

Dementia and behaviours that challenge

People living with dementia have reduced cognitive abilities, which have an effect on:

- memory
- thinking
- reasoning
- logic
- planning
- problem-solving
- communication
- orientation
- social connection
- the ability to perform everyday tasks

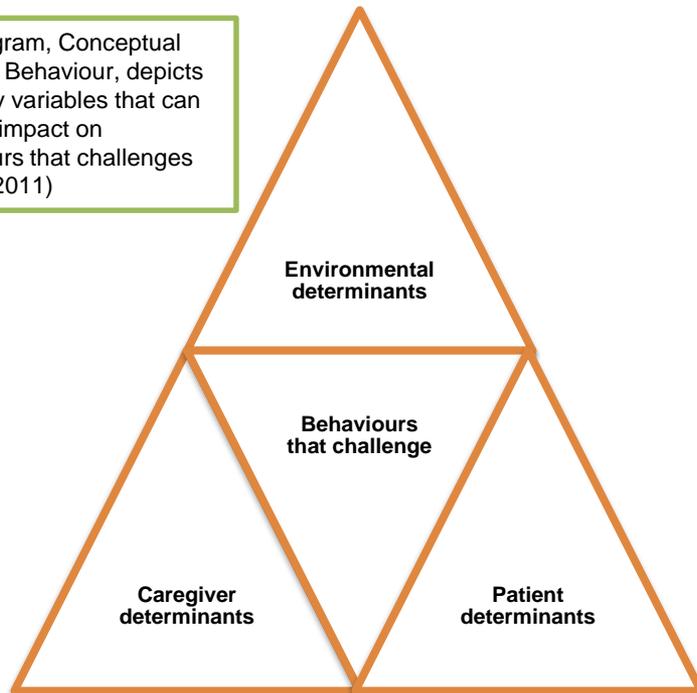
Their symptoms can cause changes in:

- emotions
- reactions
- behaviour
- personality
- mood

The changes may increase as dementia progresses, creating new challenges for people living with dementia, their families/whānau and caregivers

- Behaviour and psychological symptoms of dementia (BPSD) is a term used by health professionals, which focuses on symptoms of dementia (James 2011) because it implies that problematic behaviours are linked directly to the dementing process
- When looking at behaviours that challenge it is important to recognise that not all behaviours are caused directly by dementia. Many behaviours are normal coping strategies used by all of us to deal with difficult situations
- The term 'behaviours that challenge' shifts the focus of attention away from individual pathology towards an understanding that the behaviour challenges carers and service providers to find solutions
- People living with dementia experience changes in their ability to express and resolve their needs
- People living with dementia respond from their reality, which we cannot change: but we can change our approach to support them

This diagram, Conceptual Model of Behaviour, depicts the many variables that can have an impact on behaviours that challenge (James 2011)



Environment determinants	Patient determinants	Caregiver determinants
<ul style="list-style-type: none"> ▪ Unfamiliar or unstructured environment ▪ Too large, too small, too much clutter ▪ Over/under-stimulation ▪ No orientation information or cues 	<ul style="list-style-type: none"> ▪ Have their basic needs been met? ▪ Impaired vision or hearing? ▪ Acute illness, dehydration or constipation? ▪ Effects of medication, fatigue? ▪ Pain or physical discomfort ▪ Stress, coping abilities ▪ Expecting unfamiliar tasks beyond their abilities ▪ Cultural influences, life experience 	<ul style="list-style-type: none"> ▪ Experience/ education/ understanding ▪ Support – financial situations ▪ Other responsibilities ▪ Response to stress/resilience ▪ Adequate breaks, fatigue ▪ Communication, approach/workplace culture

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Understanding some common challenging behaviour with solutions for people living with dementia:

Calling out/vocalising

The need to communicate never goes away. All vocalising behaviour has a meaning – it is an attempt to communicate or express a need. It may be true distress as a result of feelings of loss and being overwhelmed

It can be difficult and frustrating to work out what people with dementia need and may seem like they are expressing behaviours that challenge for no apparent reason

Assess and look for the meaning behind the behaviour

Common triggers:

- Physical: pain, hunger, the need to use the toilet
- Environment: too busy or loud, a change in routine, unfamiliar environment, too hot or too cold
- Psychological loneliness, boredom, anxiety, depression, delusions

Strategies to understand and find a solution:

- Assessment – use tools to collect evidence, eg, behaviour charts, pain assessment
- Identify and remove triggers
- Don't ignore or talk over the person
- Find out information about them to personalise the response:
 - attend to the need not the behaviour
 - try social interaction and sensory stimulation
 - try low stimulus environment
 - consider relaxing approaches

