

Deafness and dementia: Interpreting changes in behaviour



The
Dementia
Centre.

Deafness and dementia: Interpreting changes in behaviour

An information booklet for care staff

“Although the diagnosis of my mother’s dementia still echoes through me, I am thrilled by the amazing efforts of The Dementia Centre, HammondCare and the booklet they created. I feel confident this information will help provide many carers with the education and support needed to provide positive, loving care for deaf people with dementia to live their best lives.”



Mary Jane ‘MJ’ Grant, CODA (Child of Deaf Adults)

Acknowledgement



Deafness Foundation

We thank the Deafness Foundation for funding and reviewing this resource.

We thank Mary Jane Grant, Uniting Mullauna Blacktown, Access plus WA Deaf and all others that have contributed to the development of this resource.

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Foreword



Connection through communication is a birthright of all human beings; a birthright I have had the privilege of accessing my entire life.

My journey began as the youngest of two hearing daughters born to Deaf parents who used sign language to communicate. As a young, curious adolescent, I volunteered in various care homes, reading to residents, doing activities or simply sitting and engaging in conversations. Early on, I could see that what defines connection for people is the ability and opportunity to communicate, to connect with others.

I often felt drawn to residents who were living with dementia as I could see in their eyes, the need for connection and understanding. Little did I know the seeds of providing loving care for my own mother with dementia, were being planted.

Thirty years later, I lovingly took on the role as my mother's carer, yet not without struggles. While raising four children and owning and operating a full-time business, my husband and I, along with the assistance of my older sister, did our best to seek support for my mother's care. The disheartening realisation that there was no accessible care in our area for Deaf individuals living with dementia left us with no other option than to move her into our home; a home where we could provide direct access to communication in sign language and the loving care she needed. Over time the progression of dementia became increasingly more difficult and we made the painful decision to move her into a memory-care home.

Educating staff was essential to my mother having a positive experience at her new home and the burden was on us as a family to do so. However, due to high turnover among staff, continuous education became challenging. Over time, visits with my mother became her only opportunity to freely express her feelings of isolation and loneliness. With the financial strain of paying for care that was not fully accessible and witnessing her increased isolation, we moved her back into our home where she continues to reside.

We realise that caring for my mother and educating providers about her specific needs will be an ongoing endeavour while continuing to balance all of life's demands. My mother needs and deserves compassionate care and effective communication that does not further isolate her. I do believe it is possible for a system to be more inclusive and supportive of her needs.

The challenge, and one that should not be overlooked, is how to be as inclusive as possible. This booklet is an incredible step in the right direction.

I am thrilled to witness the amazing efforts The Dementia Centre, HammondCare has put into developing this comprehensive booklet. This is a must-have guide to ensure individuals such as my Deaf mother can live their best life possible through positive, loving communication and connection. After all, it is the birthright of all human beings.

MJ Grant

Mary Jane 'MJ' Grant, CODA (Child of Deaf Adults)



This booklet has been developed for people who are caring for or supporting a Deaf/deaf person living with dementia.

It aims to provide an introduction to dementia and changes in behaviours that a person may experience living with the condition.

Introduction



In Australia, approximately 1 in 6 people live with hearing loss and within this group, there are a number of people that have no hearing at all.

People who are born Deaf and are part of the Deaf community in Australia belong to a diverse group with many distinctive characteristics including language, values and behaviours. The sign language used by the Australian Deaf Community is Auslan and currently there are approximately 30,000 users nationally. Many hearing people and people with significant hearing loss move between the Deaf culture and hearing worlds and use many different methods of communication.

It is unknown how many deaf people live with dementia but for those that care for them, resources are hard to find. The following information has been brought together from the knowledge and experiences of deaf people and dementia experts and can support you in your role as a carer of a deaf person living with dementia.



Definitions

There are different terms used to describe people with varying degrees or kinds of deafness. The most common of these terms are defined below.

Deaf (with an uppercase 'D')	People who use sign language (for example, Australian Sign Language – Auslan or British Sign Language) to communicate, and who identify as members of the signing Deaf community. They are more likely to have been born deaf or become deaf early in life.
deaf (with a lowercase 'd')	A more general term to describe the physical condition of not hearing. It also describes people who are physically deaf but do not identify as members of the signing Deaf community.
Hard of Hearing (HoH)	Those who have acquired a hearing loss in late childhood or adulthood, or who have a mild or moderate hearing loss. This term is often applied to people who are losing their hearing gradually due to age. These people usually communicate using speech, lip reading and residual hearing (often with the use of hearing aids).

