



# Understanding changed behaviour

A guide for people with dementia and their family/whānau





## A dementia friendly New Zealand

*Aotearoa, he aro nui ki te hunga mate wareware*

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### Disclaimer

This booklet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person affected by dementia or memory loss (including family/whānau and others who provide support) should seek professional advice about their individual situation. Alzheimers NZ is not liable for any error or omission in this publication, as a result of negligence or otherwise.

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# Introduction

While receiving a diagnosis of dementia can be a shock for everyone involved, a lot can be done to help people – as well as their families/whānau – to live positively and well with dementia.

This booklet is designed to provide information on some common changed behaviours and challenges you may encounter as you support someone with dementia. It includes information about what might be causing the behaviour and some tips to help you support the person with dementia to live well.

This booklet is one of a series of booklets about dementia.

Other titles in the series are:

- **About Dementia:** a guide for people diagnosed with dementia
- **Living well with dementia:** a guide for people diagnosed with dementia
- **Supporting a person with dementia:** a guide for family/whānau
- **Transitioning into residential care**
- **The later stages of dementia and end of life care**

By necessity, this booklet contains clinical terminology and is structured so you can easily find a certain situation such as agitation or hallucinations. When faced with out of character challenging situations it is important to remember and focus on the individual person during the challenging times, remember we are all complex individuals and that is reflected in how we behave. We all feel – that's what makes us human – we feel anxious, angry, agitated at times, but for people with dementia it may happen more often and more intensely.

Remember that you are not alone – help is only a phone call away. Contact your local Alzheimers organisation for support or information on **0800 004 001**.

More detailed fact sheets about many of the topics covered in this booklet can be found at **[www.alzheimers.org.nz](http://www.alzheimers.org.nz)**

# Dementia

## What is dementia?

Dementia is an umbrella term used to describe a group of symptoms that affect how well our brains work. Alzheimer's disease is the most common form of dementia. Dementia can affect anyone, and as people get older the chances of developing dementia increase.

The symptoms each person experiences depends on the parts of the brain that are affected. However, the most common dementia symptoms include changes in memory, thinking, behaviour, personality and emotions. These changes affect a person's ability to perform everyday tasks and may interfere with their everyday lives.

Dementia is progressive, which means that for most people the changes gradually spread through the brain and lead to the symptoms getting worse.

Dementia is different for everyone – what they experience, and how quickly they are affected is unique to them. What they (you) can do, remember and understand may change from day to day.

## Early symptoms


The early signs and symptoms of dementia can be subtle and hard to recognise. Many conditions, such as stroke, depression and infections, as well as normal ageing, can cause dementia-like symptoms. It's important not to assume changes are due to dementia.

It's also very important to see your doctor as soon as you have any concerns. If your symptoms are caused by a treatable condition, you will be diagnosed and treated.

If your symptoms are caused by dementia, an early diagnosis means you and your family/whānau have early access to support, information, and any appropriate medication. You also have time to plan for your future.

If you're concerned someone you know may have dementia, take action by seeing a doctor for a full assessment. Also see [www.alzheimers.org.nz](http://www.alzheimers.org.nz) for more information about dementia.





Fact sheets covering the different types of dementia are available for download at [www.alzheimers.org.nz](http://www.alzheimers.org.nz)

## Forms of dementia

There are many different diseases that cause dementia and, for most people, there's no known reason why they develop. Some of the most common forms of dementia are:

### **Alzheimer's disease**

This is the most common form of dementia – around two-thirds of people with dementia have Alzheimer's disease. Although we are still learning about the causes, there are typical changes seen in the brain, such as shrinkage and a build up of abnormal proteins (plaques and tangles).

### **Vascular dementia**

This is the second most common form of dementia. This group of conditions is caused by poor blood supply to the brain as a result of a stroke or several mini-strokes, or by the slow build-up of blood vessel disease in the brain.

Vascular dementia symptoms can begin suddenly after a stroke, or can come on gradually as disease in the blood vessels worsens.

Some people might have a combination of vascular dementia and Alzheimer's disease.

### **Lewy body disease**

This disease is characterised by the presence of 'Lewy Bodies', which are abnormal clumps of protein in the brain.

These cause changes in movement, thinking, behaviour and alertness. People with Lewy Body disease can fluctuate between almost normal functioning and severe confusion within short periods, and may also have hallucinations, seeing things that aren't really there.

### **Fronto-temporal dementia**

Fronto-temporal dementia is a group of conditions which affect the frontal and/or temporal lobes of the brain.

