Identifying and understanding changes in behaviour

Dementia Support Australia

About this guide

Many people living with dementia experience changes in behaviour. This guide explores the most common behaviours, showing you what to look out for, why it might be happening and practical strategies that can help, whether you're caring for a loved one at home, supporting residents in aged care, or working as a health professional in an acute setting.

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.

Dementia Support Australia provides support for people living with dementia and is available anytime day or night on 1800 699 799 or live chat at **dementia.com.au**

Dementia Support Australia

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Contents

Understanding **dementia and behaviours**

Dementia affects everyone differently and is a personal experience for each individual. Changes in behaviour are common and can appear gradually or more suddenly over time which can be confusing or unexpected for those providing support.

This handbook recognises the impact these changes can have on everyday life, including how people connect, communicate and experience care. It has been developed to support understanding and provide practical, person-centred strategies, whether you're a family member, an aged care team member, or a health professional.

Why changes in behaviour occur

There are many reasons why someone living with dementia may begin to behave differently. Physical changes in the brain affect memory, judgement, communication and emotional regulation. However, behaviour is also shaped by a person's environment and experiences.

Pain, discomfort, confusion, over-stimulation, fatigue or unmet needs — even something as simple as hunger or needing the toilet — can all influence behaviour. Changes in routine, surroundings or care environment may also contribute.

For many people living with dementia, behaviour becomes a primary way of communicating when words are no longer easy to find. Understanding what someone may be trying to express through their behaviour is an essential part of providing compassionate support.

These behaviours are never deliberate

It's important to understand that behaviours such as anxiety, agitation, aggression, or social withdrawal are not intentional. They are signals that the person may be feeling distressed, overwhelmed, unsafe or unsure of what is happening around them.

Though these moments can be challenging and at times upsetting, an empathetic, person-centred approach can make a significant difference for the person living with dementia and those supporting them.

How this handbook can help

This handbook explores ten of the most common changes in behaviour associated with dementia. For each behaviour, you'll find:

- Examples of how it may present
- Possible causes or contributing factors
- Practical strategies you can use in any care setting

While each person's experience with dementia is unique, recognising the meaning behind changed behaviours is a powerful step towards more person-centred, supportive care. It's also a valuable way to reduce stress and improve quality of life for both the person living with dementia and everyone involved in their care — whether family, friends or care professionals.

Anxiety

Anxiety is very common in people living with dementia. It can be hard to identify what is making the person anxious and what other behaviours it might trigger.

It's important to try to understand the kinds of worries or fears they may be experiencing, to help improve their quality of life.

Identifying the signs of anxiety

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 familiar people or primary supports
- Show signs of nervousness, like shortness of breath, sighing, nausea, shaky hands, or excessive tension
- Worry excessively about finances, health or safety
- Be unable to sit still for long or are restless.

Understanding the cause of the anxiety

There can be more than one issue causing anxiety, but consider:

- Changes in temperature — too hot or too cold
- Changes in routine or daily activities
- Being hungry or thirsty
- Changes in their environment or surroundings
- Sensory overload (too much noise, activity, or stimulation)
- Uncomfortable clothing or footwear
- Confusion, depression, or underlying health conditions
- Unfamiliar people or new care staff
- Medication changes or side effects.

Ask yourself:

What might they be concerned about?

Ways you can provide support

- Listen to their feelings, validate concerns and offer reassurance in a calm, gentle way.
- Practise slow breathing together (for example, ten slow breaths) to help in the moment.
- Maintain familiar routines and restore usual patterns if there have been changes.
- Encourage connection with familiar people, including consistent staff in care settings.
- Create a calm, quiet space and offer soothing activities such as gentle walks or familiar music.
- Share information in small, manageable amounts to avoid overwhelming them.

Apathy

Apathy is when someone lacks motivation to do things or seems not to care about what's going on around them. This can be particularly challenging for those providing support, especially when the person shows little interest in family, friends, or activities they once enjoyed. Apathy is very common in people living with dementia and there are strategies that can help.

Identifying the signs of apathy

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 tasks or activities
- Not start conversations and show little interest in people around them
- Withdraw from social situations
- Look tired or be sleepy
- Lose interest in eating, and even have difficulty doing so.

Understanding the cause of apathy

- 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.
- Environmental factors such as lack of stimulation or changes in care setting.

It's important to distinguish apathy from depression. With apathy, a person is simply not motivated

Ways you can provide support

- Maintain a daily routine using a calendar or a whiteboard.
- If there are interests and hobbies the person enjoyed before, share them together now. Demonstrate 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.
- In care settings, communicate preferences and past interests with all team members to ensure consistency.
- Mix and match — try different strategies on different days and see what works best. It's completely normal for some approaches to work better than others.
- Be patient and avoid pressure — forcing participation can increase resistance.

