

Understanding behaviour: the impact of dementia



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Understanding the impact of dementia

Sometimes the actions and expressions of a person living with dementia are perceived as ‘behaviours’ that are concerning, challenging and confronting. These ‘behaviours’ are often considered to be caused by the condition and a symptom of dementia. Unfortunately they are often managed using medication, restraint, isolation and a disregard for the person as a human being.

However, we now have a better understanding of why these so-called ‘behaviours’ occur. **These can be explained as:**

- » An unmet need: such as hunger, thirst, tiredness or boredom
- » Being too cold or too hot
- » An underlying physiological issue such as pain or infection
- » A person living with dementia may be restless at certain times of the day as a reflection of previous life routines.

When an expression is viewed as a ‘behaviour’ it is seen in isolation, and generally as inappropriate. When it is viewed as a result of an unmet need or physiological issue, it can be considered in context and is generally seen as appropriate.

It is useful to think about how you might respond if you felt you were losing your independence, or couldn’t communicate in a way that others could understand you.

The lived experience

Every person's experience of living with dementia is different. The condition may present differently, and the impacts may be felt differently for each person.

A person's past experiences and personality play a factor in how they experience life with dementia. The different types of dementia can also impact how a person interprets, perceives, rationalises or processes their experience of life.

This is called the 'lived experience' of dementia.

To help you understand the lived experience of dementia, consider the scenarios on the following pages. In all three scenarios; imagine you are yourself, the age you are now, with no cognition problems.

Scenario 1

Imagine you are at work and two people who you have never met before approach you and tell you it is time for your shower. You are unable to communicate in a way that can be understood, although you try. The two people aren't listening to you and say you're not making any sense to them. They take you by the arm and try to walk you out of the room you are in.

How would you feel?

- » Confused?
- » Scared?
- » Embarrassed?
- » Think that the strangers are abducting you?
- » Upset?

What would you do?

- » Try and get away from the strangers and return to what you were doing?
- » Pull away from the strangers?
- » Defend and protect yourself from the strangers?
- » Laugh at them?
- » Ask other people to help you?
- » Withdraw and comply to the strangers' requests?

What would you say?

- » Ask who they are?
- » Ask if this is a practical joke?
- » What are you doing?
- » Tell the strangers to go away and leave you alone?
- » Scream for help?

Reflection

A person living with dementia in this scenario:

- » May not be orientated to time and place (or situation)
- » May not be able to communicate in a way that is understood by others
- » May not recognise the support person as someone who is trying to help them
- » May not understand that they require assistance with showering
- » May not feel like a shower, may feel pain in the shower, may value their dignity, privacy, rights to choice and independence
- » May believe that they are more than capable of showering themselves, as they always have done - if this is the belief of the person at this time, there will be little purpose in trying to advise them of anything different.

Scenario 2

Imagine you are walking around the shopping centre or around the park and the same person keeps approaching you and telling you to sit down.

How would you feel?

- » Confused?
- » Concerned that they may have mental health problems?
- » Annoyed?

What would you do?

- » Ignore them?
- » Sit down?
- » Try and find out if they are lost?

What would you say?

- » I am shopping/walking my dog?
- » I have things to do, please leave me alone?
- » Go away or I will call the police?
- » Why do you want me to sit down?
- » Have you confused me with someone else?

Reflection

Now think of a person living with dementia that is often observed walking. They:

- » May not recognise their environment
- » May feel lost or anxious
- » May be looking for someone/something
- » May be in pain and walking to try and stop the pain
- » May need to go to the toilet
- » May believe that they are at work
- » May be bored
- » May be in the only space they have to walk
- » May just enjoy walking.



Scenario 3

Imagine you are in your own home and decide to do some spring cleaning. A stranger approaches you and takes the items you are holding out of your hands, takes you by the arm and tells you “This is not your room. Leave those things alone”.

How would you feel?