If a person has affected frontal lobes they will have increasing difficulty with motivation, planning and organising, controlling emotions and maintaining socially appropriate behaviour. If temporal lobes are affected the person will have difficulty with speaking and/or understanding language. Symptoms often begin in a person's 50s or 60s.

# Why does behaviour change?

A person's behaviour can change for many reasons. Sometimes it's indeed the dementia, which results from changes in the brain that affects a person's memory, mood and behaviour.

In other instances, there may be changes happening in the person's environment, their health or medication that trigger the behaviour. Perhaps everyday activities, such as taking a bath, is too difficult, or they're feeling unwell from something unrelated to the dementia and this is expressed through unusual or odd behaviour.

Dementia affects people in different ways and a person with dementia may not be able to tell you what is wrong. Understanding why someone is behaving in a particular way may help you to figure out what is happening and to come up with some ideas about how to cope.

If you're seeing behaviour changes, always talk to a health professional, your GP or nurse. They will be able to check whether there's a physical illness going on, or maybe something is making them physically uncomfortable. They may be able to treat it and/or give advice.



# Understanding

## changed behaviours

There are five main categories of possible causes for changed behaviours: health (physical, emotional and psychological), the person's history, their environment, the task itself, and communication. These are explained in more detail below.

### Health factors

- Effects of medication – People with dementia might be taking too much medication, or they might be reacting badly to various drug combinations and their side effects. The drugs can sometimes cause increased confusion and sudden changes in how well the person can function. It is important to note that sometimes medications that suited someone before they had dementia don't suit them so well now, the balance between side effects and benefits of the medication can change.
- Impaired vision and hearing – Both of these problems can affect the person's ability to understand what's happening or being said.
- Acute illness – It's not always easy to know when someone with dementia is suddenly ill with something else because they may not be able to say what they're feeling, or what their symptoms are. Illnesses such as urinary tract infections (painful urination or needing to go often), pneumonia (chesty cough), gastrointestinal infection (tummy upset) or fever (high temperature) can lead to the person being more confused.
- Chronic illness – Ongoing illnesses such as angina, heart problems, diabetes or the pain associated with arthritis, ulcers or headaches, can affect a person's mood and level of functioning.
- Dehydration – Many people with dementia can no longer recognise when they're thirsty or they forget to drink, which means they might not get enough fluid. Signs that someone is dehydrated can include increased confusion, dizziness, dry or flushed skin, fever and a rapid pulse.
- Constipation – Not doing poos can be very uncomfortable and can lead to painful bowel problems and sometimes to increased confusion, restlessness and agitation.
- Depression and anxiety – Many symptoms of depression and anxiety, such as impaired concentration, memory loss, apathy and sleep disturbances, are like those of dementia. It's often difficult to tell which are caused by the depression, anxiety, dementia, or a combination of all three. Therefore it is important to see your GP for a diagnosis.



- **Fatigue** – Disrupted sleep patterns can cause restless, angry or agitated behaviour.
- **Physical discomfort** – The person with dementia might be hungry, bloated or need to go to the toilet. They could also be too cold or too warm. Work through these factors to see if it's a problem easily fixed.
- **Unmet emotional needs** – People with dementia still want to feel useful and needed. Like all of us, they need to feel they belong, have meaningful roles, are included, and that their skills are being used.

## Personal history

Sometimes the person with dementia may think they are living in the past and this can explain what appears to be an unusual behaviour. Look at the person's childhood or early life for clues to what might be happening now.

## Environmental factors

- **Their environment is too large** – Sometimes it can be overwhelming for a person with dementia to be in a big space.
- **Too much clutter** – Having too many things in their environment can be too much to absorb and they may become overwhelmed.
- **Excessive stimulation** – Having too much going on, such as the TV or music playing while people are talking or too many people around, can cause behaviour changes.
- **Confusing sensory environments** – Lighting that causes too much glare or too dim, visual contrasts between the floors and walls, and in how colours are used, can all affect a person's behaviour and ability to function well, for example:
  - Dim light might make it hard for them to see the food on their plate so they don't eat.
  - Patterned floor tiles can look like steps, causing them to trip or become uncertain.
  - Glare from direct sunlight or a highly polished floor can affect their vision.
  - Shadows may make them see things that aren't there.

- Changing routines – Some people with dementia, particularly in the early stages depend on a certain amount of routine and daily structure. Consistency helps minimise stress.
- Unfamiliar environments – Places that are new or unfamiliar can be confusing and stressful for someone with dementia because they have problems with learning new things, memory and perception.