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 can be 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.

Identifying the signs of sleep changes

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 sleepwalking or 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).

Understanding the cause of sleep changes

The brain produces a hormone, melatonin, as the body's natural way of inducing sleep. There are a number of ways this can be disrupted:

- 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, residential care, or moving between care settings
- The physical environment could be too loud, or too hot or cold
- A specific response to a new medication
- Sharing a room with others in care settings.

Ask yourself:

Is the care setting or changed lifestyle, contributing to disturbed sleep?

Ways you can provide support

- 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 sleeping environment 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 afternoon tea/coffee a decaf.
- Stay active during the day to avoid sleeping in the afternoon
- In care settings, try to maintain consistent sleep routines and minimise disruptions from night checks where safe.
- Consult with a GP or health professional to check if the change is from any physical or medical causes.

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 concern if it causes emotional distress to the person with dementia or those around them. In some cases, excessive walking can also cause physical discomfort, including exhaustion or joint pain.

Identifying the signs of walking or pacing

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.

Did you know: "wandering" (walking without reason) is sometimes incorrectly used to describe this behaviour.

Understanding the cause of walking or pacing

- The person may be feeling bored or under-stimulated.
- 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.
- In care settings, trying to find the way out or looking for familiar surroundings.

Ways you can provide support

- Avoid noise and bright lights in the environment.
- People living with dementia may stand, walk or avoid sitting due to pain. Stay 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. Seek medical advice if pain is suspected.
- Use signs, images, familiar objects to help the person find rooms, exits, 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 and rest periods.
- In care settings, consider creating safe walking paths or enclosed outdoor areas where the person can walk safely.
- Ensure footwear is comfortable and appropriate to prevent falls.

Distress during personal care

Distress during personal care relates to a negative response that may occur 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.

Identifying the signs of distress during personal care

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 communicating they need to use the toilet
- Refuse to have a shower or participate in personal care
- Be unable to sit still for long or are restless.

Ask yourself: Are they trying to tell you this is causing distress?

Understanding the cause of the distress

- They may be unable to recognise the task being suggested.
- 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 someone of the opposite gender.
- A change in body senses due to dementia.
- It may be related to past trauma.
- It could be related to not being asked or given choice about the care.
- They might be experiencing pain — e.g. wincing, clenching teeth, groaning or frowning.
- Lack of privacy, especially in shared care environments.
- Unfamiliar care staff providing intimate care.
- The person may not understand what is happening or why.

Ways you can provide support

- Consider their personal routine and preferences, such as bathing times or products they are familiar with.
- Create a comfortable environment with warmth, good lighting, privacy, and familiar items like favourite soaps or towels.
- Introduce yourself and explain each step calmly using simple language.
- Simplify the task by focusing on one step or body area at a time, while maintaining dignity and privacy.
- Support the person to do as much as they can independently.
- If they become upset, step back and wait quietly until they are ready for help. Bathing a few times a week may be enough.
- Where possible, have familiar people provide care — consistency helps build trust.
- Keep track of what works, knowing strategies may vary.
- In care settings, document preferences for all team members.
- Respect and support the person's cultural preferences and background.

Wanting to leave or go home

Wanting to leave or wanting to go home is common in people living with dementia and can be quite challenging for those providing support. 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. It's particularly common for people living in aged care homes.

Identifying the signs of wanting to leave or go home

When a person living 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

Ask yourself: Is 'home' a place or feeling?

Understanding wanting to leave or go home

- They don't recognise their surroundings or the people around them — they are seeking a sense of safety, comfort and 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 in their own home or long-term residence.
- 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.
- Recent admission to hospital or aged care home.
- Change in care staff or daily routine.

Ways you can provide support

- Ask where and why they want to go, allowing time to respond and acknowledging their feelings.
- Explore what 'home' means to them — such as safety, loved ones, or purpose.
- Redirect their attention to something familiar, enjoyable, or meaningful.
- Make the environment feel familiar with photos, music, or personal belongings.
- Avoid arguing about whether they can leave, as this may increase distress.
- Keep items like keys, coats, and bags out of sight.
- In care settings, create homelike spaces with familiar belongings.
- Consider a GPS device or trackable item to support safety and peace of mind.
- Reminisce about positive memories rather than debating their location.
- Encourage meaningful activity and social connection.

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.

Identifying the signs of agitation

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.

Ask yourself: How can I remain calm?

Understanding the cause of the agitation

- Recent changes in their environment (no matter how small).
- Being in a completely different setting, e.g. hospital, aged care home.
- Sleep disturbances.
- Communication barriers or difficulty expressing needs.
- Over- or under-stimulation, e.g. noise, light, number of people, weather.
- Physical changes such as pain and infection.
- Confusion or restlessness in the late afternoon and evening.
- Too many people in the space or conflicting instructions from different staff members.
- Unmet needs such as hunger, thirst or needing the toilet.