- » Scared?
- » Confused?
- » Intimidated?
- » Unhappy?

What would you do?

- » Try and get them out of your house?
- » Take your things back from them?

What would you say?

- » Who are you?
- » This is my house
- » Get out of my house
- » I will call the police

Reflection

Think of a person living with dementia, living in a residential aged care facility, who goes into other residents’ rooms and takes their belongings. They:

- » May not recognise their environment
- » May believe that the items are theirs
- » May like the items they are taking
- » May get comfort and security from the other person’s items. The items may remind them of a positive experience in their life
- » May not recognise you and believe that you are an intruder in their home
- » May feel they have access to all rooms as it is their place of residence.

This scenario is an example of how cognitive changes can affect a person’s executive functions such as judgement, inhibition, reasoning, understanding of consequences, relating to actions, impact on others and impulse control.

Labelling behaviour

Language is very powerful and can influence our understanding of others. Once a person living with dementia has been labelled with certain words, it can be very difficult for them to be viewed as anything else. This contributes to society’s stigma around dementia which leads to assumptions and inappropriate support.

By simply changing the language used to describe a person, or their actions, you can help yourself and others to better understand their needs.

In the table on the next page, the left hand column lists words that are sometimes used to describe the ‘behaviour’ of a person living with dementia. The right hand column suggests reasons why a person living with dementia may express themselves in this way.

Common 'behaviours' and their true meaning

Labelling language	Human experience of a person living with dementia
Agitated	Feeling frustrated, angry, unheard, loss of independence. Can't express oneself. Feeling pain. Boredom.
Anxious	Unable to communicate feelings. Feeling distressed, worried, frightened, nervous, lost, lonely. Always been an anxious person. Feeling little connection to environment.
Argumentative	Feeling frustrated, disempowered, angry. Trying to assert oneself, stand up for self. This could be a sign of wellbeing.
Depressed	Many people experience depression. It is not necessarily caused by the condition, although it could be an experience of living with it. Hopelessness.
Intrusive	Unsure of environment. In the person's reality they are where they think they should be. They may be lost. In an unfamiliar environment. It may feel like home where they have access to the whole home. Seeking connection. Boredom.
Lacks judgement	Enthusiastic. Wants to be independent. Feelings of spontaneity.
Manipulative	Memory loss. Disorientated. Confused. Looking for ways to be heard. Feel they need to be able to fulfil their needs. Loss of control in life. Boredom.
Misidentifies	A different experience of time, place and person. Believes items belong to them. Recognises faces but unsure who they are.
Vocalises noisily	Speaking loudly. Hearing problems. Trying to communicate. Nobody is listening to them. Needing help. Feeling lonely. Seeking contact with others. Not realising their voice is coming across loudly or that they are even vocalising at all.
Physically aggressive	Scared of what is happening to them. Position of defence - defending themselves. Fear of being hurt, having no control. Trying to communicate an unmet need. Feeling frustrated, irritated, angry. Feeling pain. Desperate to communicate, may have had many failed attempts leading to this point.
Resists care – non compliant	A person might refuse to have something done that they feel uncomfortable with. May be the only time they have the opportunity to have a sense of independence and control. Unclear of why they need to take medication, what it is for, or why they might need assistance with personal care.
Verbally aggressive	Trying to communicate an unmet need. Feeling frustrated, ignored, misunderstood.
Wanders	Walking. Exercising. Looking for someone or something. Unsure of environment. Boredom. Restlessness. Seeking change of environment, spending too much time in the same environment.
Withdrawn – compliant	Feeling disempowered. Bored. Internalising feelings. Resigned. No longer able to communicate their experience. Depressed. Loss of drive or initiative.

More information about common changes

As dementia progresses, the condition will affect different parts of the brain. The changes that occur in the brain as a result of dementia can lead a person to behave in a different way to what you are used to or how you might expect.

These changes are caused by the condition, and often the person living with dementia has no control over how they are expressed.