Source: Deaf Australia and Deafnav

Using the wrong words can easily cause offence. For example, Deaf people usually do not like the term 'hearing impaired', often perceiving it as negative and clinical. Hard of hearing people often do not like the terms 'Deaf' or 'deaf'. When referring to a mixed group of people it is best to use more than one term. If you are not sure which term to use, it is advisable to check with the person you are talking with or about to determine which term they prefer to use. This resource will use deaf with lowercase 'd' when referring to both groups.

Chapter 1 ~ Dementia

What is dementia?

Dementia is a term that describes a range of progressive disorders that affect the brain. While dementia may be experienced by people of any age, it is much more common in older age. However, dementia is not a normal part of the ageing process. Each person's experience of living with dementia is different, regardless of which type of dementia is diagnosed.

What are signs of dementia?

The early signs of dementia are often subtle and easily missed or explained away and they vary from person to person. Problems with memory are often present. A person with dementia may, for example, forget appointments, or not remember events that occurred in recent days. Long term memory may stay intact initially but this can change over time. For example, a person living with dementia may have difficulty recognising familiar places and people as the dementia progresses. Shapes and colours may also become difficult to identify and distances might be misjudged.

Some other common changes experienced by a person living with dementia are problems with organisation and planning. Performing familiar tasks such as making a cup of tea or cooking a meal may become difficult. Communication skills might also deteriorate. A Deaf person with dementia who uses sign language to communicate might, for example, have problems with finding the correct sign, or the signing space or range of handshapes might be reduced. In some forms of dementia, personality changes may also occur.



What causes dementia?

There are more than a hundred forms of dementia. The most common causes of dementia include Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

TYPE OF DEMENTIA	CHARACTERISTICS
Alzheimer's disease	Usually characterised in the initial stages by gradual onset of memory difficulties, particularly short-term memory, and problems with orientation.
Vascular dementia	Changes in the brain affect blood circulation, causing small strokes. In this condition there often is a noticeable step-like decline in the person's thinking ability and functioning.
Dementia with Lewy bodies/ Lewy bodies disease	This type of dementia often starts with problems such as thinking and memory that fluctuate from day to day or even hour to hour. Visual hallucinations (seeing things that aren't visible to others) and Parkinsonism are typical of this form of dementia.

Other forms of dementia include frontotemporal dementia, Huntington's disease, alcohol-related brain damage and many other conditions.

While there are many different forms of dementia, it is usually a progressive condition whose symptoms worsen over time.

Chapter 2 ~ Communication

People who are deaf communicate in different ways depending on multiple factors:

- The age at which deafness began
- The type of deafness
- English language skills
- Lip reading skills
- Speech abilities
- Family, social environment and educational background

Some people who are deaf use lip reading, sign language or communicate through writing only, while some people will use a combination of methods. Therefore, always check how the deaf person prefers to communicate.

Sign language

People who are Deaf use different sign languages depending on where they come from. In Australia, Auslan is the most common visual form of communication. It is a language that was recognised officially by the Australian Government in 1987. Auslan involves a combination of hand shapes, facial expressions and movements to deliver messages. It has its own grammatical structures, which are different from those found in English. Two examples are displayed below.

ENGLISH	AUSLAN
I am going to the shop tomorrow	Tomorrow shop me go
I saw a beautiful red car this morning	Red car beautiful this morning I saw

Source: Deafnav and NDP

There are two clear distinguishable Auslan dialects, known as the Northern and Southern dialects. Language variations also exist between states and sometimes even within states.

While the majority of Deaf people use Auslan to communicate, there are other types of sign language that can be used as below.

TYPES OF SIGN LANGUAGE	DESCRIPTION
Auslan signed in English	Auslan signs are produced in a grammatical structure that more closely reflects English grammatical structures.
Signed English	Signing to exactly replicate the English language.
Indigenous sign language	Sign language that is specific to the cultural area of the Indigenous person. Indigenous sign languages are amongst the oldest sign languages in the world.
Fingerspelling	Fingerspelling manual alphabet is used by signers in the Auslan community when there isn't a commonly understood sign for a particular word, such as the names of places or people. Studies show that fingerspelling is used in about 10% of communication by Auslan users.



There is an online Auslan Signbank which is a language resource website for Auslan. It includes a dictionary, the ability to search for signs, signs related to medical and health topics and videos of Deaf people using the listed Auslan signs. This is a useful resource for care staff to learn simple signs to help communicate with the people they care for.

Members of Deaf communities are often bilingual and bi-cultural. They may use Auslan in the Deaf and Hard of Hearing communities and English in the hearing community with varying degrees of fluency. The sign for dementia is quite new within Auslan communication, so it may not be known by all sign language users. Fingerspelling of the word is a good alternative.