## Communication

- They can't understand you – People with dementia may become angry or agitated because they don't understand what you're saying or what you want them to do.
- You can't understand them – They might also feel frustrated because they can no longer make themselves understood.

## Managing the task

- The task is too complicated – Because dementia is progressive, a person with dementia may be suddenly unable to do a task they've been able to do up until now. Sometimes it can be helpful to break the task down into smaller steps to make it easier for the person with dementia to do.
- The task is unfamiliar – People with dementia gradually lose their ability to learn new tasks or skills, so expecting them to learn something new may be unrealistic.







# Coping with changed behaviours

Coping with changed behaviours can be very difficult and finding the best way to cope, or prevent the behaviour, is often a matter of trial and error.

Always remember the behaviour is not a deliberate attempt to cause others to be upset. Anger and aggression are often directed against family members and carers because they are closest. Often unusual behaviour actually makes sense to the person with dementia because they are reacting to being frightened, confused or feeling frustrated.

They often simply need reassurance that they are safe, loved and cared for, even though the behaviour may not appear that way.

## Problem solving

One way of coping with changed behaviours is to have a plan or strategy about how you might respond to the behaviour or situation. It's easier to have a plan of action, than to try and think what to do when the behaviour happens.

Be creative and think about what you might do. Maybe ask someone else for any suggestions they might have. If you have several strategies, decide which one you are going to try first.

After the situation has happened, review your strategy. Did it work? If it did, remember how you dealt with it – maybe even write it down. If it didn't, be prepared to try another strategy should the behaviour happen again.







### General tips to deal with changed behaviours:

- Dementia is always changing and unique for each person. One suggestion may work today but not tomorrow.
- A calm, unstressed environment in which the person with dementia follows a familiar routine can help to avoid some difficult behaviours.
- Try to keep the surroundings familiar. People with dementia can become frightened if they find themselves in a strange environment or among a group of unfamiliar people where they feel confused and unable to cope. Feeling that they are not meeting other people's expectations might cause the person with dementia to feel frustrated or embarrassed and may trigger a change in behaviour.
- It may be better not to attempt any form of physical contact during some behaviours. Rather than trying to restrain or lead them away, or approach them from behind, it may be better to leave them alone until they have recovered. You can also call a friend or neighbour for support.
- Try not to take it personally, or become provoked or drawn into an argument.
- Try not to raise your voice. Instead speak slowly, in a calm and reassuring way.

## Types of changed behaviour

Dealing with these behaviours on a day-to-day basis can be extremely demanding but the behaviours aren't meant deliberately to upset you.

Remember to look after yourself and take regular breaks. Having a way of 'escaping' when things are getting on top of you is important, even if it's just to take a walk around the block, popping in to see a neighbour, or just having some time alone in another room.

### Anxious and repetitive behaviours

Some people may become worried and anxious but can't tell you what's upsetting them. They might be restless, pace or fidget or say things over and over again. They might also become very clingy and shadow you, even following you to the toilet.

This can be very frustrating and demanding for family members. Repetitive behaviours can sometimes make it seem like the person is stuck in a groove and can't move on.

Physical changes in the brain, as well as feelings of loss, tension, grief or failure can contribute to these behaviours. Anxious

behaviours could also be a symptom of depression, so it's important to talk to their doctor if this is suspected.

### Aggression and agitation

If the person with dementia has aggressive or agitated behaviours it can be difficult and challenging to cope with.

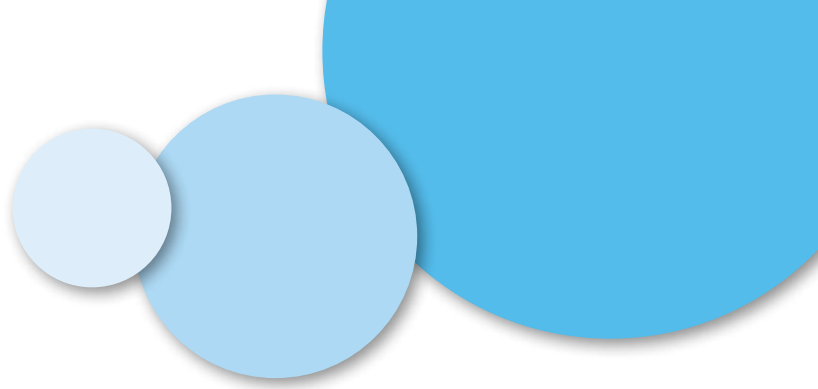
Aggressive behaviour can include:

- verbal threats and abuse
- hitting out
- damaging property.

