



# Information on Dementia in English

English

## Foreword

I am delighted to welcome you to 'Information on Dementia in English', a talking book developed by Bolton Clarke in collaboration with Dementia Australia.

This talking book was co-designed with support from Alfred Health, Dementia Australia's clients and their carers, the Care Connect Aboriginal Social Support Group in Laverton, Victoria and the Balee Aboriginal Social Support Group in Hastings, Victoria.

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Dementia is a national health priority for the Australian Government and is the third leading cause of death in Australia. Dementia has profound consequences for the health and quality of life for people with the condition, as well as their families and friends. In the absence of prevention or cure options, estimates suggest that between 2010 and 2050, the number of people with dementia will triple, rising to around 900,000 by 2050.

Bolton Clarke is committed to assisting all people to learn about their health and to better manage their health problems. 'Information on Dementia in English' presents information on how to look after yourself in a way that is easy to understand. You have a choice of reading the information or listening to it. In total, 9 important topics on dementia are covered to help you, your family and carers better manage your condition. Information provided in this book is drawn from the Dementia Australia Help Sheets. The full set of Dementia Australia Help Sheets in English and multiple languages is available at [www.dementia.org.au](http://www.dementia.org.au)

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## Note

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## Is it normal to forget things?

It is normal to forget things from time to time.

We have all misplaced our wallet or purse. We have all forgotten a person's name or phone number. This is normal.

It is normal to forget things more often as we get older.

Important points about forgetting things as we get older:

- The most common change that we complain about is change to our memory
- Changes to memory does not get in the way of everyday life
- You may walk into a room and forget what you went there for
- Recalling your memories may be slower but your memory is still working.

Each person is different. As we get older, memory loss will be different for all of us.

If you are worried about your memory, speak to your nurse or doctor.

## What can I do if I am worried about my memory?

There are differences between memory loss as part of normal ageing and as a symptom of dementia.

There are other reasons people may have memory loss. One reason may be we do not have enough key chemicals in our body for our memory to work properly. Another reason may be that brain cells are damaged and connections between brain cells are lost. The memory loss may be caused by depression or effects from the medicines we take. Infections may also cause memory loss.

In these instances, the memory loss can improve and be treated. If you are worried about your memory speak to your nurse or doctor. This will ensure that you get the right treatment.

If the memory loss is caused by dementia, a diagnosis is important. Doctors are able to diagnose dementia.

The early signs of dementia can be hard to notice but can include:

- More and more memory loss
- Confusion
- Changes to personality
- Loss of interest
- Loss of ability to complete everyday tasks.

## What is dementia?

Dementia is a term that describes problems with memory, thinking and behaviour. Dementia can happen to anyone, but it is more common in older people. It is important to remember that not all older people get dementia. There are different beliefs about what causes dementia. There is currently no cure for dementia but this is being researched.

The medical explanation for dementia is a collection of symptoms that are caused by diseases affecting the brain. In most cases, why people develop these diseases is unknown.

The brain takes in information and then it helps us to make decisions. Dementia can affect all areas of the brain over time. Doctors can diagnose dementia if one or more functions of the brain are damaged. These functions can include memory, language skills, understanding information, emotions, judgement and attention.

Dementia affects:

- Thinking and making decisions
- Behaviour
- Ability to perform everyday tasks
- Managing money
- Driving.

For more information about dementia speak to your nurse or doctor.

You can also call the National Dementia Helpline on 1800 100 500. If you need a professional telephone interpreter call 131 450 and ask to be connected to the National Dementia Helpline on 1800 100 500. There is no cost to you for the telephone interpreter.



## What can I do if I have dementia?

Being told you have dementia can be upsetting. It is important to remember that there are people who can help. Start by contacting Dementia Australia. They provide support to people with dementia, their families and carers.

Tell your family and friends about your dementia when you are ready. Those close to you can provide you with support.

It is important to know that:

- The changes you are experiencing are because of a disease of the brain
- You will have good days and bad days
- Each person is affected differently
- The signs of dementia will change
- There are people who understand what you are going through and can help you

For more information about dementia speak with your nurse or doctor.

You can also call the National Dementia Helpline on 1800 100 500. If you need a professional telephone interpreter call 131 450 and ask to be connected to the National Dementia Helpline on 1800 100 500. There is no cost to you for the telephone interpreter.

# Stages of dementia

Every person with dementia is different.

The three stages of dementia may happen quickly over a few months, or slowly over many years. Some people may not go through all the stages.

## 1. Early dementia

It is often impossible to identify the exact time dementia began. The early signs of dementia are not easy to notice. For example, the person may:

- Become more forgetful of details of recent events
- Be more likely to repeat themselves
- Forget words and lose track of their conversation.

## 2. Moderate dementia

At this stage the problems are more obvious. For example, the person may:

- Be confused about time and place
- Become lost if away from home
- Forget names of family or friends.