Dementia, deafness and communication

A person's way of communicating will often change over time as dementia progresses. A Deaf person with dementia might also go through similar changes in communication as a hearing person with dementia. They may have problems understanding you or finding the right words or signs and this might cause frustration. We may need to adjust our ways of communicating while still ensuring the person with dementia is engaged in a way that is respectful and dignified. It is important to let the person finish their messages even if it doesn't seem to make sense, and then try to clarify the intended communication.

As dementia progresses some people lose skills they have developed over the course of their lives and may revert to the way they were communicating at an earlier stage of life. Ask the person and their family about how they communicated when they were younger. Many Deaf sign language users and people with acquired hearing loss will have learned to lip read. However, this ability may diminish if a deaf person develops dementia and lip reading becomes increasingly challenging.

Eventually a person may stop using language to communicate altogether. Speech and signing are not the only ways to communicate. Body language is important and can be used to help someone feel calm and cared for through touch, eye contact and facial expressions. A simple smile can do a lot. Try to avoid showing sadness, impatience or anger when communicating as the person might be confused about what you are trying to say.

Top communication tips:

- Get the person's attention by placing a hand on their shoulder (not when approaching from behind), waving in front of them or switching the light on and off. The best approach will be guided by the person and should be recorded in the care plan.
- Keep your message simple and straightforward, focus on one topic at a time.
- Communicate slowly and clearly, take a deep breath between sentences.
- Be mindful of your body language and show signs that you are listening and understanding.
- Make sure the area where you are communicating is well lit.
- Ensure assistive devices are in working order (e.g. glasses are clean). Although it is not very common, a deaf person may have a cochlear implant or hearing device to aid communication. Make sure these are switched on and that batteries are working.
- Ask closed questions as this will be easier for the person to answer. For example, "would you like a cup of tea or coffee?" as opposed to "what do you want to drink?"
- Model the activity for the person by acting it out so they can better understand what you are trying to achieve.
- Use picture cards to ask a question or to show what you would like to do.
- When you have trouble communicating, stop and take a break before trying again.

You may need to try different approaches to see what works best. Once you have determined the best way to communicate, document this in the care plan. Review this regularly with the person, relatives and your colleagues because the progression of dementia might affect the preferred communication method over time.

Tips for communication through Auslan or speech (lip reading)

This page provides some general tips about communicating with a Deaf person that communicates through Auslan or speech (lip reading).

THINGS TO DO

Look directly at the person and make sure that your hands, face and lips are always visible. If you need to wear a face mask consider alternatives such as a face mask that includes a see-through panel. Check how the deaf person prefers to communicate in this situation.

Communicate at eye level so the person does not have to look up or down.

If speech/lip reading is the preferred method speak clearly. If Auslan is the preferred method learn some common signs and phrases.

Use gestures to back up what you mean when appropriate.

THINGS TO AVOID

Try not to repeat yourself more than once if the person doesn't understand you. Instead rephrase what you are saying rather than using the same words.

Try not to over pronounce or shout. This can distort your speech and you may look impatient or angry.

Don't cover your mouth or have anything in your mouth while you are speaking.

Don't stand in front of a light source such as a window or bright light.

Tips for communication through writing

Always check with the person whether they prefer written communication and take into consideration the person's reading and writing skills as these may vary. A whiteboard can be a helpful tool for communication. Keep a small whiteboard or notepad and marker pen in different rooms and spaces throughout the home so these can be used at any time.

Sign language interpreting

Auslan Interpreters help to facilitate communication between Auslan users and English speakers.

Professional interpreting

In any health care or medical appointment, it is important for Deaf people who are reliant on signing to communicate, that a professional interpreter is present. Ensure that there is an interpreter booked when a medical assessment or appointment is needed. It is not only important to interpret during health care professional visits, but also at other times, such as admission to the care home or for a review of the care plan.

All aged care providers and aged care assessment services (such as My Aged Care) have access to free sign language and interpreting services. An interpreter can be arranged through Auslan Connections. Free interpreting services for private health care appointments are provided by the National Auslan Interpreter Booking and Payment service (NABS). Health care practitioners in a public health care setting need to pay for the costs of an interpreter themselves unless the Deaf person is from an Aboriginal and/or Torres Strait Islander background. Services that are covered by NABS include General Practitioners (GPs), specialists, physiotherapists, occupational therapists, psychiatrists and dentists. Find out more about Auslan Connections and NABS in the list of 'Useful services' at the end of this booklet.

Interpreting by family members

It can be tempting to rely on the Deaf person's relatives to interpret, but there are a number of reasons not to do this, especially for medical and health care interpreting. Firstly, it is easy for untrained interpreters to make mistakes in interpreting medical terminology. Also, it is important that the interpretation provided is impartial, which can be difficult if a family member or friend is interpreting. For example, relatives may not feel the need to interpret everything the person says directly and may summarise information instead. They may also insert their own opinions or impose their own judgement as they interpret.

