and acronyms used within this report, along with shortened and simplified definitions to provide a base level of familiarity with the topics and language being used. Many of these terms are further expanded upon within the report itself.

- **Sensory Loss/Impairment**: A generalised term describing any impairment or alteration in the ability to perceive external stimuli (e.g., hearing, sight, pain, etc.,).
- **deaf, hard of hearing (HoH)**: A form of sensory loss resulting in an impairment or complete loss in the ability to hear. The level of hearing loss often occurs across a spectrum, and can range between mild, moderate, severe, or complete.
- **deafblind:** A form of dual sensory loss in which both hearing and sight are affected to some degree. As above, deafblindness also often occurs across a spectrum where the level of deafness or blindness will vary.
- **Death literacy:** Death literacy is a phrase that describes the knowledge and understanding of death-related issues, including the processes of dying, grief and end-of-life planning.
- **Deaf, Deafblind, deafBlind** (N.B. capitalised letters): This is used to refer to culturally Deaf and Deafblind communities or individuals. This includes congenitally deaf individuals, native or cultural Auslan users, children or family members of Deaf or Deafblind individuals, and more. It is a personal choice by an individual as to whether they associate as part of the culturally Deaf or Deafblind communities.
- **Advance Care Planning (ACP)**: The process of thinking about, talking about, and implementing decisions, wishes, or directives regarding one's own future medical care and treatment, in the event they will not be able to communicate those decisions themselves in the future.
- **Advance Health Directive (AHD)**: The Western Australian State Government's statutory legal document allowing an individual to make voluntary medical treatment decisions regarding their future medical care in the event that they are unable to communicate those decisions themselves.
- **Enduring Power of Guardianship (EPG)**: The Western Australian State Government's statutory legal document allowing an individual to appoint a person/s of their choosing to make important health, lifestyle, and medical treatment decisions on their behalf, in the event that they are unable to make those decisions for themselves.
- **Enduring Power of Attorney (EPA)**: The Western Australian State Government's statutory legal document allowing an individual to appoint a person/s of their choosing to make financial and property decisions on their behalf, in the event they are unable to make those decisions for themselves.
- **Auslan**: The primary Australian sign-language used by Deaf and Deafblind communities. It is unique and separate from English, containing its own grammar, vocabulary, and culture.
- **CODA**: Child/Children of D/deaf (or D/deafblind) Adults.
- **WA**: Western Australia
- **Palliative Care Western Australia (PCWA)**: The peak body for the palliative care sector in Western Australia.
- **Western Australian Primary Health Alliance (WAPHA)**: Part of the Australian Government's national Primary Health Network program which aims to strengthen, improve, and connect the primary care system.

- **National Accreditation Authority for Translators and Interpreters (NAATI)**: The national standards and certifying authority for the translating and interpreting sector, and the only organisation to issue credentials or certification to people who wish to work in this profession.
- **Web Content Accessibility Guidelines (WCAG)**: These are the web accessibility guidelines published by the World Wide Web Consortium, the primary international standards organisation for Internet use. They are a set of recommendations for making Web content more accessible, primarily for people with disabilities.

8 Appendix 2: Search Terms

Database: MEDLINE (Search date: 03/02/2025)

Population	Concept	Results
Deaf* OR “hard of hearing”, “hearing impair*” OR “hearing loss*” OR “hearing disorder*” OR MH “Hearing Disorder+”	“Advance care*” OR “end of life*” OR “advance health directive*” OR “advance decision*” OR “advance healthcare plan*” OR “Palliative care” OR “end of life care” OR “hospice care” OR MM "Advance Care Planning+" OR MM "Advance Directives+" OR MM "Palliative Care" OR MM "Hospice Care"	117

Database: CINAHL (Search date: 03/02/2025)

Population	Concept	Results
Deaf* OR “hard of hearing”, “hearing impair*” OR “hearing loss*” OR “hearing disorder*” OR MM "Hearing Disorders+" OR MM "Deaf-Blind Disorders+"	“Advance care*” OR “end of life*”, OR “advance health directive*” OR “advance decision*” OR “advance healthcare plan*” OR “Palliative care” OR “end of life care” OR “hospice care” OR MM "Advance Care Planning" OR MM "Advance Directives+" OR MM "Palliative Care" OR MM "Hospice Care" OR MM "Advance Directives+"	51

Database: PsycINFO (Search date: 03/02/2025)

Population	Concept	Results
Deaf* OR “hard of hearing”, “hearing impair*” OR “hearing loss*” OR “hearing disorder*” OR DE "Hearing Disorders" OR DE "Hearing Loss"	“Advance care*” OR “end of life*”, OR “advance health directive*” OR “advance decision*” OR “advance healthcare plan*” OR “Palliative care” OR “end of life care” OR “hospice care” OR DE "Advance Directives" OR DE "Palliative Care" OR DE "Hospice" OR DE "Advance Directives"	34

