



The carer handbook for understanding changed behaviours

Many people living with dementia experience changes in behaviour. This guide explores each behaviour – showing you what to look out for, why it might be happening and some practical things you can do to help.

**Dementia Support
Australia**

Funded by the Australian Government
A service led by HammondCare

The information in this guide is not intended to replace medical care by a qualified professional.

Every person living with dementia is unique. They may show different signs across many behaviours relating to pain, infection or even side effects of medication.

Support should always be tailored to meet a person's individual needs.

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Understanding anxiety

Anxiety can be very common in people living with dementia. It can be hard to know what is making the person anxious and what other behaviours it might trigger. That's why it's important to try and understand the kinds of worries or fears they may be experiencing, to help improve their quality of life.

What are they worried about? Listening, understanding and validating someone's feelings is very important.

Things you may notice

When a person with dementia experiences anxiety, they may:

- Sweat or shake
- Experience palpitations or a rapid pulse
- Seem flushed or restless, perhaps not sleeping well
- Display signs of anxiety when separated from you/family carer
- Show signs of nervousness, like shortness of breath, sighing, nausea, shaky hands, excessively tense
- Worry excessively about finances, health or safety
- Be unable to sit still for long or are restless.

Why this might be happening

- Changes in temperature – too hot or too cold.
- Changes in routine.
- Being hungry or thirsty.
- A change in their home.
- Sensory overload.
- Wearing uncomfortable clothing.
- Confusion or depression.

Tips you can try at home

- Make time to listen to their feelings and validate concerns.
- Take ten slow breaths together to calm in the moment.
- Routine is important. If there have been changes to usual activities or environment, try to restore this to the original routine where possible.
- Encourage visits from important friends or family.
- Suggest relaxing activities like walking, gardening, or music.
- Try not to ever overwhelm the person with too much information at once.





Understanding apathy

Apathy is when someone lacks motivation to do things or seems not to care about what's going on around them. As a carer, it can be particularly disheartening to see this, especially around family and friends, but apathy is very common in people living with dementia, and there are some things you can do to help.

It's very important to distinguish apathy from depression. With apathy, a person is simply not motivated – and this can be distressing when they don't want to do activities they may have enjoyed before.

Things you may notice

When a person with dementia experiences apathy, they may:

- Show a disinterest in activities (although may join in when prompted)
- Sit quietly and not complete previous household tasks
- Not start conversations and show little interest in family or friends
- Withdraw from all social situations
- Look tired or be sleepy
- Lose interest in eating, and even have difficulty doing so.

Why this might be happening

- Apathy can occur due to changes in the brain as a result of dementia.
- Apathy is a very common behaviour and is likely to occur in all types of dementia as it progresses.
- It is often associated with Alzheimer's disease and frontotemporal dementia due to the area of the brain that is typically affected.



Tips you can try at home

- Keep a daily routine using something visual like a calendar, chalkboard or similar device.
- If there are interests and hobbies you know the person enjoyed before, share them with them now. Show how it's done rather than simply telling. If you get them started, they may continue by themselves.
- Try using positive active phrases such as, 'It's time to go on our morning walk,' rather than asking if they would like to go.
- Mix and match – try different strategies on different days and see what works best. It's completely normal for some ideas to work better than others.



Understanding sleep changes

Maintaining good sleep is vital, yet changes in sleep occur in most people as we age, including taking longer to fall asleep, waking more often or very early. For a person living with dementia, these sleep changes are even more extreme because dementia directly affects the body clock. This may result in not being able to tell the difference between night and day.

The ‘body clock’ in the brain controls our circadian rhythm – helping regulate the cycle of day and night. Losing control of this can be disorienting and distressing.

Things you may notice

When a person with dementia experiences sleep changes, they may:

- Nap a lot during the daytime
- Experience difficulty falling asleep or increased waking through the night
- Get confused about daytime and night
- Have night time leg cramps
- Display sleep behaviours including sleep walking/talking (common in Huntington’s disease)
- Be unable to find the toilet at night and/or have urinary issues (going to the toilet three or more times a night).