Consider the following as potential reasons for a change in a person's behaviour:

- » Is the person feeling scared, frustrated or helpless?
- » Is the person hungry or thirsty?
- » Is the person bored or tired?
- » Is the person in pain or ill?

If you are caring for someone living with dementia it is important to note that all of these factors can contribute to a change in a person's behaviour, particularly if they are unable to express themselves verbally. Keep notes about changes you have noticed, as this may help you to identify possible triggers.

Not all people living with dementia will experience all of the changes listed in this booklet. If you are concerned or need support or information, speak to your GP or call Alzheimer's WA on [1300 66 77 88](tel:1300667788).

Apathy

Apathy is a common symptom of dementia and can increase as dementia progresses. A person living with dementia experiencing apathy may appear disinterested, disengaged or lacking an appropriate emotional response. Apathy can also be caused by a lack of stimulation in the person's environment.

- » Help the person to complete tasks
- » Try an activity that is easy for the person living with dementia to engage in and tailored to their interests such as cooking, listening to music, exercise or pet therapy
- » Cholinesterase inhibitor medications may help in people diagnosed with Alzheimer's disease, although they do not provide positive results for everyone living with dementia
- » Options should be discussed in consultation with your GP.

Delusions and hallucinations

People living with dementia may experience delusions or hallucinations as a symptom of the condition. A person may experience the symptoms regularly or infrequently.

- » Try to identify possible triggers; consider the person's history and whether the current environment or changes to the person's health (such as infection or disorientation) or routine may be contributing to the delusions or hallucinations
- » Avoid arguing with the person, as the experience is real for them
- » Witnessing a person having delusions or hallucinations can be distressing. Seek support to help you understand what is happening.

Depression

Depression can be caused by changes in the brain due to dementia. Depression in a person with dementia may present as feeling unhappy or crying, withdrawing from people or losing interest, fatigue, hopelessness, or changes to sleep and appetite. Symptoms of depression can mirror dementia, and it can be difficult to diagnose.

Sometimes the depression is related to not being able to do the things they used to enjoy, or to do them to the same level; expectations not meeting reality or ability.

A person living with dementia has an increased risk of developing depression if they are female, have experienced depression in the past, or have a family history of depression.

Depression can be mild, moderate or severe. If a person is severely depressed, refusing to eat or drink, or acting in a way that may be dangerous to you or themselves, consult your GP immediately.

- » Support the person's identity by talking about their strengths and abilities
- » Modify a previously enjoyed activity, if necessary, so they are still able to participate
- » New activities which may give enjoyment are still worth trying, with support
- » Focus on what the person can do
- » Speak to your GP about cognitive behavioural therapy
- » Human touch, affection, appreciation, gentle understanding and meaningful engagement should not be underestimated as antidotes to depression

Anti-depressants may work well in some people, with some types of dementia.

Distress

Distress in a person living with dementia can lead to aggression, anxiety, agitation and calling out.

Aggression

Aggression may be a symptom of the changes that happen in the brain of a person living with dementia. Aggression is usually directed at the main carer and can vary depending on the type of dementia.

- » Try not to argue or reason with the person
- » Approach the person in a non-threatening way
- » Try to identify triggers that cause the aggression
- » If safe to do so, remove yourself from the person to allow them time to calm down
- » Consult with your GP if you feel you are at risk of harm.

Agitation

Agitation in a person living with dementia may present as restlessness or repetitive behaviour such as pacing or calling out. Sometimes, agitation may become worse in the early evening. Agitation is common in people living with dementia and can increase as dementia progresses.

- » Look for environmental factors or clues that may cause the person distress
- » Approach the person in a non-threatening way
- » Acknowledge the person's concerns
- » Try to engage the person in another activity
- » Alternatively if safe to do so, remove yourself from the person to allow them time to calm down.