Agitated behaviour can include:

- pacing
- fiddling
- vocalisations such as constant talking, repeating words and phrases, crying, swearing or screaming
- repetitive questioning.

As with all behaviours that change, it's important to discuss any concerns with a health professional, such as a doctor or nurse. They can examine the person to see if they have any physical problems, depression or side-effects of their medicine that could be contributing to or causing the behaviour changes.



### What to try:

- Be aware of the warning signs and try developing strategies to stop it starting.
- Ensure there's an unrushed and consistent routine.
- If possible, work out what's causing the behaviour and take care of those underlying feelings.
- Avoid confrontation by either distracting their attention or suggesting doing something else – such as having a drink together, going for a walk or looking at a magazine.
- Make sure they get enough exercise and participate in meaningful activities.

Managing agitated or aggressive behaviours can be very frustrating and at times may make you feel unsafe. If you do lose your temper, don't feel guilty but do take it as a sign you need some extra support. Talk it over with your doctor, a friend, other family/whānau members or your local Alzheimers organisation.

If you do feel physically threatened don't try to restrain them unless absolutely necessary as this can make matters worse. You may need to stay out of reach or leave them until the person has had time to calm down.

### Catastrophic reactions

Some people with dementia over-react to what seems like trivial setbacks or minor criticisms. They might scream, shout, make unreasonable accusations, become very agitated or stubborn, or cry or laugh uncontrollably or inappropriately. At the other end of the scale they might become withdrawn.

This tendency to over-react is called a 'catastrophic reaction'. Sometimes it's the first indication of dementia. It may be a passing phase, disappearing as the condition progresses, or it may go on for some time.

A catastrophic reaction may be a result of:

- stress caused by excessive demands of a situation
- frustration caused by misinterpreted messages
- another underlying illness.

This behaviour can appear very quickly and can make family/whānau members feel frightened. However, trying to figure out what triggered a catastrophic behaviour can sometimes mean that it can be avoided.

It might help to look for patterns so you can prevent such situations from starting. Making a note of what happened, when it happened, and what else was happening around the person with dementia, can be a way of helping to identify a pattern.

## Hoarding

- **Isolation** – When a person with dementia is left alone or feels neglected, they might focus completely on themselves. The need to hoard is a common response.
- **Memories of the past** – Events in the present can trigger memories of the past, such as living with brothers and sisters who took their things, or living through the Depression or a war with a young family to feed.
- **Loss** – People with dementia continually lose parts of their lives. Losing friends, family, a meaningful role in life, an income and a reliable memory can increase a person's need to hoard.
- **Fear** – A fear of being robbed is another common experience. The person may hide something precious, forget where it's been hidden and then blame someone for stealing it.

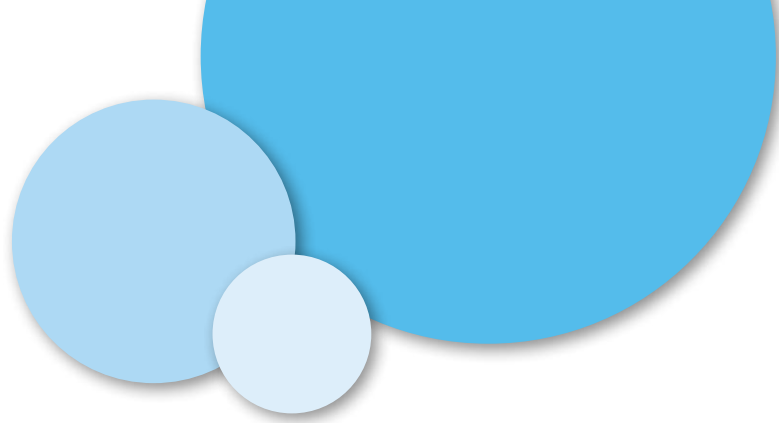
## What to try:

- Learn the person's usual hiding places and check there first for missing items.
- Give them a drawer of odds and ends to sort out as this might satisfy their need to be busy.
- Make sure the person can find their way about, as an inability to recognise the environment may be adding to the problem of hoarding.









## Hallucinations and false ideas

People with dementia sometimes experience a range of conditions that can mean they don't see things as they really are. Although hallucinations and false ideas are imaginary, they seem very real to the person experiencing them and can make them extremely anxious and even panicky.