Repetitive actions

A person living with dementia may do or say something over and over again – like repeating a word, question or activity, pacing, or undoing what has just been done. In most cases they are looking for comfort, security and familiarity. These actions are rarely harmful but can be stressful for the caregivers

Look for a reason – try to find out if there is a specific cause or trigger for the repetitive behaviour

Focus on the emotion rather than reacting to what the person is doing – respond to how they are feeling

Turn the action or behaviour into an activity – if the person is rubbing a hand across a table, provide a cloth and ask for help with dusting

Stay calm and be patient – reassure the person with a calm voice and gentle touch (if appropriate)

Provide an answer – give the person the answer they are looking for even if you have to repeat it several times. It may help to write it down and post it in a prominent position

Engage the person in an activity as they may simply be bored and need a distraction, eg, take them for a walk or engage them in a puzzle

Use memory aids – offer reminder-like notes, photographs, clocks or calendars

Take a break – if the person is in a safe environment and you are able, walk away and take a moment for yourself

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Wandering, walking – common causes	<ul style="list-style-type: none"> ▪ Memory loss: they may not remember their destination, it may be part of their past routine, eg, going to work or meeting a friend ▪ Physical needs: a need to go to the toilet, pain, hunger, thirst, etc ▪ Social needs: boredom, loneliness, over- or under-stimulation ▪ Sleep deprivation: increased mental fatigue due to lack of sleep can contribute to confusion and disorientation ▪ Side effects from medication: causing disinhibited behaviour and restlessness, which can result in wandering ▪ Disorientation: confusion regarding time, place and identity combined with memory loss and an inability to recognise familiar people and environments may cause wandering in an effort to reach a more familiar and comfortable place 	
How you can make a difference	<ul style="list-style-type: none"> ▪ Individualised person-centred care ▪ Focus on early intervention and prevention as well as treatment ▪ Focus on accurate assessment ▪ Develop a culture of caring that prioritises quality of life ▪ Create a social and physical environment that is responsive to changing needs 	<ul style="list-style-type: none"> ▪ Involve family, whānau and friends ▪ Reduce stress for the person with dementia ▪ Focus on staff education ▪ Do more of what works well
Why do people with dementia resist care?	<ul style="list-style-type: none"> ▪ Lack of insight ▪ Level of cognitive functioning ▪ A reduced ability to communicate their needs ▪ They can't understand what they are being asked to do or how to make it happen ▪ Mobility and dexterity ▪ Depression ▪ Unable to perform complex tasks involving a series of movements or goal-directed behaviour ▪ Unfamiliar environment ▪ Fatigue 	<ul style="list-style-type: none"> ▪ Embarrassment or humiliation ▪ Loss of dignity or privacy ▪ Apathy, loss of strength and stamina ▪ Suspiciousness, there is not enough trust ▪ Self-determination – sense of independence, they may feel they are being bossed about or controlled ▪ Visual disorders – not recognising or identifying objects ▪ Design and layout making access difficult ▪ People working with them or they themselves not knowing how much assistance they need
Suspiciousness, blaming, accusing	Memory and confusion may cause a person living with dementia to perceive things in new and unusual ways. Sometimes they may misinterpret what is seen or heard and become suspicious of those around them, even accusing others of theft, infidelity or other behaviours	
Don't take offense	Listen to what is troubling them and try to understand. Be reassuring, respond to the feeling and let the person know you care	
Don't argue or try to convince or correct	Consider that the accusations may be based on past experiences. What they are experiencing is real to them. Allow the person to express their ideas and acknowledge what was said. Validate their feelings: keep conversations simple. Try and find the underlying reason	
Switch the focus to another activity	Engage the person in an activity or ask for help with something	

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Sleeping difficulties	People with dementia may have problems sleeping. Although the exact cause is unknown, sleep changes can result from the disease's impact on the brain. Discuss sleep disturbances with a doctor to help in identifying causes and possible solutions.	
Make a comfortable environment	The sleeping area should be at a comfortable temperature. Use nightlights and take other steps to keep the person safe, such as installing appropriate door and window locks.	
Maintain a routine (sleep hygiene)	<ul style="list-style-type: none"> As much as possible encourage a regular routine of waking up, taking meals and going to bed at appropriate times Reduce or avoid alcohol, caffeine, nicotine and other stimulants, which can all affect the ability to sleep 	<ul style="list-style-type: none"> Most experts encourage the use of non-pharmacological measures first, eg, relaxation techniques, hot drink, etc Discourage screen use during periods of wakefulness at night as it can be stimulating
Exercise	Physical activity may promote restfulness at night – this may include walking, swimming, etc	