## 3. Advanced dementia

At this final stage, the person needs total care. For example, the person may:

- Lose their ability to understand or talk
- Be incontinent
- Be unable to walk and be bedridden.

## Dementia and diagnosis

If your memory loss is caused by dementia a diagnosis is important. There may be treatment available. Early diagnosis also allows you time to plan for the future. Doctors diagnose dementia. If you are worried about your memory, speak to your nurse or doctor.

Early symptoms of dementia vary from person to person. Some people may not want to speak to their doctor, even when they notice something is wrong.

The early signs of dementia are not easy to notice but can include:

- Changes in memory
- Confusion about time and place
- Changes in behaviour
- Loss of interest
- Loss of ability to complete everyday tasks
- Problems with language and remembering words
- Problems with judging distance
- Losing things
- Problems with driving.

Your doctor may do the following tests to find out why you have memory loss:

- Physical examination
- Blood test
- A test to assess your thinking
- A test to identify treatable illnesses such as depression
- A brain scan that takes an image of your brain.

These tests will also help your doctor to make referrals to specialists, if required.

## Why is early diagnosis of dementia important?

Diagnosis of dementia is important because it may not be dementia.

Many conditions have symptoms similar to dementia. Do not assume that someone has dementia. Strokes, depression and alcoholism can cause dementia-like symptoms. So can infections, poor nutrition and brain tumours. Memory loss as a result of these conditions can be treated.

**A correct diagnosis is important.**

It is important you speak to your doctor as early as possible. Only a doctor can diagnose dementia.

Medical tests may identify a treatment. This will ensure that you are treated correctly. The tests may confirm that you have dementia. Your doctor may refer you to a specialist.

Some people may not want to speak to their doctor. They may not be ready to hear that something is wrong. They may not realise that there is anything wrong with them.

**If the person will not visit the doctor:**

- Speak with other families and carers who have had to deal with similar situations
- Speak to your doctor for advice
- Call the National Dementia Helpline on 1800 100 500. If you need a professional interpreter call 131 450 and ask to be connected to the National Dementia Helpline on 1800 100 500. There is no cost for the telephone interpreting.

## Do you tell the person with dementia about their diagnosis?

The decision to tell a person with dementia about their diagnosis can be a difficult and emotional issue. It is generally recommended that a person with dementia be told of their diagnosis. However, there are many beliefs and reasons for not telling the person that they have dementia:

- The family is responsible for making this decision not the doctor
- Older people are greatly respected in some communities and families, and it may be considered as disrespectful
- It may be felt that the person will become very distressed by the discussion
- A belief that the person will lose hope and make the condition worse.

### **Why a person with dementia should know about their diagnosis:**

- People have a right to know medical information about themselves
- The diagnosis of dementia can be a relief, as they now know what is causing their problems
- It helps a person make important plans for the future, particularly about legal and money issues
- It allows for discussion about dementia amongst family or friends.
- It can provide access to information and help.

## Dementia and changes in communication

As dementia progresses, the person may find it more difficult to communicate. They may find it more difficult to express themselves clearly. They may also find it difficult to understand what others say.

Losing the ability to communicate can be one of the biggest problems for people with dementia.

It is important to check the person's hearing and eyesight. Make sure that hearing aids and glasses are used and cleaned correctly.

Changes you may notice are that the person with dementia might:

- Have trouble finding the right word. Another word may be used instead
- Speak well, but not make sense
- Have trouble understanding you
- Not be able to respond when spoken to
- Change back to using their first language. If the English language is the last language they learned, this will be the first language they lose.

# Communicating with a person with dementia

We communicate through the words we use, the tone of our voice and body language. It is important to think about how you communicate with a person with dementia.

## Ways of talking:

- Remain calm and talk in a gentle way
- Keep sentences short and simple
- Only talk about one idea at a time
- Allow plenty of time for the person to understand what you are saying.

## Body Language

So that you are better understood by the person with dementia, it may be useful to use hand gestures and facial expressions. Pointing at what you are talking about may help. Touching and holding their hand may help keep their focus on what you are telling them.

## What not to do

- Do not argue, it will only make things worse
- Do not correct the person repeatedly
- Do not order the person around
- Do not tell the person what they cannot do, tell them what they can do
- Do not ask a lot of questions
- Do not talk about the person with other people, as if they are not there.

## Communicating with your doctor

Your doctor can provide you with long term support and care. It is important to help your doctor understand your experience with dementia. Let your doctor know what you need. If you do not understand what is being said, you should ask for it to be repeated or explained in a different way.

If you need a professional interpreter, you must ask for one. Your doctor can provide you with an interpreter at no cost to you.

Think about the questions you would like to ask your doctor before your appointment. Ask your family or a friend to help you make a list of questions. Your discussions with your doctor are confidential and will not be shared with anyone without your permission.

Sometimes it may not be easy to get the information you need. Talking to other people about their experiences with doctors can help.