Hallucinations can involve any of the senses, but are most often visual or auditory, meaning seeing or hearing things that aren't happening. They might see people who aren't there, hear voices or experience strange and frightening noises.

Having dementia means the brain can't properly interpret the information it's receiving so the person with the condition has trouble recognising things or people, or understanding situations.

These problems can lead to several behaviours:

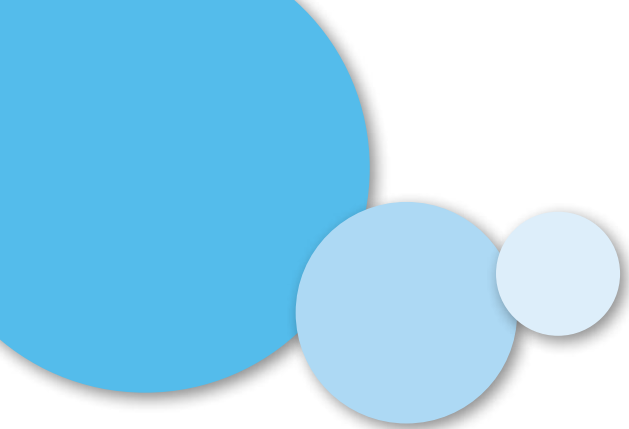
- **Suspiciousness** – People with dementia sometimes become quite suspicious, accusing others of stealing things. They might accuse their partner of being unfaithful and that can lead them to becoming fearful and resisting their partner's attempts to care for them.
- **Paranoia** – These are characterised by unrealistic beliefs, usually of persecution (thinking everyone is out to harm them) or grandeur (thinking they have superhuman powers).
- **Delusions** – Such as ideas that aren't based on reality but the person with dementia believes are true. Delusions are often about people stealing money or other possessions, or thinking people are intending to harm them.
- **Misidentification** – People with dementia can misidentify other people, or even themselves. Sometimes they don't recognise their partner as being the person they have known. They might think their reflection in the mirror is another person and be frightened, or think voices on the radio or television are from people in the room with them.



### What to try:

- Don't argue – it's better to acknowledge that the person is frightened by what they're experiencing.
- Provide reassurance and support.
- Investigate their suspicions – they may be true.
- Distraction can help take their mind off their fears – try music, exercise, activities, conversations with friends, looking at old photos.
- Offer a reassuring hug or touch may be helpful but make sure the person likes to be hugged/touched.
- Keep their environment as familiar as possible – don't move furniture or possessions out of their normal place.
- Turn on more lights to get rid of dark areas/shadows. Perhaps use a bright night light.
- Don't take any accusations personally and be aware the person can't control this behaviour or work out that what they are seeing isn't actually there.
- Address the underlying feelings if you can.
- Some hallucinations and false ideas can be ignored if they're harmless and don't make the person agitated

Medication may be useful in some situations but not all. Quite often the issue will resolve as the person's dementia develops further, and sometimes hallucinations may be a sign of a more acute illness. Ask your doctor's advice and always ensure that medications are reviewed on a regular basis.



## Disinhibited behaviours

Disinhibited behaviours are things people do or say that are out of character and are tactless, rude or offensive. It's when people don't follow the usual social rules about what or where they say or do something.

Such behaviour can place enormous strain on families/whānau and anyone who cares for someone with dementia. They can be particularly upsetting when someone who has previously been private and sensitive behaves in a disinhibited way.

Disinhibited behaviours may include the following:

- **Tactless or rude remarks** – A person with dementia might say tactless things about how someone looks. They can appear to have lost their social manners and seem like they're deliberately trying to embarrass or upset the other person.
- **Bold behaviour** – A person with dementia may inappropriately flirt with someone or make sexual comments.
- **Exposure** – They may take some, or all, of their clothes off at inappropriate times or in inappropriate places.
- **Fondling themselves** – Forgetting social rules, a person with dementia may fondle themselves or masturbate in front of others.

### What to try:

- Look for a reason behind the behaviour, as this may help you respond to it – for example, a person who is trying to undo their trousers may need to go to the toilet.
- Try not to over-react even though the behaviours may be very embarrassing – remember it's part of their condition.
- Give the person plenty of appropriate touching, such as a hug or holding their hand – it could be they just need gentle reassurance.
- For inappropriate sexual behaviours, quietly and gently remind them it's not something they should be doing in public, then encourage them to go somewhere private to continue what they are doing.





