

Communication and engagement



alzheimer'swa
the dementia experts

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Communicating and engaging with a person living with dementia

Imagine if you were unable to communicate how you felt, what you wanted or needed, or engage in conversation with those around you.

Dementia can have an impact on a person's ability to communicate verbally. It can also affect word finding, comprehension, concentration, reasoning, interpretation and processing of information. This can be challenging for both the person living with dementia and for those around them.

Share these tips with family and friends to help them understand it is still possible to communicate with a person, even if they have dementia.

To engage with a person with dementia, a verbal exchange or the use of words is not always necessary. Sometimes it can be enough to simply sit with a person, share a moment, or offer your time and attention.

Five simple tips

Alzheimer's WA has five simple tips to help people better connect with a person living with dementia.

These following tips were developed in conjunction with people living with dementia.

- » **Talk to me:** Please talk to me, not my carer, family member or friend. Don't prejudge my level of understanding.
- » **Keep questions simple:** Providing information in smaller chunks will really help me.
- » **Body language:** Make eye contact and speak clearly, use short sentences, with one idea at a time. Avoid jargon, as I might not understand.
- » **Be patient and understanding:** Sometimes it takes a little longer for me to process information and find the right answer. Don't rush me, allow me time to speak.
- » **Distractions cause disruptions:** Less noise and fewer distractions will help me to focus.

Impact of dementia on communication

The following describes some of the specific impacts dementia may have on a person's ability to communicate. Not all people living with dementia will experience all of these symptoms. The impacts of these symptoms can make it difficult for a person living with dementia to connect and engage with others and to express themselves.

Impact	Experience
Word finding	Difficulty recalling and finding words. May substitute words they cannot remember with descriptions. May forget names of things, people and places.
Difficulty explaining or understanding abstract ideas and concepts	May have difficulty explaining how they feel emotionally or physically.
Unable to initiate conversation	Require prompts from others to start conversation.
Difficulty following thread of conversation	May make comments that do not fit the circumstance or flow of conversation. Has difficulty absorbing more than one idea or concept at a time.
Repetitiveness	Person may say the same things or ask the same questions multiple times.
Word sequencing	May jumble sequence of words.
Shortened attention span	May be easily distracted.
Reasoning	May not be able to use reason when discussing ideas.
Limitations with verbal communication	May rely more on reading body language of others and their tone of voice.

Listening tools

Empathetic listening, validation, and acknowledgement can be used to let a person with dementia know you are listening to them and trying to understand their experience.

Empathetic Listening

This involves paying attention to what is being expressed by the person, not just listening to the words. Listen to their tone of voice, and observe their facial expressions and body language for important messages. It is about trying to understand the person and letting the person know you have heard them. This can build trust and validate the person's experience.

Validation

Validating means acknowledging the expressed reality of a person, without judgment or alteration. This can be done verbally or through body language. Nodding, leaning forward and smiling all show understanding and interest.

Acknowledgment

Acknowledgment involves being honest with a person about what you see and feel in the moment you are with them.

For example you might say:

- » 'I can see you are happy / upset / sad'
- » 'I would like to understand what you are experiencing'
- » 'I can see it is hard for you to communicate with me'
- » 'I want you to know that I am here, right beside you and I see you.'

Some helpful hints

- » The person may not know who you are but they will remember the way you make them feel
- » Focus on who the person is now
- » Smile, use eye contact and positive body language to help the person understand you are speaking to them
- » Keep questions and sentences short, and introduce one topic at a time
- » Use prompts in your conversation to help a person remember a time, place or person. For example:
 - » 'I really enjoyed seeing you yesterday when we walked to the park'
 - » 'This is a lovely photo of your grandson, Ben'
- » It may take the person longer than usual to respond, be patient
- » Try to get the person's attention, for example use their preferred name at the start of the conversation
- » Converse at eye level, do not hover over the person
- » Reduce distractions, turn off the television or radio
- » Recognise the life story of the person, the roles and responsibilities that may once have been an important part of the person's identity.