Make appointments at a good time for you. If early morning or late afternoon is hard for you, do not make appointments at this time. Ask for a longer appointment if you feel you need more time with your doctor.

You have the right to change doctors, if you believe your needs are not being met.



## Why does behaviour change?

Sometimes changes in behaviour may be related to dementia. Other times, the change in behaviour may be caused by changes in the person's environment or their health.

Dementia is a result of changes that take place in the brain. Dementia affects a person's memory, mood and behaviour. Changes in the behaviour of a person with dementia are very common. These can also worsen as the dementia progresses. This may place a lot of stress on families and carers. It can be very upsetting when someone who was gentle becomes aggressive.

The change in behaviour may be caused by:

- Changes in the person's environment
- The person may not be feeling well
- Medicines a person is taking
- Not coping with daily tasks such as, taking a bath.

If you are worried about changes in behaviour, it is important to speak to your doctor. Your doctor will help determine what is causing the change in behaviour.

You can also contact Dementia Support Australia on 1800 699 799. This national service is available for families, carers and care workers who are concerned about the behaviours of people with dementia. The service is available 24 hours a day, 7 days a week.

If you need a professional interpreter call 131 450 and ask to be connected to Dementia Support Australia on 1800 699 799. There is no cost for the telephone interpreting.

## How to cope with changes in behaviour

Sometimes changes in behaviour may be related to dementia. Other times, the change in behaviour may be due to changes in the person's environment or their health. Understanding why someone is behaving in a particular way may help you with ideas about how to cope.

Coping with changes in behaviour can be difficult. Always remember that the behaviour is not deliberate. Anger and aggression are often directed against family members and carers, because they are closest. The behaviour is out of the person's control and they may be quite frightened by it.

### What may help

- A calm environment where the person follows a routine
- Try to keep the environment familiar. People with dementia can become confused in a strange situation or around unfamiliar people
- Do not use physical contact such as restraining or leading the person away
- It may be better to leave them alone until they have settled
- Try not to use a loud voice
- Try not to get into an argument.

If you are worried about changes in behaviour, speak to your nurse or doctor. You can also contact Dementia Support Australia on 1800 699 799. This is a national telephone advisory service. This service is available for families, carers and care workers who are concerned about the behaviours of people with dementia. The service is available 24 hours a day, 7 days a week. If you need an interpreter call 131 450 and ask to be connected to Dementia Support Australia on 1800 699 799. There is no cost for the telephone interpreting.

## Catastrophic reactions

Some people with dementia may react badly to a small problem. This might involve them:

- Screaming or shouting
- Becoming very agitated or stubborn
- Crying or laughing
- Becoming withdrawn.

These behaviours are part of the disease and are called catastrophic reactions.

**A catastrophic reaction may be a result of:**

- Stress caused by extra demands
- Frustration caused by misunderstood messages
- Another condition
- Environmental factors such as loud noises or crowds.

This behaviour can happen very quickly and can make other people feel frightened. Try and work out what has caused the reaction, as it can be avoided sometimes.

For more information about dementia speak to your nurse or doctor.

For general advice you can also call the National Dementia Helpline on 1800 100 500. For advice on coping with behaviours of people with dementia call Dementia Support Australia on 1800 699 799. These telephone services are available 24 hours a day, 7 days a week.

If you need a professional telephone interpreter call 131 450 and ask to be connected to the National Dementia Helpline on 1800 100 500 or Dementia Support Australia on 1800 699 799. There is no cost to you for the telephone interpreter.

## Anger and aggression

Aggressive behaviours such as hitting, swearing, making threats towards another person or damaging property can be common.

**Some common causes of aggressive behaviour can be:**

- Anger, fear or frustration
- Problems with communicating
- Weakness and tiredness
- Not enough sleep
- Pain, fever, illness or constipation
- Effects of medication
- Impaired vision or hearing causing the person to misunderstand
- Hallucinations and false ideas
- Environmental factors, such as loud noises and crowds.

**What may help:**

- Activity and exercise may help prevent some outbursts
- Approach the person slowly and in full view. Explain what is going to happen clearly, such as “I’m going to help you take your coat off”. This may avoid the feeling of being attacked and becoming aggressive as a self-defence response
- Check whether the aggressive behaviour is about getting what the person wants. If so, try to anticipate their needs.

## Hoarding

People with dementia may often search for something that they believe is missing. As a result they may hoard things for the future e.g. food, money or clothes.

### Hoarding behaviours may be caused by:

- When a person with dementia is left alone or feels unsafe, they may focus on themselves. The need to hoard is a common reaction
- Events in the present can cause memories of the past. The person with dementia may remember living through a war
- Losing friends, family and an income can increase a person's need to hoard
- A fear of being robbed is common. The person may hide something precious, forget where it has been hidden, and then blame someone for stealing it.

### What may help

- Learn the person's usual hiding places and check for missing items
- Make sure the person can find their way around their home. Not being able to recognise the home may add to the hoarding behaviour.