### **Changed sexual behaviours**

A person with dementia may no longer know what to do with sexual desire, or when and where to appropriately show their desire.

It's important to remember that, as with any strange or uncharacteristic behaviour, this is part of their condition and isn't directed in a personal way.

**Increased sexual demands** – Some partners find a person's desire for sexual activity increases, which can lead to unreasonable and exhausting demands, often at odd times or in inappropriate places. Occasionally some people might get aggressive if their needs aren't met.

**Decreased sexual interest** – Many people with dementia lose interest in a physical relationship and can become very withdrawn. They may be fine with people touching them but don't themselves offer physical affection to their partner, who might feel hurt by their lack of interest.

**Loss of inhibitions** – People with dementia sometimes lose inhibitions and might make sexual advances to others, or undress or fondle themselves in public. Sometimes it's because they've forgotten where they are or who the person is, mistaking the other person for their partner. Sometimes actions – such as a woman lifting her skirt – simply means she needs the toilet.

## **Sleep disturbance and night-time waking**

Sleep disturbances are common for people with dementia, and often lead to the people who care for them also having problems with their sleep.

A person with dementia may get up repeatedly during the night and may become disorientated when they wake. They may get dressed or try to leave the house. All this night-time activity can make them tired during the day and they may sleep for long periods.

All of this can be very stressful and tiring for carers, but the person with dementia may not be aware they are having any problems during the night.

### **What to try:**

- Make sure the person sees plenty of daylight and does lots of activity during the day.
- Think about improving the sleeping environment. Make sure the room is a comfortable temperature, quiet and appropriately lit. If it's too light, consider blackout blinds.
- Cut down on caffeine and alcohol in the evening.

- Consider putting a clock next to the bed that shows whether it's day or night.
- If they like to have something to cuddle, consider a soft toy.
- Going for a walk, having a warm milky drink, or having a relaxing bath or shower before bed may help the person relax and sleep better.

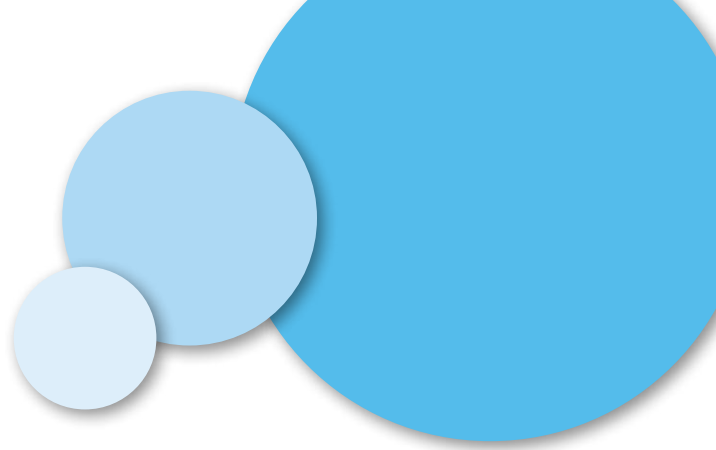
## **Afternoon restlessness (sundown syndrome)**

Sometimes people with dementia might become more confused, agitated, restless or insecure late in the afternoon or early evening, which is why this condition is called the 'sundown syndrome' or 'sundowning'.

This pattern may continue for several months and often happens in the middle to later stages of dementia. It can be particularly hard for those caring for them if they are trying to relax or enjoy some quiet at that time.

### **What to try:**

- Give the person something meaningful to do at this time of day, using past activities as a guide.



- Plan quiet and relaxing activities for late afternoon/evening for the person with dementia, and also for anyone else around them.
- Think about what's happened during the day. Could the person's behaviour be about them needing the toilet, feeling hungry or being in pain?
- Try giving the person something to eat and drink about half an hour before they usually get restless.

## Walking around

Many people with dementia feel a strong need to walk around. They might walk repeatedly around the house, or get up and leave the house at any time of the day or night.

The walking isn't a problem in itself as it can help to relieve stress and boredom and give the person exercise. But people with dementia can become disoriented and might have difficulty finding their way home. This can be very worrying for those who care for them and may put the person in danger, so it's important to find a solution that preserves the person's independence and dignity but still keeps them safe.

This type of behaviour is often referred to as 'wandering'. However, this term is unhelpful because it suggests it does not have purpose, that it is aimless, whereas the walking around often does have a purpose – perhaps they think it's time to go to work, or to pick up the children from school.