Practical ways to stay connected

Staying connected to friends, family and community can help a person living with dementia retain a sense of self-worth, identity and self-esteem.

- » Don't stop inviting the person to social gatherings
- » If large gatherings are becoming too overwhelming, try visiting the person at a place where they are comfortable, such as their house
- » Find common interests to talk about or engage in such as cooking, gardening, reading, walking or playing card games
- » If the person likes animals, try introducing supervised visits with a pet
- » Nurture the person's abilities and encourage the person to be involved
- » Create a life story book (refer to page 9 for more information)
- » Reminisce over photos, watch a favourite television show or listen to music.

Use of language

Language associated with dementia can unknowingly stereotype a person.

Language that stereotypes has the power to easily diminish a person's self-esteem.

Language can influence the way others think, understand, perceive and respond to a person living with dementia. It can create barriers to how the person is viewed or treated in our community, and can continue to foster stigma.

Often people are unaware of the language they use and the impact it may have on a person with dementia. Language with negative connotations can lead to a person with dementia withdrawing and isolating themselves.

Try to use language that does not label, stigmatise or box people in. Use language that enables and empowers, supports independence and the ability of the person with dementia.

Instead of these words	Use
Sufferer, suffering	Living with dementia
Wanders	Walks
Negative behaviours / non compliant	Responding to the environment Unable to make choices
Fading away / not all there	Living with dementia
Them	The person living with dementia



Stigma

What is stigma?

When a person is labelled by their illness, it creates an "us and them" divide, where the person is seen as the illness, and not who they are as an individual.

Stigma is often created through misunderstanding or fear. Stigma can shape understandings and can easily become a defined opinion. Stigmas become generalisations that remove the individualism or uniqueness of a person.

The impacts of stigma are far-reaching and can erode a person's sense of self and wellbeing.

Stigma commonly associated with dementia

The following table identifies some stigmas that are commonly associated with dementia.

Stigma	Potential impacts for person living with dementia
Dementia equals suffering.	People may become disheartened after being diagnosed, believing it is not possible to live well with dementia.
People with dementia do not understand what is going on around them.	Could leave the person feeling useless, frustrated, with a sense of no control and a lack of autonomy. Reduces opportunities provided for participation in life.
People with dementia are helpless and need someone to take control of things.	Can be left out of conversations, be ignored, excluded. Could leave the person feeling isolated, with no sense of purpose.
People with dementia are not really 'here'.	They will likely experience feelings of not being seen, understood or acknowledged, being constantly looked over.
If you have dementia you will become aggressive and have 'behaviours'.	May lead to people being misunderstood when just expressing themselves. Loss of human right to express emotions in response to adverse circumstances.
If you have dementia your personality will change.	Changes in the person may be misunderstood, and regarded only as part of the disease, not who they are as a person.
People with dementia do not have capacity to make decisions for themselves.	The person may experience others making decisions about them without them, making them feel helpless and 'trapped'.
People with dementia do not understand their reality as it actually is.	An assumption that a person's reality is different, making it hard for people with dementia to try and relate to others.
Someone with memory loss must have dementia.	While memory loss is common with dementia, there are many reasons for memory loss. Assuming memory loss is caused by dementia could be hurtful and disheartening for people.
Anti-psychotics and other restraints are needed for what is called 'challenging behaviours'.	The person may be medicated inappropriately and the impacts of this can be devastating to their physical and emotional health.
People with dementia revert back to being a child.	Children do not possess the rich life stories of adults. Being treated as a child is embarrassing and degrading, and can lead to people not being taken seriously, or being ignored.
There is no hope if you have dementia.	This can lead to pessimism and hopelessness, if people with dementia feel all those around them believe they have 'no hope'.
Making assumptions about the symptoms a person may be experiencing.	We are all unique and each person's dementia journey is different. Making assumptions about the symptoms a person may be experiencing can limit the person's ability to live a full and meaningful life. When abilities are not recognised a person can become disempowered, isolated, and lose their sense of purpose, meaning and identity.