## Repetitive Behaviour

People with dementia may say or ask things over and over. They may also become very needy and want to always be with you. They may even follow you to the toilet. These behaviours can be very upsetting.

### What may help

- Keep the person busy. A walk, an activity or food may help
- Acknowledge the feeling expressed by the person. For example, “What am I doing today?” may mean that the person is feeling lost and uncertain
- Do not remind the person that they have already asked the question
- Give the person something else to do such as, clothes to fold.

If you are worried about changes in behaviour, it is important to speak to your nurse or doctor.

For general advice you can also call the National Dementia Helpline on 1800 100 500. For advice on coping with behaviours of people with dementia call Dementia Support Australia on 1800 699 799. These telephone services are available 24 hours a day, 7 days a week.

If you need a professional telephone interpreter call 131 450 and ask to be connected to the National Dementia Helpline on 1800 100 500 or Dementia Support Australia on 1800 699 799. There is no cost to you for the telephone interpreter.

## Depression and dementia

Depression is very common among people with dementia. Symptoms of depression occur in half of people with dementia.

**The following may be contributing to a person's depression:**

- The side effects of medicines
- Physical illness
- Reaction to diagnosis and the effect on their life
- Loneliness
- Weakness and tiredness
- Environmental factors, such as loud noises and crowds.

### Symptoms of depression

It can be very difficult to know if a person with dementia is depressed. Some symptoms are:

- Loss of interest in activities that were previously enjoyed
- Lack of energy
- Lack of sleep
- Loss of appetite and weight
- Expressing feelings of worthlessness and sadness
- Being unusually emotional, angry, agitated or crying
- Increased confusion.

If you are worried about changes in behaviour, it is important to speak to your nurse or doctor.

You can also contact Dementia Support Australia on 1800 699 799. This is a national telephone advisory service. This service is available for families, carers and care workers who are concerned about the behaviours of people with dementia. The service is available 24 hours a day, 7 days a week. If you need an interpreter call 131 450 and ask to be connected to Dementia Support Australia on 1800 699 799. There is no cost for the telephone interpreting.

## Pain

People with dementia experience pain. They may not be able to tell you about their pain. They may show their pain through behaviour. As a result, the pain is often unnoticed and untreated.

The following medical conditions are examples of what may cause pain for older people:

- Osteoarthritis
- Osteoporosis
- History of hip and other types of fractures
- Back pain
- Constipation
- Dental problems
- Infections
- Pressure sores.

Recognising that someone with dementia is in pain is not always easy. A person with dementia may not know how to tell you in words that they are in pain. They may use other ways to tell you such as, holding themselves tight around their middle, crying out when touched or refusing to move.

All indicators of pain should be taken seriously. Always discuss your concerns with your doctor. Your doctor will be able to provide advice for managing any pain and may give medicine for the pain. There may be other things you can do to reduce the pain. Consider whether a bath or massage would help.



## Sexual behaviour

Dementia may lead to changes in behaviour in some people. When with other people, these behaviours may be inappropriate:

- Touching and grabbing people
- Making suggestive and rude comments
- Exposing parts of the body and undressing
- Touching parts of the body
- Becoming over interested in sex.

Sexual behaviours that are not acceptable, are usually caused by the disease. This may cause a lot of distress and embarrassment to the person and those around them. Family and friends may be unsure what to do when these behaviours occur.

Speak to your doctor who will be able to help identify any treatable causes of the behaviour. Some common causes may include:

- A side effect of medication
- An illness including an infection, depression or pain
- A need for more attention
- Feeling lonely
- Not understanding other people and their relationship.

It is important to remember:

- Family and friends will be most affected
- The person is often not aware what they are saying or doing
- Do not make the person feel bad
- Provide an activity or conversation that may distract the person from the behaviour
- Get help to work out solutions to better manage the behaviour.

You can contact Dementia Support Australia on 1800 699 799. This is a national telephone advisory service. This service is available for families, carers and care workers who are concerned about the behaviours of people with dementia. The service is available 24 hours a day, 7 days a week. If you need a professional interpreter call 131 450 and ask to be connected to Dementia Support Australia on 1800 699 799. There is no cost for the telephone interpreting.

## Looking after yourself

It is important to look after yourself. There are plenty of things you can do to keep yourself active and independent for as long as possible:

- Visit your doctor regularly
- Exercise regularly and stay active. Continue to do things you enjoy
- Eat healthy foods
- Rest when you feel tired
- Don't drink too much alcohol
- Ensure you take your medicines correctly. Your pharmacist can help to pack age your medicines.

You may find it harder to do the things you used to do easily. It is important to:

- Give yourself more time; don't be hurried
- Take a break if you are finding a task difficult
- Try breaking a task down into smaller steps
- Ask people around you for help.

Changes caused by dementia may mean you experience different feelings. It is important that you talk with someone about your feelings. You may like to join a support group to share your experiences.