Here are a few tips when you are working with an interpreter.

THINGS TO DO

Make sure there is sufficient lighting.

Ensure the interpreter is seated next to the main speaker and the Deaf person sits opposite to the main speaker.

Make sure the Deaf person can always see the speaker's face and lips.

Look at and speak to the Deaf person, not the interpreter.

Speak clearly and naturally, use clear language and short sentences.

THINGS TO AVOID

Don't speak or read too fast, instead take your time.

Don't say things like, "tell her..." or "does he understand?"

Avoid using slang or expressions (e.g. 'over the moon' or 'piece of cake').

Keep in mind that the interpreter is a few words behind the speaker. Give them time to finish so that the Deaf person can ask questions or join the discussion.



It can be helpful to think of some changes in behaviours as responsive behaviours as behavioural expressions – they are not always caused by dementia. It may also be an expression of someone's needs, which could be physical, emotional, social or spiritual.

Chapter 3 ~ Understanding behaviour

Behaviour is an essential part of each individual and can be influenced by both internal and external factors.

Internal factors may be things that are part of a person's personality or emotional response, such as feelings of happiness or fear, or daily habits and routines. External factors which can influence behaviour are things in the environment, such as flashing lights and busy places (which might influence behaviour in a negative way) or the feeling of sand between your toes at the beach and the smell of the ocean inducing peace and calm.

Changes in the behaviour of a person with dementia are very common. These changes are often described clinically as behaviours and psychological symptoms of dementia (BPSD). It can be helpful to think of some changes in behaviours as responsive behaviours – they are not always caused by dementia. It may also be an expression of someone's needs, which could be physical, emotional, social or spiritual. Changes in behaviours may also indicate that a person is in distress. This might be expressed in restlessness, anxiety, or physical aggression.



In the table below you will find some of the most common changes in behaviours experienced by people with dementia and tips on how to understand and support the person. These include a few simple strategies that may help you to respond to the changes in behaviour. You might need to try different strategies to see what works best. The strategies that you have chosen might not work all the time and you may need to try a different approach.

ISSUE/BEHAVIOUR	EXAMPLES	POSSIBLE STRATEGIES
<p>False beliefs, seeing things that aren't present</p>	<ul style="list-style-type: none"> • Saying or signing things that you know are not true such as someone is stealing from the person or trying to poison their food. • Thinking that they need to go to work or school when they don't have that role or responsibility anymore. • Seeing things that are not there such as animals or small children. 	<ul style="list-style-type: none"> • Arrange a medical check-up with a General Practitioner (and interpreter) to rule out physical causes of the behaviour. • Consider that what the person is experiencing is real to them, so try not to argue or change the person's reality. Instead try to use the principles of validation (page 29). • Try to remain calm. The person may not be upset about what they are seeing so it may not be a problem for them. • Provide activities related to what is real for the person at the time (for example, sanding wood for someone who used to be a builder/carpenter or rolling bandages for someone who used to be a nurse).

ISSUE/BEHAVIOUR	EXAMPLES	POSSIBLE STRATEGIES
<p>Changes in mood, impatience, irritability</p>	<ul style="list-style-type: none"> • A change in temperament to being more irritated than usual. • May become sad or angry very quickly with no obvious reason. • Shouting, swearing or using body and facial expressions that show anger or frustration, attempting to push and shove while waiting for an activity. 	<ul style="list-style-type: none"> • Don't argue, use the principles of validation (page 29). • Try to remain calm. Sign, speak or write in a calm way and be aware of your facial and body expressions. Before you respond, take time to think about what you are going to communicate. • You might also consider giving the person some space and leaving the room for a short time if you think it is safe to do so.
<p>Doing or saying things repeatedly</p>	<ul style="list-style-type: none"> • Asks the same questions again and again. • Needing to shadow you or another person all the time. • Pacing, picking at things, opening or unpacking drawers over and over or repeatedly taking off their clothes. 	<ul style="list-style-type: none"> • Using notes, a clock, calendars or photographs could help if the person keeps asking the same questions. • Stay calm and be patient, avoid arguing or showing frustration at the behaviour. • Engage the person in an activity that they enjoy, redirecting them from the repetitive behaviour. • If the above strategies are not working, consider if the person has any underlying pain.