What not to do

Ask the person if they remember you

It can be a difficult experience if someone close to you can no longer remember your name or the context of your relationship. However, asking the person if they remember you can feel like a test for a person living with dementia. It can put a lot of pressure on them and this may cause further confusion and distress.

In some cases, reminding the person of your relationship with them may not cause distress but rather put the person at ease. This will be specific to the situation, nature of your relationship, and the person.

Promise something and not follow through

Many people assume a person living with dementia is not affected when a promise or statement is not followed through on. It is important to understand that the person's emotional experience is still very much intact, and although they may not recall what you said, they will remember how you made them feel.

Correct the person

Try to avoid correcting a person living with dementia wherever possible. Correcting a person, especially in front of others, can feel humiliating or embarrassing. It can lead to a person withdrawing, feeling useless or incapable.

Discount the person's expressed reality

This can happen when a person with dementia tells you something that doesn't seem real to you. Instead of dismissing what they have said, try to respond to the person's expressed reality through validation.

There has always been a lot of debate about how to best respond to a person living with dementia if they share something that seems to be a delusion, not reality, or not what is actually happening. Understand that just because it is not how we see the person's reality, doesn't mean we should discount it as it not being theirs.

Edna

Edna is living with dementia and lives at home with her husband of 40 years. Edna is still able to do many things for herself. At a recent appointment with their doctor, her husband spoke about Edna not being able to shower and dress on her own anymore and wondered if in-home support might help. The doctor organised for a community care assessment.

Both Edna and her husband were present at the assessment. When the assessor asked Edna how she managed her showering and dressing, Edna's response was that she manages perfectly on her own and that she showers and dresses herself every morning without help. Edna's husband was in the background quietly indicating that this is not the truth.

There could be many reasons why Edna is communicating that she can manage on her own:

- » She may want to hold on to her independence for as long as possible
- » She may be struggling with coming to terms with losing some of her abilities
- » She may be a very private person and not want strangers to help her with matters so personal
- » She may be fearful of what might happen
- » She may think that she still does this for herself
- » She may be in denial.

Consider a stranger coming to your home and asking about your ability to shower and dress yourself. If you respond that you can manage, yet someone else tells this stranger that is not the truth, that you cannot do these things on your own, how might you respond?

It is imperative to listen to the person living with dementia. They may have an unmet need, concern or fear that needs to be addressed.

If a support worker arrives unexpectedly at Edna's home to shower her, the support worker also needs to know that Edna does not believe she needs any help. This information can help the support worker to facilitate a positive outcome.

Life story books

A life story book is a wonderful way to bring back memories for a person with dementia, and at the same time provide useful information to caregivers about the person.

What should I include in a life story book?

- » The person's full name and preferred name
- » Date and place of birth
- » Names of parents, siblings, childhood pets and friends
- » Occupation
- » Partner's name
- » Names of children
- » Important life events

Consider the following statements:

- » Three words that describe me...
- » I really enjoy...
- » I really dislike...
- » I am afraid of...
- » I struggle when...
- » My favourite music is...
- » Things about me that are important to me are...
- » If I couldn't communicate, I would like to tell my caregiver...
- » Things that are important you know about my (partner/relative/friend) are...
- » Favourites: music, animals, holiday, colour, clothes, food, sport, place, weather...

More information about creating a life story book can be found at alzheimerswa.org.au/life-story-book





OUR VISION

A world where people with dementia and their families are supported and valued on their dementia journey.

OUR PHILOSOPHY

Dementia is a lived human experience rather than just a biological condition. We therefore embrace and support a holistic, person-centred approach that respects the individuality and the experience of those living with dementia.

OUR PURPOSE

To improve the lived experience of those on the dementia journey through our advocacy, leadership, innovation, education, partnerships and holistic, person-centred care and support, and to support the pursuit of risk reduction, treatment and cure for dementia.

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