## Your feelings and adjusting to change

Changes related to dementia may lead to a range of different emotions. Feelings of shock, sadness, frustration, embarrassment, anger and loss are common. These are all normal to experience.

Never be ashamed to cry. Crying and laughing can be very helpful. These will help relieve the sadness that you feel.

Talking about your feelings often helps you to better understand them. You might like to speak to your doctor, a social worker or a counsellor at Dementia Australia.

Doing something you enjoy can help. If you are feeling sad go for a walk, spend time with your family. Religious and spiritual activities may help you. Focus on the things you are still able to do, and enjoy them as much as you can. Talk with someone about happy memories you share, e.g. holidays.

You are experiencing changes that are not your fault. These changes are part of your condition. You may need more time to do or remember things, so be patient with yourself.

## Exercise and activities (1)

Changes with dementia can mean changes to usual exercise and activities. It is important to keep active in things you enjoy.

### Exercise

- It is important to exercise. Exercise may help reduce depression and anxiety.
- Exercise should include the things you enjoy. Many people walk, bowl, play golf or tennis. Others do exercise classes such as yoga or tai chi.
- Other activities such as gardening and household chores can also keep you fit and active.

### Keep your mind active

- Mental activities help keep your mind active.
- Some mental activities that people enjoy are crosswords, reading, or doing puzzles and games.

If you have trouble with an activity or an exercise, ask someone to help you.

## Exercise and activities (2)

### Social Activities

- Some people enjoy social activity and others prefer to stay at home. If you enjoy socialising with others, it is important to do this as much as possible.
- Social activity may include attending a senior citizens group or other social groups, where they speak your language. Visits to friends and spending time with family can all be enjoyable.
- Some people find being among large groups of people too hard. You may find it easier to be with one or two people.

### Religious or spiritual activities

- For many people their religious or spiritual activities are an important part of dealing with dementia.
- If you find attending your place of worship difficult, a person from that group may be able to visit you at home.
- It is important to keep enjoying anything that provides a sense of happiness or peace.

### Creative activities

- Many people find knitting, woodwork, sewing, painting or playing a musical instrument enjoyable.

If you have problems with an activity or an exercise, ask someone to help you.

## Help with taking your medicines

There are no medicines that can cure dementia.

A number of medicines are currently available in Australia that may help with the memory and thinking problems for people with dementia.

Speak to your doctor about dementia and your medicines.

You may have medicines that you have to take for other conditions such as diabetes, anxiety or depression. Taking your medicines correctly is important. It is very easy to forget to take your medicines, or to take them twice.

It is important to keep your medicines organised. Your pharmacist will be able to help you with organising your medicines. The pharmacist can refill your medicines every week. This will help your family and carers keep track of your medicines and remind you if you have forgotten to take them.

If you are worried about your medicines speak to your nurse or doctor.

If you are worried that you have taken too many medicines or the wrong medicines call 000, and ask for an ambulance.

## Understanding the reasons for changes in behaviour

People with dementia will have changes in their behaviour. Sometimes the behaviour will be due to changes in the brain. The person's health, the environment or a task may also cause changes in behaviour.

### The person's health

- Effects of medicine
- Impaired vision and hearing
- Not feeling well
- Constipation
- Depression
- Change in sleeping pattern
- Physical discomfort – hungry, needing to go to the toilet.

### The environment

- Too much clutter
- Noise from the radio or television during conversation
- Bright or dark lighting
- Change of routine
- Unfamiliar surroundings.

### The task

- Tasks that are complicated
- Tasks that are unfamiliar.

Families and carers need to watch what may be causing the behaviour. If you know what is causing the behaviour it may be easier to stop it from happening.

## Your feelings and adjusting to change

Caring for someone with dementia can be very rewarding. It can also be hard at times. You may experience different feelings as the needs of the person with dementia change over time. You may feel guilt, grief, loss and anger.

### Guilt

It is very common to feel guilty. You may feel guilty for losing your temper or for not wanting the responsibility of caring for the person with dementia. You may feel guilty if the person with dementia goes to hospital or into an aged care home, even though you did the best you could.

### Grief and Loss

Grief is our response to loss. This could be the loss of a relationship, moving house, loss of good health or death. Grief is a very personal feeling and people will feel and deal with grief differently.

### Anger

It is okay to feel angry. Angry at having to be a carer. Angry with people who do not seem to be helping. Angry at a person with dementia for their difficult behaviours and angry at aged care workers.

Feelings of distress, frustration, guilt, being tired and annoyed are very common. It is important to learn how to control your anger.

It is important that you speak with your nurse or doctor.



## Having a break

It is a good idea to have a break from caring for a person with dementia. Caring for someone with dementia can be very tiring. Families and carers can feel alone, especially if they cannot leave the person they are caring for.

It is good for the person with dementia to get help from others. It is a chance to meet other people.

### What can stop you from having a break?

- A strong belief that it is your role to provide the care
- Feeling you do not deserve a break
- Putting your own needs last
- Not knowing what help is out there.