ISSUE/BEHAVIOUR	EXAMPLES	POSSIBLE STRATEGIES
<p>Refusing support or help with activities of daily living</p>	<ul style="list-style-type: none"> • Refusing help with showering, going to the toilet or getting dressed. • Refusing help with: <ul style="list-style-type: none"> – cooking or finances – going to bed – help with, or taking, medicines – eating. 	<ul style="list-style-type: none"> • Keep the person’s daily routine the same as much as possible. Don’t enforce a routine unnecessarily e.g. a shower every other day may still be okay. • Include the person in making decisions and make sure they feel respected and understand what is happening. • Consider if the person can recognise objects needed for the activity and what they are for (for example, a toilet or cutlery). You could demonstrate the action or activity you would like them to do. • If these strategies are not working, consider if the person has any underlying pain.

ISSUE/BEHAVIOUR	EXAMPLES	POSSIBLE STRATEGIES
<p>Loss of interest, apathy</p>	<ul style="list-style-type: none"> • Sitting quietly without paying attention to what's going on around them. • Loss of interest or motivation in participating in activities that they would normally enjoy. 	<ul style="list-style-type: none"> • Set up a daily routine or schedule to follow and keep it visible (e.g. use a large calendar or schedule on a whiteboard). • Break things down into smaller steps to help make things easier (e.g. guiding them through an activity step by step). • Use things that the person is known to enjoy through their interests and hobbies to help get them started such as: <ul style="list-style-type: none"> – visits with family (grandchildren) – visits from pets or animal therapy – participation in creative activities such as art or gardening.



ISSUE/BEHAVIOUR	EXAMPLES	POSSIBLE STRATEGIES
<p>Changes in sleep or appetite</p>	<ul style="list-style-type: none"> • Reversed day-night rhythm. • Frequently waking up during the night and sleeping during the day. • Eating much more or less than usual and/or has gained or lost weight. • Consuming food or drinks they previously would not or in a way that is unusual. 	<ul style="list-style-type: none"> • Check that the person can find the toilet during the night (leave a night light on and the toilet door open). • Arrange a medical check-up with a General Practitioner (and interpreter) to rule out physical causes of the behaviour. • Provide information to help the person distinguish night from day (e.g. day/night clock, wearing a dressing gown to indicate bedtime, opening curtains/blinds during the day). • Ensure that the person spends time outside during the day. • Involve the person by asking what they would like to eat and prepare it together. • Be flexible with mealtimes and share meals with the person so they have social cues as prompts. • Check whether there are any problems with swallowing or using cutlery.

Physical factors

A change in someone's behaviour may be caused by the dementia itself or be the symptom of another disease or physical condition. Included below are common physical factors that might impact on a person's behaviour.

FACTORS	OBSERVATIONS
Pain	<ul style="list-style-type: none">• Ask the person if they are sore, tender or have pain anywhere.• Look for signs of pain in their behaviour (changes in facial expression, body language, behaviour or being pale or flushed in the face).• Does the person have a limp while they walk or lean while sitting?• Do they have a history of illnesses that might cause pain like angina or osteoarthritis?
Infection	<ul style="list-style-type: none">• Is there any sign of infection (pain, redness or swelling in a certain area of the body)?• Does the person have any cold or flu symptoms (shortness of breath, runny nose, pale skin or cough)?
Bowels	<ul style="list-style-type: none">• Are the person's bowels regular?• Have you noticed them holding their tummy?• Are they drinking enough water?
Medications	<ul style="list-style-type: none">• Have there been any recent changes in the person's medication?• Is the person taking more than 5 medications in a day?
Other	<ul style="list-style-type: none">• Dehydration, malnutrition, discomfort (e.g. skin irritation, feeling too hot/cold, hunger), difficulty sleeping, fatigue, and hearing and vision problems.

Another physical factor to consider is eyesight. Vision changes with age, but it can also be affected by particular types of dementia. For a deaf person vision is particularly important. Good eye care and regular check-ups should be considered.

If you identify that the person with dementia is experiencing any of the physical factors above, or if you have concerns about either general health or a specific medical condition, it is important to speak to the General Practitioner.

The effect of pain

Carrie lives with her daughter Kirstin and her husband Jack on their farm since her dementia diagnosis. Kirstin helps her mother daily with some personal care and notices that her mother is often quite agitated when she helps her take a shower and get dressed. Apart from that, Carrie also seems to be getting more confused in her signing. Kirstin sees her mother rubbing her wrist and back regularly and asks her mother if she is in pain. Carrie's signing is not very clear, and Kirstin decides to take her mother to the GP. Tests show that Carrie has arthritis and pain medication is prescribed. In the following weeks they try different pain and anti-inflammatory medications. Kirstin also takes more time to help her mother start her day and warms up the bathroom on cold mornings. After some time, Carrie's agitation and confusion reduce.