Why this might be happening

The brain produces a hormone, melatonin, as the body’s natural way of putting you to sleep. There are a number of ways that this can be disrupted and lead to poor sleep, including:

- Harsh, bright lights or staring at a blue screen (phone or computer).
- Consuming stimulants, e.g. a cup of coffee late in the day.
- A change in location/routine, e.g. hospital, a hotel or visiting family.
- The physical environment could be too loud, or too hot or cold.
- A specific response to a new medication.

Tips you can try at home

- Aim for at least 30–60 minutes of safe daylight exposure every day to help reset the ‘body clock’ and regulate a sleep pattern.
- Ensure the bedroom is a good temperature and not too loud or bright.
- Create a relaxation routine before bed – a warm drink (e.g. milk and honey), maybe a warm bath, hot water bottle, adequate bedding and other soothing things to make them comfortable.
- Reduce alcohol intake and make any afternoon tea/coffee a decaf.
- Stay active during the day to avoid sleeping in the afternoon.

Visit your GP to check if the change is from any physical or medical causes.



Understanding walking or pacing

Walking or pacing is exactly that – a deliberate walking up and down in an area repeatedly. This can be okay if the environment is safe, but becomes a problem if it causes emotional distress to the person with dementia or those around them. And in some cases, excessive walking can also cause physical discomfort, including exhaustion or joint pain.

The term ‘wandering’ (walking without reason) is sometimes incorrectly used to describe this behaviour. In fact, there can be many reasons, and understanding them is helpful.

Things you may notice

When a person with dementia is walking or pacing, they may:

- Be happy walking for long periods of time, day or night
- Experience changes or disruptions to sleep
- Experience falls or fractures due to the time on their feet
- Be withdrawn from social situations, preferring to walk/pace instead
- Not want to sit down when asked
- Seem to be in distress or discomfort, yet continue to stay on their feet.

Why this might be happening

- The person may be feeling bored or understimulated.
- Perhaps they're looking for something – company, the toilet, people such as family members or friends, or an object or destination.
- Akathisia – where someone feels driven to move, despite being uncomfortable. (It can be a side effect of antipsychotic drugs.)
- A response to the environment – such as an area that is noisy or too brightly lit.
- The person may be walking or pacing due to feeling anxious, worried or concerned.
- Expressions of anxiety and/or depression.
- The person may be experiencing pain or physical discomfort.

Tips you can try at home

- Avoid noise and bright lights throughout the home.
- It is common for a person with dementia to stand, walk or avoid sitting due to pain. So keep alert to signs of pain or discomfort from their facial expressions, other changes to behaviour and/or mood, how they communicate or abnormal rubbing, leaning or limping. Visit your GP if pain is suspected.
- Use signs, images, familiar objects to help the person find a room, exit, or access to outdoors.
- Support the person to engage in activities that are meaningful and relevant to them, e.g include a regular walk after lunch or watching the evening news. Where possible, encourage the person to have regular breaks.



Understanding distress during personal care

Distress during personal care relates to a negative response you may get while assisting during activities such as dressing, showering or toileting. Personal care is important for health and comfort, however, it is also an intimate activity that may make a person feel vulnerable.

If someone is receiving personal care and unable to let you know how they feel, this can cause distress. It's important to look very carefully at all the different possible causes.

Things you may notice

When a person with dementia becomes distressed during personal care, they may:

- Become very upset, shout or scream
- Actively push away or scratch
- Freeze, turn away or cry
- Have difficulty telling you they need to use the toilet
- Refuse to have a shower.

Why this might be happening

- They may be unable to recognise the task you're suggesting.
- Sensory changes that may make the feeling of running water uncomfortable and distressing.
- Cultural beliefs concerning gender roles, e.g. feeling uncomfortable being washed by a friend or family member of the opposite gender.
- A change in body senses due to dementia.
- It may be related to past trauma.
- It could be related to simply not asking, e.g. if they wanted to have a shower.
- Look for signs they might be in pain – e.g. wincing, clenching teeth, groaning or frowning. Address any pain with your local GP.