Other family members and friends may be happy to help to give you a break from caring. Often you just need to ask.

The government also funds breaks for carers from caring for people with dementia. This is called 'Respite'. 'Respite' can be provided in your home, out in the community or in aged care homes.

For more information on how to access 'Respite' services contact My Aged Care on 1800 200 422 in business hours or the Commonwealth Respite and Carelink Centre on 1800 059 059 outside of business hours.

If you need a professional interpreter call 131 450 and ask to be connected to My Aged Care on 1800 200 422 or the Commonwealth Respite and Carelink Centre on 1800 059 059. There is no cost for the telephone interpreting.

## Safety inside and outside the home

Dementia affects each person differently. Often problems with mobility and co-ordination can affect a person's safety. Family, carers and friends can help the person with dementia to feel and be safe.

### Safety in the home

- Keep rooms free from clutter
- Remove loose rugs
- At night use lights to help the person find their way to the toilet
- Safely store medicines and harmful chemicals (such as bleach)
- Remove electric blankets and hot water bottles
- Install safety switches
- Install smoke detectors and test and replace batteries every six months
- Remove sharp utensils (such as, scissors and knives)
- Install safety taps for hot water.

### Safety outside the home

- Keep pathways clean and clear overhanging branches
- Make sure latches on gates are working
- Remove harmful tools or chemicals from garden, sheds and garages.
- Make sure the person with dementia has an identification bracelet in case they become lost.

Involve the person with dementia to decide on changes that can keep them safe. Change as little as possible. This will help reduce confusion and disorientation.

## Activities

Each day all of us do many different activities. With some help from others, the person with dementia can continue to take part in many activities.

Using skills that have not been lost, gives the person with dementia a sense of feeling useful and promotes wellbeing. It may include activities such as household work, gardening, craft or hobbies.

A person with dementia may enjoy going out, even if they do not remember where they have been. It is important that the moment is enjoyed, even though they may soon forget.

Give the person time and space. Break down activities into simple steps with one instruction at a time.

Ideally, activities should:

- Promote self-esteem
- Maintain old skills and not involve learning something new
- Provide enjoyment, pleasure and social contact.

To ensure success it is important to consider the times of day when the person is at their best.

Mistakes will happen. Don't let the person with dementia feel like a failure.

## Help with continence

Incontinence is an accidental or involuntary loss of urine (wee) from the bladder or faeces (poo) from the bowel.

Our brain sends messages to our bladder and bowel telling them when it is necessary to empty them. When there is memory loss because of dementia, incontinence may occur.

### **Dementia can interfere with a person's ability to:**

- Recognise the need to go to the toilet
- Be able to wait to go to the toilet
- Find the toilet
- Recognise the toilet
- Use the toilet properly.

Incontinence can also be caused by infection or constipation. Constipation is hard poo. Many of these conditions are treatable. Speak to your nurse or doctor about tests to find out why the incontinence is occurring.

You can also contact the National Continence Helpline on 1800 330 066. This is a telephone advisory service. If you need an interpreter call 131 450 and ask to be connected to the National Continence Helpline. There is no cost for the telephone interpreting.

## Help with keeping clean

It is quite common for people with dementia to have difficulty with, or forget to keep themselves clean. This can be upsetting for families and carers. It is important to work out ways of coping without argument or confrontation.

### What might help

- Pull down the blinds, or close curtains and doors to create a feeling of privacy
- Cover mirrors if the person does not recognise themselves
- Make sure the bathroom is warm and inviting
- Provide good lighting in the bathroom, especially during evening hours
- Choose the best time of day for bathing, at a time when the person is most relaxed
- Use the type of bathing the person is used to, such as, a bath, shower or sponge bath
- Offer simple choices, such as, “would you like to have your shower now or before bed?”
- Let the person feel the water before they get into the shower.

Getting dressed, having a wash and brushing teeth can be very hard to do for the person with dementia.

### What might help

- Break down the activities into simple steps. Gently explain each step. Use simple language
- Encourage the person to do as much of their own care as possible
- Put out the soap, washcloth, towel and clean clothes in order to make it less confusing
- Label items and use pictures to help the person with dementia to recognise the object.

## Help with dressing

Getting dressed can be hard to do because there are so many steps. Helping a person with dementia to get dressed can take a long time.

Some people with dementia can't remember whether they are getting dressed or undressed. Others may forget to change their clothes. They may also have problems with buttons, zips and shoe laces.

Some people with dementia may not be able to sense hot and cold. This may mean they add more layers of clothing than necessary or wear shorts in winter. If the clothes are not causing discomfort it may be easier to leave them as they are.

Some people with dementia may undress themselves. This can be embarrassing for the family or carer. The person may no longer understand what is appropriate.