Environment

The environment where a person with dementia lives or receives care is known to influence wellbeing and behaviour. For example, older people need about twice as much light as younger people to carry out everyday tasks comfortably and the need is even greater for people with dementia. Whether a person with dementia is still living at home or in a care home, there are various small design changes and adjustments to the environment which can enable a person to maintain as much independence as possible and continue to participate in activities of daily living. It is very common for people to be more disorientated when they first move into residential care or if they move rooms within a care home. Making the environment homely and familiar, calm and as easy to navigate as possible is a good start.

Consider the below factors and think about whether or not they might be affecting the person living with deafness and dementia.

FACTORS	OBSERVATIONS
Contrast and colour	<ul style="list-style-type: none"> • Are items easily recognisable through contrast and colour? Examples: Does the toilet blend into the wall or can it be easily identified? Is the food on the plate easily distinguished from the colour of the plate?
Lack of familiarity	<ul style="list-style-type: none"> • Are there items in the home or in the person's room that keep them connected with home and friends/family?
Lighting	<ul style="list-style-type: none"> • Is the lighting bright enough to help the person see clearly both during the day and at night?
Access to outside	<ul style="list-style-type: none"> • Are there any barriers to the person accessing the outdoors? Are doors locked or difficult to open? • Is there a garden or nice space to sit? Is it shaded from the sun or sheltered from rain or wind?
Overstimulation	<ul style="list-style-type: none"> • Is the environment cluttered or busy?
Under stimulation	<ul style="list-style-type: none"> • Does the person have meaningful activities available to them that they enjoy?
Wayfinding	<ul style="list-style-type: none"> • Can the person find their room or the toilet easily?
Cultural considerations	<ul style="list-style-type: none"> • Are there any hygiene or grooming practices, creative interests or ceremonies/rituals that will need to be supported and is there a safe space to do so?
Lack of privacy	<ul style="list-style-type: none"> • Are there any barriers to maintaining the person's privacy and personal space?

Adapting the environment

Andy had noticed that his father George seemed to be unusually cautious moving around his living room and corridors at home. He seemed uncertain about making his way to the kitchen and looked to be focusing very carefully on his movements. George would react defensively if he was disturbed while he was moving from room to room. It became apparent that the lighting wasn't bright enough for George. Large lamp shades caused shadows on the floor that were confusing and disorientating, and the corridors were dark. George had to work harder to concentrate and navigate his way through the room and around the furniture and shadows. Changing the light bulbs and the lamp shades helped to make the room brighter and reduced the strain on George finding his way.

Clear signage

Clear signage may assist people to find their way around the home and to locate different rooms, such as the bedroom and toilet. Signs can also be used to help locate everyday items, for example, a sign on a kitchen cupboard for teacups. Signage using words may be appropriate for people who still have the ability to read; for those who have never been able to read or have lost the ability to read, pictures may be useful. A combination of both could also be used, two examples are shown below.



Assistive devices that flash or vibrate can alert someone to a safety feature such as a smoke detector. Similar assistive devices can be connected to a telephone or a doorbell. If these are being used, check regularly that the device is working and that it doesn't cause confusion.

Validation

An approach which can be very helpful is called validation where we identify the emotional aspect of what is being said. It is about respectfully acknowledging or validating the feelings the person is experiencing, offering help and redirecting the person's attention to something more pleasant if they are upset or distressed.

Example 1:

Bill keeps looking for his car keys, rattling the front door and trying to leave. He is worried and insists he has to go to work.

Try:

"You seem really worried Bill, I would be worried too if I couldn't find my car keys."

"I am not sure where they are either, in the meantime..."

- "Come and have a coffee/tea with me."
- "Can you help me with the filing?" (or something that they would normally have done at work)

Avoid:

"You are not going anywhere."

"You're retired. Don't you remember?"

"It's Saturday and you don't work on Saturdays."

"You can't drive anymore."

Example 2:

Helen is very restless, looking for her children who are grown up and no longer live with her. She becomes distressed when she cannot find them. Helen always enjoyed baking with the children.

Try:

"You look upset Helen."

"I am sorry you are so upset about it."

- "Let's look at some of the pictures of the children."
- "I am about to make a cake, come and help me. I remember how much the kids liked it when you baked for them."

Avoid:

"Stop it. Don't you remember, your children are grown up."

"I don't think they would want you to behave like this."

A deaf person doesn't have the audible cues to help them understand or identify what is happening around them.

Chapter 4 ~

Activities and engagement

If you are supporting a deaf person with personal care you may need to schedule more time for this than usual, because communication may be more difficult.

Make sure you have enough time, so you don't need to rush. Keep describing, signing or showing what you are doing when you are supporting or guiding a person to do a certain activity, even when you think the person may not understand what you are trying to say.