Tips you can try at home

- Consider their personal routine, e.g. does the person prefer a warm bath before bed, or have they always taken a morning shower?
- Make things as comfortable as possible – warm and well-lit with favourite soaps, favourite colour towel/cloth or playing their favourite music.
- Try simplifying the task – focusing on one half of the body at a time (whilst maintaining dignity/privacy throughout).
- If they become upset at any time, take a step back and wait quietly until they are ready for your help again. Be flexible if it doesn't go to plan – showering just a couple of times a week is okay.
- Keep a record of what is working and what's not. Some strategies may work on some days and not others, that's okay.



Understanding wanting to leave or go home

Wanting to leave or wanting to go home is common in people with dementia and can be quite confronting or confusing for carers. Sometimes known as 'absconding' (an outdated term) or 'elopement', it typically happens when a person doesn't recognise their own surroundings. This may prompt a person to seek out a familiar and comforting environment.

A person living with dementia can become very distressed if they are redirected or told not to go out.

Things you may notice

When a person with dementia experiences wanting to leave or go home, they may:

- Attempt to leave or exit through any door
- Ask others, 'How do I get out?'
- Pack bags, try to get in the car, and demand to 'go home'
- Pace constantly or follow visitors
- Enter other rooms or rummage through drawers.



Why this might be happening

- They don't recognise their surroundings or the people around them – they are seeking a sense of safety/comfort/familiarity.
- They are reminded of a previous home and it causes confusion.
- They may think they're trying to go home, even if they are at home.
- They may be unhappy, uncomfortable, bored or lonely.
- There is something they think needs completing, e.g. 'I need to pick up John from school'.
- It may be too noisy, bright or unfamiliar and they are trying to escape the situation.
- They're genuinely lost – having difficulty with direction and finding their way around.

Tips you can try at home

- Ask where and why they want to go, giving them time to answer and addressing any wishes and concerns. Acknowledge their feelings.
- In the moment, try to redirect the person's attention to something they enjoy.
- Have a think about their usual environment – has it changed recently? Are there things to make it feel more familiar, e.g. photos, objects/art/keepsakes or their favourite music.
- Store items such as keys, coats, handbags, and suitcases out of sight.
- Consider a personal GPS device such as a watch or trackable item that can be worn and allows you peace of mind to find them if need be.



Understanding agitation

People living with dementia may experience agitation for a variety of reasons. How a person expresses agitation may vary and it may seem to 'come out of nowhere'; however, there are usually signs to look for and ways to help.

There are many reasons why the person you care for may experience agitation. Remaining calm is important.

Things you may notice

When a person living with dementia experiences agitation, they may:

- Constantly call out or ask questions
- Have difficulty concentrating
- Say that they want to go home
- Seem visibly upset, easily angered and possibly aggressive
- Pace/walk, unpack drawers or remove clothing
- Continuously pick at something, e.g. furniture or bedsheets.



Why this might be happening

- Recent changes in their home (no matter how small).
- Being in a completely different location/setting, e.g. hospital/hotel.
- Sleep disturbances.
- Communication barriers.
- Over- or understimulation, e.g. noise, light, people or weather.
- Physical changes such as pain and infection.
- Confusion or restlessness in the late afternoon and evening.

Tips you can try at home

- Remain calm and avoid arguing or reasoning.
- Ask or look for any signs of pain/discomfort, such as wincing, groaning, clenching teeth or frowning. Seek support from a GP or pharmacist if pain is observed.
- Try a 'change of scene' to improve their mood – asking if they'd like to go for a short walk, ideally outdoors.
- Acknowledge how they are feeling and reassure them. Do they need comfort or just some space?
- Avoid mentioning the agitation again and move on to something new.

In addition, if sudden changes in behaviour are seen, ask their GP to check for any infections or other physical causes.



Understanding aggression

Some people living with dementia may become verbally or physically aggressive at times towards a person, people, or objects. It is important to remember that there is often a reason why the person is becoming aggressive. By identifying the reason we can best support the individual and reduce the impact of the aggressive behaviour.

A better understanding of aggressive behaviour can have positive results.

Things you may notice

When a person with dementia experiences aggression, it may be physical:

- Pushing out at others forcefully
- Scratching, hitting, kicking, slapping, biting or pinching others when they attempt to provide care or come into their personal space
- Throwing objects and damaging property.