### What might help

- Prompts may help the person to get dressed by themselves
- Put out the clothes in order to make it easier
- Make sure the room is warm
- Provide good lighting
- Provide privacy and a quiet place to get dressed and undressed
- Let the person do most of the tasks, if they can
- Let the person select their own clothes by offering choice of two outfits.

## Help with eating

Some people with dementia forget how to chew and swallow. They may have loose dentures, or may not be able to chew and swallow easily. The person may be embarrassed and this can result in a loss of appetite.

### What might help

- Ensure there are no medical causes for loss of appetite, such as illness or depression
- Provide meals at regular times each day
- Allow the person to eat when they are hungry
- Encourage physical activity which might improve appetite
- Provide meals that are high in fibre and nutrients
- Try to provide familiar foods
- Try to make meal times relaxed
- Allow enough time for the person to eat their meal
- Speak to their doctor if there is change in weight
- Leave snacks available.

### What might help at the table

- Serve one dish at a time
- Remove distracting items from the table such as, extra cutlery, glasses or table decorations
- Use familiar crockery and utensils
- Try serving finger foods if cutlery is too difficult
- Eat with the person so they can copy you.

## Help with sleeping

Problems with sleeping are common for people with dementia. Some people sleep during the day and are awake and restless at night. Some are no longer able to tell the difference between night and day. Others are simply not as active as they used to be and need less sleep.

The changes in the brain caused by dementia can affect our sleep.

### Causes

- The bedroom may be too hot or too cold
- Poor lighting may affect a person's sleeping patterns
- Changes in the environment such as, moving to a new home or having to be hospitalised, can cause disorientation and confusion
- Going to bed too early
- Sleeping too much during the day
- Agitation following an upsetting situation.

Sleep problems can be the most difficult symptoms of dementia to manage. Families and carers must also be able to get enough sleep themselves.

### What might help

- Keep the home and person's routines as familiar as possible
- Provide good lighting
- Remove mirrors if they cause confusion.

If you are worried about changes in the person's sleeping patterns speak with your nurse or doctor. You can also contact Dementia Support Australia on 1800 699 799. This is a national telephone advisory service. This service is available for families, carers and care workers who are concerned about the behaviours of people with dementia. The service is available 24 hours a day, 7 days a week. If you need an interpreter call 131 450 and ask to be connected to Dementia Support Australia. There is no cost for the telephone interpreting.



## End of life care

There is no cure for dementia. Care provided for the person when they are dying is called 'Palliative care'. This type of care provides emotional and practical support for families and carers, through to the death of the person with dementia.

Knowing the person's wishes for care in the future is important. This can provide guidance when they are no longer able to talk.

As death nears, it is important to remember that the person can still hear and may understand what is being said.

Provide comfort to the person with dementia. Comfort is important during end of life care e.g.:

- Position of the body in the bed
- Care of the mouth
- Care of the skin
- Care of the bowel
- Emotional support.

Responding to the spiritual and religious needs of a person with dementia is an important part of end of life care. It may include rituals and practices of religion.

For more information about 'Palliative care' speak to your nurse or doctor.

You can also call the National Dementia Helpline on 1800 100 500. If you need a professional interpreter call 131 450 and ask to be connected to the National Dementia Helpline on 1800 100 500. There is no cost for the telephone interpreting.

## Driving

Dementia can affect your ability to drive a car in the following ways:

- Finding your way around on the roads
- Judging the distance between cars and objects
- Judging the speed of other cars
- How quickly you can react
- Recognising road traffic lights and signs.

Having dementia does not mean that you need to stop driving. However, by law you must tell the licence authority of your dementia. They may ask you to see your doctor to advise if it is safe for you to keep driving. They may place conditions on your licence. A condition might be to only drive short distances from home.

Any changes in your ability may mean that you should stop driving. The following may help you decide.

### When driving do you:

- Need direction?
- Become lost in familiar areas?
- Confused about which way to turn?
- Become tired?
- Have difficulty in understanding traffic lights and signs?
- Drive more slowly?
- Take longer to react?
- Drive on the wrong side of the road?
- Ignore traffic rules?
- Use accelerator or brakes incorrectly?

Remember, the most important thing is your safety and the safety of others.

## Alternatives to driving

Dementia can cause changes to memory, concentration and eyesight. This can affect your ability to drive. You may be at risk of serious injury or injuring others through your driving.

Some people decide to give-up their licence. A doctor can sometimes recommend that you should stop driving.

Some people find giving up driving one of the hardest things to do. A car may be an important part of your independence, and without it your life may change.

Here are some things to do instead of driving:

- Ask a family member or friend to give you a lift
- Use a bus or train
- Apply for a Taxi Card and use a taxi service
- Walk
- Community transport provided by your local council.

Reduce the need to drive. Find different ways to get around. This will help you stay active, mobile and socially connected.

## Driving for families and carers

The law requires all drivers to tell the licence authority of any medical condition that may affect their driving. It is very important that you do this.