A deaf person doesn't have the audible cues to help them understand or identify what is happening around them. For example, they don't hear the rattling sound of cutlery or pots and pans while a meal is being prepared. Involve the person in what you are doing by showing it to them or help to make them part of the activity.

It is important the person remains involved in activities that they enjoy and are familiar with. Tapping into someone's life history and experiences and reinforcing things from their past that they identify with, can help support a person experiencing changes in behaviour(s). This might require the help and understanding of others close to the person.



Role, identity and meaningful engagement

Anthony recently moved into a care home and it was hard for him to settle at his new place. Anthony was often physically aggressive when staff attempted to care for him. He would place himself on the ground and would be very distressed, shouting at staff and pushing them away when they attempted to help him up. Staff learned that Anthony had been a published author and was a prominent member of the local community. They started to focus on the importance of meaningful engagement with Anthony that would enhance and build on his community role. While staff worked to support Anthony to reassert his identity in a positive manner, family brought his desk, desk furniture and reproductions of his degrees and other certificates. These certificates were prominently displayed. Staff could see that spending time at his desk and “at work on his new book” is important to Anthony. They are better able to interpret Anthony’s actions and feel more confident in responding to his needs. Anthony is enjoying his renewed status as an important and respected member of the community.

Having a few activities and resources available that you know the person enjoys may improve their level of engagement. This could be favourite movies or TV shows (ensure closed captions or subtitles are always turned on at a larger font), gardening equipment if they like gardening or craft supplies if they enjoy the arts. A small box or bag of items that the person recognises or uses regularly may help to initiate a conversation or activity. Support the person to spend time outdoors and be involved in what they like doing. Remember, the person might need to be helped at the start of an activity until they can continue on their own.

When the deaf person with dementia participates in group activities with hearing people, consider how you can help the person to be engaged with the activity. For example, let the deaf person sit nearest to the focus of the activity and/or the person who is leading it.

Getting to know the person

Susan had worked as a registered nurse in a hospital for many years. She is a very caring person and had always looked out for other people. Susan became deaf later in life following a stroke. When Susan needed more support and moved into a residential aged care home, her family shared her life history, daily routine, likes and dislikes with the staff to help them develop a good understanding of Susan. With the knowledge of Susan's past role as a nurse, the staff in the care home identified that she liked to have her nursing background acknowledged and enjoyed filling in blank charts and progress notes. She would often sit with staff in the office when it was quiet.



Summary ~

How to support the person



Communication

Always check how the deaf person prefers to communicate and review this regularly with the person. Use the communication tips in this booklet for sign language, speech and/or writing.



Sign language and interpreting

If you are supporting a person that prefers to communicate through sign language, make sure there is a professional interpreter booked for assessments, important appointments and evaluation of care through the available free interpreting services. Prepare for the session with the interpreter with the provided tips.



Changes in behaviour

Identify the cause(s) of the changes in behaviour. Each person with dementia is unique. Look at physical factors, likes and dislikes of a person and the environment.



Adapt your strategies

Adapt your strategies in response to changes in behaviour. They may be very successful at one point and then become less so over time. You may need to set aside a previously effective strategy and try new ideas. At other times you might find yourself returning to earlier strategies.



Validation

Validation can be a helpful tool to acknowledge the feelings that a person with dementia may be experiencing and to ensure that the person feels respected.



Meaningful activities

Help the person to remain involved in meaningful activities.

Useful services



Depending on the stage of the dementia and the specific needs of the person with dementia there are several services you can contact for support.

Auslan Connections

All aged care providers and aged care assessment services (such as My Aged Care) have access to free sign language and interpreting services. Sign language services are available in Auslan, Aboriginal and Torres Strait Islander languages, American Sign Language, International Sign Language, and Signed English. Both face-to-face and online interpreting, including on-demand video remote interpreting, will be offered nationally, seven days a week and after business hours when required. For Deafblind people tactile signing and hand over hand are available.

When your organisation contacts the sign language interpreting service for the first time to organise an appointment, further information about your organisation will be collected to fully register your organisation on the booking platform. Once registered you will receive a booking code which can be used each time you book an interpreting service. Bookings can be made through Auslan Connections' booking service.

Contact details: Phone 1300 010 877 or
email: interpreter.bookings@deafservices.org.au

Deaf services providers

Every state has its own service for Deaf and hard of hearing people. This includes interpreter services, events and activities for the Deaf community and workshops to learn more about the Deaf community.