Or it may be verbal:

- Yelling or shouting at others
- Making threats.

Why this might be happening

- Recent changes in their home.
- Being in a completely different location/setting, e.g. hospital/hotel.
- Over- or understimulation, e.g. noise, light, people or weather.
- Sleep disturbances.
- Communication barriers.
- Disinhibition.
- Confusion or delirium.
- Pain and discomfort or infection.
- Confusion or restlessness in the late afternoon and evening.

Tips you can try at home

- Be prepared to give the person space to vent or express themselves safely and come back when they have calmed down.
- Observe and note down what occurs and how often it occurs. This can help identify patterns and potential causes to look out for in future.
- Consider what happened before you noticed the aggression to understand if there have been recent changes for the person or other potential reasons (e.g. pain, confusion).
- Support the person to engage in an activity that is meaningful and relevant to their likes and interests, e.g. spending time in the garden or listening to music.

Remember that any undiagnosed pain can lead to aggression, so contact their GP to discuss other treatments if needed.



Understanding disinhibition

Disinhibited behaviours involve those where the person living with dementia says or does impulsive things that are out of character or confronting. This can be confusing or confronting for carers and family members – often causing significant distress, as well as feelings of embarrassment and stress about going out in public.

It's important to understand that the person is not trying to offend or embarrass you.

Things you may notice

When a person with dementia experiences disinhibition, they may:

- Make hurtful, rude or impulsive comments
- Talk to strangers as if they know them
- Lose sexual inhibition, hugging or kissing someone in an inappropriate way
- Undress in an unexpected setting or situation
- Buy items they would normally never buy.



Why this might be happening

- If dementia affects the frontal lobe of the brain, this can result in losing the 'filter' that normally gives us the ability to know what is 'normal' social behaviour and what is not.
- It may also be caused by changes within the environment.
- Sometimes it is a response to being misunderstood – through verbal comments or physical contact.
- Disinhibition can also be seen when someone is confused from a delirium, e.g. think they're at home, when actually out in a public place.

Tips you can try at home

- In the moment, remain calm and try not to react in a negative way. A quiet response is often helpful.
- Remember, the person is not deliberately trying to offend or embarrass you.
- Try to redirect the person's focus onto something else and, if possible, move to a different environment.
- Consider carrying a checklist with you to help quickly identify possible causes as to what may have happened that led to this behaviour.



Understanding hallucinations

A hallucination is when you see something that actually isn't there, or when you hear (music, voices), smell, taste or touch things that don't exist. Hallucinations are a common symptom of dementia, often (but not always) bringing out other behaviours covered in this guide, such as aggression.

Dementia can impact all of the senses in different ways and it is completely individual. It is important to believe any distress caused, and then find small ways to reduce that distress.

Things you may notice

When a person with dementia experiences hallucinations, they may:

- Describe seeing unusual things/objects
- Tell you they hear voices, music or noises
- Experience other sensory things such as taste, smell or touching things that are not there.

Why this might be happening

- Typically it's the result of sensory impairment – so if someone is not wearing glasses, visual hallucinations are most likely. No hearing aid may bring about auditory hallucinations.
- The environment can also be a trigger – including furniture or items of clothing and patterns.
- Past trauma may result in 'voices' or other stimuli.
- Some drugs may have side effects or withdrawal symptoms that include hallucinations.
- Changes to the brain due to dementia may trigger delirium and/or hallucinations.
- In rare cases, epilepsy or brain tumours may be the cause.

Tips you can try at home

- It's important to note not all hallucinations cause distress – however, may cause someone to become angry or scared. Each instance may be different.
- Keep a log of when and what hallucinations are experienced – see if there is a pattern in environment or factors leading to a hallucination.
- Remember to validate their feelings – letting them know that you believe what they are experiencing, as it is real to the person.
- Book a health/vision check, as hallucinations can be related to eye conditions or hearing loss.
- If family and friends are distressed, support may be needed in understanding why this might be happening.

As always, speak to their GP about other possible physical causes including infections, reactions to medication or dehydration.

Notes

Notes

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The information contained within this guide has been compiled with the assistance of Professor Sue Kurrle, Geriatrician.

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