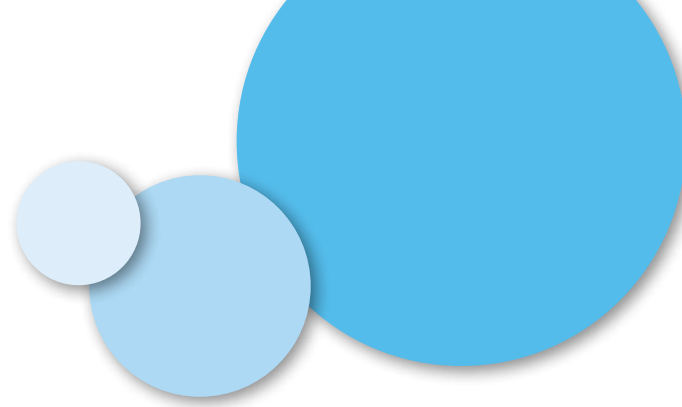
## Why might people walk around?

There could be a number of reasons why a person with dementia walks around. It may help to keep a journal for a couple of weeks to record when they walk around, and what they say when they are walking, as that could help you identify any triggers or reasons.

Once you identify what they are trying to achieve, you can start to find ways to meet their needs. That should reduce your frustration and help them to keep their independence.

Possible reasons to walk around include:

- continuing a habit
- relieving boredom
- using up energy
- relieving pain and discomfort
- responding to anxiety
- feeling lost



- searching for the past
- getting confused about the time.

### **Retaining independence**

It's very important that people with dementia are encouraged to remain independent for as long as possible. There will always be some degree of risk, whatever choices are made. Those caring for the person need to decide what level of risk is acceptable in order to maintain their quality of life and protect their independence and dignity.

The steps you need to take to keep the person safe will depend on how well they are able to cope, and what could be causing their behaviour. You will also need to take the safety of the person's environment into account – while there's no such thing as a risk-free environment, some places are safer than others.

Does the person live on a busy main road or in an urban area where people don't know their neighbours? Or do they live in a peaceful rural area where they are well known within the local community?

### **Should I stop the person from leaving the house?**

If a person with dementia wants to walk then you should try to find a solution that lets them do so safely. You may be able to get help and advice from your local Alzheimers organisation.

Some family members in caring roles decide to lock or bolt doors to prevent the person with dementia leaving the house. But remember you should never lock a person with dementia in the home if they are alone.

Less restrictive options include distracting them, deterring them from leaving by fixing a bead curtain across the front door, or painting the door the same colour as the surrounding walls. If there are outside lights it may be helpful to switch them off at night.

However, these approaches don't suit everyone and could be confusing or distressing for the person.



## Limiting the risks from walking around

To limit the risks you could try the following:

- Don't confront the person with dementia – If they're determined to leave confronting them could be upsetting. Instead try getting them to put on appropriate clothing (such as outdoor shoes and a coat) and going with them a little way before you divert their attention so you can both go home.
- Make sure they carry some form of identification – They should also have the name and phone number of someone who can be contacted if they get lost. You could sew this into a jacket or a handbag so it's not easily removed. Consider an identification bracelet, like a MedicAlert.
- Walking route – if you can, encourage them to walk along the same roads so that they have a regular route.
- Put contact numbers in their mobile phone if they use one – Make sure the phone number of the primary carer is stored in it and is easy to find. If the mobile phone is switched on it may be possible to trace the person if they go missing. Specialist locator/tracking devices are also available.

- Let others know – Tell local shopkeepers and neighbours about the person's dementia and give them your contact details as they may help keep a look out.

This type of behaviour may be a phase, and if you can take the time to understand what the person's needs are it could often resolve the problem.

**For more information and advice, contact your local Alzheimers organisation and see the factsheet on Walking Around.**

## Depression

People with dementia can sometimes also get depression and it's important to be able to tell when someone with dementia has depression as well as their dementia.

Dementia can contribute to depression because of:

- lower confidence and self-esteem
- a loss of independence and increasing reliance on others
- not being able to go out alone
- no longer being able to do fun activities
- no longer being able to do everyday tasks
- high anxiety and agitation
- confusion and memory loss.

Other factors that can contribute to depression might be:

- the side effects of medication
- physical illness
- an understandable reaction to being diagnosed with dementia
- social isolation
- tiredness and fatigue.

Having depression usually means they will seem sadder generally and less interested in doing activities they used to enjoy, together with other symptoms such as:

- a lack of energy
- inability to sleep, or sleeping too much
- changes to appetite
- feelings of guilt or worthlessness
- being unusually emotional, crying, angry or agitated
- increased confusion.