- NSW: The Deaf Society – www.deafsociety.org.au
- Victoria and Tasmania: Expression Australia
www.expression.com.au and www.tasdeaf.org.au/about
- Queensland: Deaf Services – www.deafservices.org.au
- South Australia: DeafCanDo – www.deafcando.com.au

- ACT: DeafACT – www.deafact.org.au
- Northern Territory: DeafNT – www.deafnt.org.au
- Western Australia: Access Plus WA – www.accessplus.org.au

National Auslan Interpreter Booking and Payment Service (NABS)

The National Auslan Interpreter Booking and Payment Service (NABS) is funded by the Commonwealth Government to provide free interpreting services to people who use sign language for private health care appointments. The NABS website provides all the details required including eligibility in accessing Auslan interpreting. The service is free for people who are not eligible for National Disability Insurance Scheme (NDIS) (e.g. being older than 65) and can be booked by the Deaf person or private health care practitioners.

Contact details: Phone 1800 246 945 or visit www.nabs.org.au

The National Relay Service (NRS)

This service is a government initiative that allows people who are deaf, hard of hearing and/or have a speech impairment to make and receive phone calls. Relay officers convert voice to text or text to voice. Sometimes they convert between Auslan and English.

Contact details: www.communications.gov.au/what-we-do/phone/services-people-disability/accesshub/national-relay-service

Dementia Support Australia

Dementia Support Australia (DSA) provides advice and support for carers of people with dementia experiencing changes in behaviours. The role of DSA is to improve the quality of life for people living with dementia and their carers. DSA does this by working in partnership with the person living with dementia and their care network to understand the causes or triggers that led to changes in behaviour. DSA offers support 24 hours a day, 365 days a year throughout Australia and will arrange an interpreter if needed.

Contact details: Phone 1800 699 799 or visit www.dementia.com.au

Dementia Australia

Dementia Australia provides information and education on dementia and runs programs and services such as counselling and support groups. They can also help you to find the right support in your area.

Contact details: Phone 1800 100 500 or visit www.dementia.org.au

Dementia Training Australia

Dementia Training Australia is a consortium funded by the Australian Government to provide nationwide education and training on the care of people living with dementia.

Contact details: www.dta.com.au

Hearing Australia and Cochlear

Many deaf people will not use cochlear implants or hearing aids, but there are a proportion of severely or profoundly deaf people who do use them because they can gain benefit for communication and environmental awareness.

Contact details: www.hearing.com.au and www.cochlear.com/au/en/home

Useful resources



Deafness

- **Deafnav** – A neutral, centralised portal that helps you better understand, access and connect with the Deaf and hard of hearing community.
www.deafnav.com.au
- **The Auslan Signbank Dictionary** – An online resource where people can look up any sign and view it in video format.
www.auslan.org.au/dictionary
- **Video resources for Deaf seniors**
Deaf Services Queensland
www.deafservices.org.au/services/Ageing-Well/Video-resources
- **Auslan: what you need to know**
NDP 2015
www.ndp.org.au/images/factsheets/NDP_Factsheet04.pdf
- **Guidelines on communicating with people who are deaf, hard of hearing and speech impaired**
Legal Aid New South Wales - 2014
www.legalaid.nsw.gov.au

Dementia

- **Dementia Support Australia** provides a range of helpsheets, care support guides and position papers which can be found through:
www.dementia.com.au/resources/library.
- **Understanding Psychosocial Approaches: Validation**
Dementia Support Australia – 2018
www.dementia.com.au/resources/library
- **Understanding the impact of pain and dementia**
Dementia Support Australia – 2018
www.dementia.com.au/resources/library

- **Understanding apathy in people with dementia**
Dementia Support Australia – 2020
www.dementia.com.au/resources/library
- **Dementia Australia Help Sheets** are an extensive resource for carers regarding supporting people with dementia
www.dementia.org.au/resources/help-sheets
- **Talking sense**
Agnes Houston with Julie Christie – 2018
www.dementiacentre.com/resources
- **Better bathrooms and bedrooms (sample chapter) – My home, my life: Practical ideas for people with dementia and carers**
Colm Cunningham and Natalie Duggan with Agnes Houston – 2018
www.dementiacentre.com/resources
- **Enlighten: Lighting for older people and people with dementia**
David McNair, Richard Pollock and Colm Cunningham – 2017
www.dementiacentre.com/resources
- **Diagnosis, treatment and care for people with dementia: A consumer companion guide**
Cognitive Decline Partnership Centre – 2017
www.cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia

Published by HammondCare 2020

Sydney, Australia

hammond.com.au

publishing@hammond.com.au

ISBN: 9780648679004

@HammondCare

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Design: SD creative



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HammondCare's Dementia Centre is committed to providing excellence in dementia care. Older and younger people living with dementia deserve services that are designed and delivered based on evidence and practice knowledge of what works. This is achieved through providing research, training and education, publications and information, consultancy and conferences.



ISBN 9780648679004



9 780648 679004



+61 2 8437 7355



hello@dementiacentre.com

dementiacentre.com