Ways you can provide support

- 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 health professional 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 or give the person space if it's safe to do so.
- Acknowledge how they are feeling and reassure them. Do they need comfort or just some space?
- Avoid revisiting the agitation and move on gently.
- In care settings, stay calm and don't take it personally.
- Document patterns to help the care team identify triggers.
- Communicate observations with other team members.
- If sudden changes in behaviour are seen, consult with a health professional to check for any infections or other physical causes.

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.

Identifying the signs of aggression

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

- Pushing out at others forcefully
- Scratching, hitting, kicking, slapping, biting or pinching in response to care being provided or someone entering their personal space
- Throwing objects and damaging property

Or it may be verbal:

- Yelling or shouting at others
- Making threats.

Understanding the cause of the aggression

- Recent changes in their environment or care routine.
- Being in a completely different setting, e.g. hospital, aged care home.
- Over- or under-stimulation, e.g. noise, light, number of people, weather.
- Sleep disturbances or fatigue.
- Communication barriers or frustration at not being understood.
- Disinhibition due to brain changes.
- Confusion or delirium.
- Undiagnosed or untreated pain, discomfort or infection
- Confusion or restlessness in the late afternoon and evening.
- Feeling threatened or invaded in their personal space.
- Previous negative experiences in care settings.

Ask yourself:
What is the reason for the aggression?

Ways you can provide support

- Give the person space to calm down before offering support.
- Stay calm and avoid taking the behaviour personally — it may be a form of communication.
- Remove yourself and seek support if you feel unsafe.
- Observe patterns, triggers or recent changes such as pain, confusion or unmet needs.
- Encourage familiar activities like music or gardening.
- Share helpful approaches with family or care team members.
- Provide care in a calm, unhurried way.
- Consider whether pain may be contributing and seek medical advice if needed.

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 challenging for those providing support and family members — often causing significant distress, as well as feelings of embarrassment and concerns about social situations.

Identifying the signs of disinhibition

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
- Make inappropriate remarks about people's appearance or personal matters.

Remind yourself:
This is not personal, it's the impact of dementia

Understanding the cause of disinhibition

- If dementia affects the frontal lobe of the brain, it can result in the loss of the 'filter' that gives us the ability to know what is appropriate 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 communication or physical contact.
- Disinhibition can also be seen when someone is confused from a delirium, e.g. they think they're at home, when actually in a public place or care home.
- Medication side effects.
- Unfamiliar or overstimulating environments.

Ways you can provide support

- In the moment, remain calm and try not to react in a negative way. A quiet, matter-of-fact 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.
- If in public, calmly and quietly move the person to a more private area if needed.
- Consider carrying a checklist to help quickly identify possible causes of the behaviour.
- In care settings, brief other team members on strategies that work.
- Maintain the person's dignity and privacy as much as possible.
- If sexual disinhibition is present, redirect the person to an alternative setting and maintain professional boundaries.
- Educate family members and visitors about the behaviour being a symptom of dementia, not intentional.

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 anxiety or agitation.

Identifying the signs of the hallucinations

When a person with dementia experiences hallucinations, they may:

- Describe seeing unusual things or objects that others cannot see
- Tell you they hear voices, music or noises that aren't present
- Experience other sensory sensations such as taste, smell or touching things that are not there
- Become distressed, frightened or agitated by what they're experiencing
- React to or interact with things that aren't visible to others.

Remind yourself: Any distress to the person living with dementia feels real.

Understanding the cause of the hallucinations

- Sensory impairment is a common cause — not wearing glasses or hearing aids may contribute to hallucinations.
- Environmental triggers can include patterns, shadows, reflections, furniture, or clothing.
- Past trauma may contribute to voices or other sensory experiences.
- Changes to the brain due to dementia may trigger delirium or hallucinations.
- Some medications may cause hallucinations as side effects or withdrawal symptoms.
- Poor lighting, mirrors, TV images, or busy visual environments can worsen hallucinations.
- In some cases, epilepsy, brain tumours, infections, or other medical conditions may be the cause.

Ways you can provide support

- Not all hallucinations are distressing, but they can cause fear, anxiety, or anger.
- Keep a record of when hallucinations occur to help identify patterns or triggers.
- Validate the person's feelings and avoid arguing about what is real.
- Offer reassurance and comfort, for example: *"That sounds frightening."*
- Arrange health, vision, and hearing checks, as hallucinations may relate to physical conditions.
- Ensure glasses and hearing aids are worn if prescribed.
- Improve lighting, reduce clutter, and remove mirrors if they cause distress.
- Support family, friends, and care teams to understand possible causes and triggers.
- Consult a health professional about possible physical causes such as infection, dehydration, or medication reactions.

Notes

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