Anxiety

Dementia can alter a person's sense of the environment around them, and this can cause confusion and anxiety. Anxiety may appear as worry or fear of being alone or being abandoned. Anxiety may also present physical symptoms such as tremor, fatigue, headache or nausea.

- » Try to identify triggers that lead to the anxiety
- » Reassure the person
- » Do not argue or try to reason
- » Provide a consistent routine
- » Try a regular activity that focuses on the person's abilities.

Calling out

People living with dementia may make repetitive loud noises such as yelling, groaning, singing, banging or screaming. Often the calling out will increase in the early evening as a person feels more anxious or distressed. There are a number of reasons why a person living with dementia will call out including: changes to routine, pain, boredom, anxiety or experiencing delusions, or lack of awareness that they are vocalising. Calling out can be distressing for carers and family members.

- » Be aware of triggers that lead to calling out
- » Try to engage the person in a calming activity such as listening to relaxing music, gentle exercise, or aromatherapy
- » If the person is distressed or confused about where they are, provide orientating clues such as clocks or newspapers.

Socially inappropriate behaviour

Socially inappropriate behaviour can be caused by some types of dementia and may include: insensitivity towards others or to what is socially acceptable, loss of insight into their own actions and how those actions may be perceived by others, lack of control over words spoken, inappropriate or offensive acts, or disinhibited behaviour.

Sometimes, socially inappropriate behaviour can be of a sexual nature. It is important to remember the person is not behaving this way intentionally.

- » Try to identify possible triggers and minimise these where possible
- » Reorient or redirect the person if they are misdirecting their attention
- » Consider activities that occupy a person's hands
- » Do not restrain the person
- » Speak to your GP who may be able to assist with individual strategies.

Shadowing

"Shadowing is when the person with dementia attempts to keep his or her caregiver in their sight at all times, following them like a small child would his or her parent"

- Angela Lunde, The Mayo Clinic

Connecting the dots between the behaviour and the individual

Dependence on a primary caregiver can mean a person living with dementia becomes upset when that person is not in sight. Analysing the contributing factors behind a person's need to shadow can be helpful in reducing or preventing its occurrence.

Consider the following:

- » Is the behaviour worse at a particular time of day?
- » Are there certain people, activities or events that seem to trigger the behaviour?
- » Can you think of anything from the person's past that might influence their behaviour?
- » Are there things that help to calm or distract the person living with dementia from shadowing?

You may find that a person living with dementia who shadows is more likely to do so in the evening, or before a meal, or after their morning cup of coffee. Being aware of certain triggers can help you devise strategies to overcome the behaviour.

Walking / Wandering

While many people living with dementia enjoy going for a walk, there is the potential for them to fall or injure themselves. Wandering is the term sometimes used to describe when a

person living with dementia leaves what is considered a safe environment and becomes lost. Despite the risks, it is important to enable opportunities for walking in a safe and independent manner.

- » Consider the person's history, they may have regularly enjoyed going for a walk in the past
- » Identify triggers and recognise cues that a person wants to go for a walk
- » If a person is feeling restless, try slow massage or slow tempo music to help alleviate the feeling
- » Provide opportunities for walking with a friend or support worker
- » Keep a recent photograph handy as a precaution
- » If a person is going for a walk independently, try to ensure they have identification with them. Consider a GPS tracking device if they are gone for long periods or like to walk alone regularly.

Use of medication to attempt to control a person's desire to walk is not recommended.





Our Vision

A world where people living 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 a cure for dementia.

Contact us

1300 66 77 88

alzheimerswa.org.au

PO Box 1509, Subiaco WA 6904

support@alzheimerswa.org.au

Our houses

**Mary Chester House,
Shenton Park**

1300 66 77 88

9 Bedbrook Place
Shenton Park
WA 6008

**Ella's House,
Mandurah**

(08) 9535 8772

11 Candelo Loop
Greenfields
Mandurah WA 6210

**Hawthorn House,
Albany**

(08) 9841 3755

40 Henry Street
Albany WA 6330

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