9 Appendix 3: Study characteristics

Study	Study aim	Design	Participants	Key findings
Carpenter, J. G., Ersek, M., Nelson, F., et al (2020). USA	To describe hearing and vision loss and their associations with the quality of end-of-life care and family perception of care in the last 30 days of life among a national sample of veteran decedents.	Retrospective medical record review and Bereaved Family Survey.	Medical record review of all veterans (N = 96,424). Survey results included 42,428 individuals.	In adjusted models, EOL care quality indicators and BFS outcomes for veterans with hearing loss were similar to those for veterans without hearing loss. However, slightly lower scores were recorded for pain management and less satisfaction with communication.
Cerilli, C., Katz, G., Volandes, A. et al (2023). USA	To explore Deaf ASL users' perceptions and experiences with end-of-life care and advance care planning.	Qualitative study. Eleven Deaf ASL users participated in the study with two deaf interviewers.	11 Deaf American Sign Language users	Participants reported barriers to end-of-life care including poor provider communication, inaccessible sources, and inadequate provision of accommodations, leading to patient distrust. Participants primarily gained information on end-of-life care from first-hand familial experience, peers, and media. Participants' mean advance care planning knowledge was 4.6 out of 15 (SD = 2.6).
Coyle, N., Khojainova, N., Francavilla, J. et al (2002). USA	To report the results of a three-month trial of using audio-visual communications as a complementary tool in care for a complex palliative care patient.	Qualitative case study.	1 man with hearing loss	The use of audio-visual communication (TeleEye) in palliative care enhanced communication (patient can visually lip-read the clinicians), improved monitoring, reduced need for home visits, provided instant access to support, and increases satisfaction for both the patient and family members.

Franchi. (2011). Canada	Using arts-based research, this enquiry examined end-of-life communication, situations of death, and rituals for closure by capturing video-taped narratives in American Sign Language.	Qualitative study.	10 Deaf or hard of hearing individuals	The research found Deaf and hard-of-hearing need access to health care and funeral industry professionals who are familiar and sensitive to the social and cultural issues affecting end-of-life issues. Hiring American Sign Language interpreters for anyone facing the death of a loved one or facing death themselves is essential for receiving adequate information and communication. Deaf, deafened, and hard-of-hearing individuals need accessible services whether they are the receivers of care or family members of those receiving care.
Hughes, M. C., ScheckLong, D., & Chung, K. (2023). USA	To describe the hearing aid loan program to provide free amplification devices for patients at the end of life.	Mixed-methods approach.	Deaf individual and family caregiver	The study highlights the need for more social service programs that address the hearing health needs of patients at the end of life. Caregivers are instrumental in helping the hearing aid loan program work.
Kehl, K. A., & Gartner, C. M. (2010). USA	To understand the challenges faced by a Deaf family member when a loved one is dying.	Qualitative case study.	1 Deaf individual who experienced the death of a family member	The study highlighted the physical, financial, and cultural communication barriers experienced by a deaf family member providing end of life care of loved ones. The lack of readily available and affordable sign language interpreters impacted the effective communication and decision-making. Improved cultural competence training among healthcare providers as well as further research into end-of-life care for the Deaf community are needed.
Maddalena, V., O'Shea, F., & Murphy, M. (2012). Canada	To explore the experiences of Deaf family caregivers who provided end-of-life care for a Deaf person.	Qualitative study. Eleven Deaf ASL users participated in the study with two deaf interviewers.	7 Deaf individuals from a Deaf community	Communication and health literacy are key barriers to accessing appropriate end-of-life care. Limited knowledge of Deaf culture on the part of health professionals and lack of interpreters. Pain and symptom management, consideration of physical environments, and limited access to bereavement care are common issues faced by Deaf people when caring for loved ones at the end of life.

Olson, A. D., & McKeich, M. A. (2017). USA	To describe the unique needs of patients with hearing loss who are receiving hospice care.	Qualitative case studies.	20 individuals living with a hearing loss in a hospice care	A comprehensive plan of options from screening to specific interventions has been provided. Options can be implemented to improve the overall communication for persons with hearing loss and their providers and family members. Improved communication may lead to improved quality of life and quality of care at end of life.
Ricky, L & English, K. (2016). USA	To assess the need for audiology care at the end of life.	Survey questionnaire.	240 Audiologists	240 respondents included 221 practicing audiologists responded. 98.34% agreed that hearing loss could affect the quality of palliative care, and that audiologists should be part of an interdisciplinary team in these settings (86.74%). 70% indicated they would be comfortable providing audiology services in palliative care settings, 71.43% indicated interest in obtaining more information about hearing loss and palliative care.
Shaw, G. (2015). USA	This cover story discusses the importance of hearing for people at the end of life.	Cover story/commentary	N/A	Good hearing healthcare is crucial for people at the end of life because it allows them to communicate with family, physicians, and other caregivers. Hearing impairments can hinder communication, impacting the ability to address a patient's social, cultural, spiritual, and emotional needs. This can negatively affect advance planning, emotional distress management, and counselling for patients and caregivers.
Smith, A. K., Ritchie, C. S., & Wallhagen, M. L. (2016). USA	To assess hospice and palliative care providers' perspectives, experiences, and responses to hearing loss in the clinical care of older adults.	Survey questionnaire.	510 hospice and palliative care providers	A total of 510 responses were received. 91% reported that hearing loss has some or great impact on the quality of care for older adults. 88% recalled a situation where hearing loss created a communication problem with a patient, and 56% a communication problem with a caregiver. While 61% felt comfortable with their communication skills for patients with hearing loss, only 21% reported having received formal training in its management, 31% were unfamiliar with resources for patients with hearing loss, and 38% had never heard of a pocket talker amplification device.

Wallhagen, M. I., Ritchie, C. S., & Smith, A. K. (2019). USA	To gain an understanding of hospice and palliative care practitioners' experiences with Hearing Loss and its impact on the care provided.	Survey questionnaire with an open-ended question.	510 hospice and palliative care providers	The overarching theme was "Diagnostic and Treatment Uncertainty." Non mutually exclusive categories underpinning this theme included: unable to get needed information, misinterpreting level of understanding, patient misunderstanding of instructions, and goals-of-care errors.

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