Anger and aggression

Aggressive behaviour may be

- verbal**, eg, shouting, name-calling, swearing, screaming, making threats
- physical**, eg, hitting, pushing, pinching, scratching, hair-pulling, biting

It's important to try and find out what's causing the anger and try to prevent it from occurring when possible

Triggers: think about what happened right before, which may have triggered the behaviour

Pain: can trigger aggressive behaviour for a person living with dementia

Focus on feelings not facts: look for the feelings behind the words or action

Try not to get upset: be positive and reassuring; speak slowly and in a soft tone

Limit distractions: examine the person's surroundings and adapt them to avoid similar situations

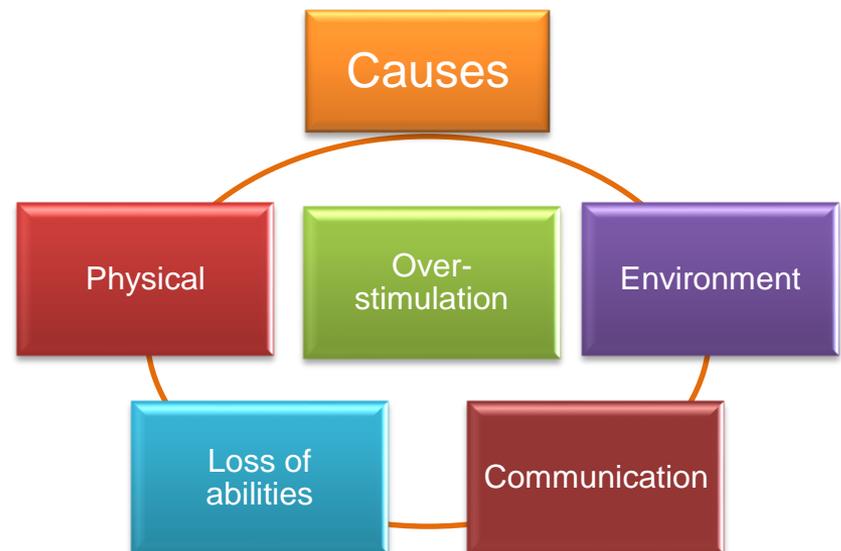
Try a relaxing activity: use music, massage or exercise (consider fiddle mitts) to help soothe the person

Shift the focus to another activity: if a situation or activity causes aggression, try something different

Take a break: if the person is in a safe environment, take a break

Ensure safety: make sure you and the person are safe. If the person is unable to calm down, seek assistance from others

Look for the causes behind the behaviour



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Interventions for behaviour assessment and management	<ul style="list-style-type: none"> ▪ Look for the causes behind the behaviour ▪ Become a detective, not a judge ▪ Contributing factors can be reduced or eliminated ▪ Address unmet needs 	<ul style="list-style-type: none"> ▪ Assessment using behaviour charts can provide evidence of frequency, patterns and identify triggers (collect evidence) ▪ Manage triggers
Other useful assessment tools	<ul style="list-style-type: none"> ▪ Cohen-Mansfield Agitation Scale ▪ Abbey Pain Scale ▪ Delirium screen and 4AT, eliminate reversible causes 	

How you interact and communicate with the person living with dementia has a direct effect on their behaviour and how they will respond. Use validation diversion and redirection techniques. Address loneliness and isolation.

Consider: sensory stimulation or a low stimulus environment, pet therapy, exercise; use their remaining abilities to occupy them. They respond from their reality which we cannot change. We can change our approach to support them.

Medication can be considered a chemical restraint when it is used to manage a person's behaviour or restrict their freedom of movement. There is now movement towards reducing the use of antipsychotic medication for challenging behaviour. Non-pharmacological approaches need to be the first method of treatment. Antipsychotics are used when there is evidence of psychosis (delusions or hallucinations) and the person with dementia is in severe distress or harm will be caused to them, those who care for them or other people.

Consider referral to Mental Health Services for Older Adults (MHSOA) when:

- assessment for dementia of psychogeriatric (PG) level of care is required
- behaviour has been assessed and a delirium screen has been completed with treatment commenced for underlying cause
- the behaviour has not responded to comprehensive non-pharmacological treatments
- behaviour is dangerous, distressing, persistent, disturbing or damaging to social relationships
- medication review/advice about antipsychotic medication is required by a specialist

Please call the MHSOA referral screener for all requests, information and advice:
 Tel: (09) 486 8945 ext 43222 (8.00am–4.30pm, Monday to Friday)
 Fax: (09) 486 8997 (for referrals)