Dementia and depression share many symptoms and it can be difficult to tell the difference. Depression also can lead to poor memory and difficulties making decisions, organising and starting activities. If a person already has dementia, the depression can worsen their symptoms as well as affect their mood.

Treating depression may significantly improve their mood and can make the person able to do the things they enjoyed again. If you think depression might be affecting someone with dementia, talk with their doctor. They will examine them to rule out other medical problems and may recommend medication, counselling or a referral to a Psychiatrist of Old Age.

## What to try:

- While in the early stages try to maintain a familiar and consistent daily routine for the person with dementia.
- Make changes to their home and immediate environment to make it more manageable.
- Reduce stress and anxiety by simplifying or eliminating tasks or activities that are becoming too difficult.
- Provide support for them so they can continue to do for themselves, and do what they enjoy, for as long as possible.
- Ensure they eat healthy meals with lots of fresh fruit and vegetables.
- Spend time outside in the sunshine every day, remembering to be sun smart.
- Make sure they have something fun to do every day.
- Make sure they have regular social contact.
- Encourage rest and relaxation periods each day.
- Encourage regular exercise – this has a proven positive impact on depression.
- Limit noise and activity in their environment if that's causing a problem.
- Large and busy group situations work well for some people but not for others, so make sure the person with dementia is responding well to their situation. Use what they liked in the past as a guide for what they might like now, but be prepared for their preferences to be different.
- Have a realistic expectation of what they can do – expecting too much can make both them and their family/whānau frustrated, upset and gloomy.
- Know when they are least fatigued and 'at their best', and do any important tasks then.
- Include them in activities and conversation so they feel part of the family or group.
- Be positive – praise will help everyone.



# Support to live well with dementia

There's support available for both you and those who support you. Your local Alzheimers NZ organisation and your doctor can let you know you about services in your local community.

These might include the following:

- Information, education, support and advocacy services offered through your local Alzheimers NZ organisation.
- Support through your Needs Assessment and Service Coordination Service (NASC), such as:
  - > assistance with household tasks
  - > assistance with personal care needs, such as showering, dressing or supervising medication
  - > day programmes
  - > carer relief
  - > respite services
  - > residential care
  - > support with ready-made meals
  - > subsidised taxi chits to help with transport costs.



**Just remember you are  
not alone. Help and  
support is available  
from your local  
Alzheimers organisation  
0800 004 001**



# For more info

## General information and support

### Alzheimers NZ

[www.alzheimers.org.nz](http://www.alzheimers.org.nz)  
0800 004 001

### Ministry of Health

[www.health.govt.nz](http://www.health.govt.nz)

### Age Concern

[www.ageconcern.org.nz](http://www.ageconcern.org.nz)

### Health and Disability Commission

[www.hdc.org.nz](http://www.hdc.org.nz)

### Senior Line

[www.seniorline.org.nz](http://www.seniorline.org.nz)

### Citizens Advice Bureau

[www.cab.org.nz](http://www.cab.org.nz)

### Carers New Zealand

[www.carers.net.nz](http://www.carers.net.nz)

## Advance care planning and end of life care

### Advance Care Planning Co-operative

[www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

### Hospice New Zealand

[www.hospice.org.nz](http://www.hospice.org.nz)

## Enduring Power of Attorney (EPA)/Wills

### Family Court

[www.courts.govt.nz/family](http://www.courts.govt.nz/family)

### Law Society

[www.nz-lawsoc.org.nz](http://www.nz-lawsoc.org.nz)

### Ministry of Social Development

[www.msd.govt.nz/epa](http://www.msd.govt.nz/epa)

### Public Trust

[www.publictrust.co.nz](http://www.publictrust.co.nz)

## Benefits, home support and residential care

### Work and Income New Zealand

[www.winz.govt.nz](http://www.winz.govt.nz)

### Needs Assessment and Service Coordination (NASC) information

[www.health.govt.nz](http://www.health.govt.nz) – search for NASC

### Eldernet

[www.eldernet.co.nz](http://www.eldernet.co.nz)

## Driving

### New Zealand Transport Agency

[www.nzta.govt.nz](http://www.nzta.govt.nz)



Alzheimers NZ

0800 004 001

[www.alzheimers.org.nz](http://www.alzheimers.org.nz)

[admin@alzheimers.org.nz](mailto:admin@alzheimers.org.nz)