### Warning signs that dementia may be affecting a person's ability to drive:

- Poor eyesight – can they see road signs and other objects?
- Hearing – can they hear the sound of cars and horns?
- Reaction time – can they stop their car quickly?
- Problem solving – can they become upset or confused easily?
- Coordination – have they started to walk differently or drop things?
- Alertness – are they aware of what is happening around them?

### Also:

- Can they tell the difference between left and right?
- Do they become confused on familiar routes?
- Do they understand traffic lights and signs?
- Are they able to stay in the correct lane on the road?
- Has their mood changed when driving?

If you have any concerns about a person's ability to drive speak to them, their families or carers or to their doctor. You can also contact the licence authority for driving in your state or territory to discuss your concerns.

## Travelling with a person who has dementia

Many families and carers have happy times travelling with a person with dementia.

They travel overseas and interstate. Trips can be for going back to the country of birth, family gatherings or sightseeing.

Travelling with a person who has dementia can be difficult. It is usually better to travel in the early stages of the illness. As the condition progresses the person with dementia may become upset when away from home.

### Warning signs against travelling:

- Wanting to go home
- A sudden change in their behaviour
- Problems with going to the toilet on their own or with help
- Teary, anxious or withdrawn in crowded and noisy settings
- Getting lost or wandering.

If any of these problems happen it may mean that travel is not a good idea. If you must travel, speak to your doctor about what might help, including possible medicine.

If none of the problems happen, it may be useful to take a short trip before taking a longer trip. This will help you decide if the person with dementia can travel.

## Early planning

Dementia affects people differently. One person may begin to lose the ability to handle money at an early stage while another person may keep this skill much longer.

Over time, the person with dementia will not be able to make their own decisions. They will not be able to make decisions about money, medical treatment and legal issues.

Planning for the future can make it easier for families and carers to manage the affairs of a person with dementia. It is important for the person to be involved in planning for the future. This is to make sure that their wishes are carried out in the way that they would like.

Wherever possible, get advice while the person with dementia can still be involved in planning for the future. It is also important for the person to make decisions while they are still legally able to sign documents.

## Decisions about medical treatment

Over time, the person with dementia will not be able to make their own decisions. They will not be able to make decisions about medical treatment and legal issues. It is important to plan for the future.

You need to choose someone who can make these decisions for you.

In most states and territories of Australia, a relative or friend can be appointed to make these decisions for you. Appointing a relative or friend to make decisions about your medical treatment, should be documented with your lawyer.

A court can appoint someone to make decisions on behalf of a person with dementia.

### Tools to help plan how decisions about your medical treatment will be made in the future:

- **‘Enduring power of attorney’ for health matters.** This allows the person with dementia to appoint a person who can make medical decisions for them.
- **Advanced care directive.** This is a written document stating the wishes of the person with dementia about medical treatment in the future.

## Enduring power of attorney

An 'Enduring power of attorney' is the name for a legal document. This allows the person you choose to look after your finances and lifestyle decisions when you are no longer able to do so. Many people have an 'Enduring power of attorney' regardless of their illness or diagnosis.

### Planning for the future:

- Ensure the person with dementia makes an 'Enduring power of attorney', as soon as possible after diagnosis and while they are legally able to do so
- Ensure family and carers also have their own 'Enduring power of attorney', in case they also need one
- Have a copy of the 'Enduring power of attorney' and know where it is kept.

### Who can help?

- Lawyer or a Community Legal Service
- Dementia Australia – Phone 1800 100 500



## Money

If a bank account is in joint names, the partner of the person with dementia can continue to use it. However problems can occur if the person with dementia uses the account inappropriately. This problem can also occur if the person with dementia has accounts in their name only and uses the account inappropriately.

To avoid problems the person with dementia can give permission, while legally able to, for another person to use their account. It is important to remember that some permissions cannot be used if the person is no longer legally able to make decisions. Speak to the bank manager about this issue.

### Planning for the future:

- Have joint signatures on all bank accounts
- Discuss future financial affairs with a financial adviser
- Arrange how and when the person with dementia will access their money.

### Who can help?

- Bank manager
- Financial adviser
- Lawyer
- Dementia Australia.

## Wills

A will gives instructions on how the property and money of a deceased person should be distributed.

A will is only legal if the person writing the will understands its content. It is important that if the person with dementia wishes to make a will or change their will, they do so while they are still legally able to sign.

### Plan for the future:

- Have an up-to-date will
- Know who the executor of the will is. The executor is the person who manages the will after a person has died
- Know where the will is kept.

### Who can help?

- Lawyer or Community Legal Service
- Dementia Australia – Phone 1800 100 500

## How to contact us:

[boltonclarke.com.au](http://boltonclarke.com.au)

1300 22 11 22

If you require a telephone interpreter to speak to us, call the National Language Line:

[boltonclarke.com.au/national-language-line](http://boltonclarke.com.au/national-language-line)

Or the National Relay Service:

[relayservice.gov.au](http://relayservice.gov.au)

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