



## Section 5

# Living well

The Dementia Guide is for anyone who has been impacted by any form of dementia. The information in this guide is divided into sections. Each section relates to a particular stage of your dementia journey.

It is important to remember that everyone living with dementia is unique. The content in this guide is general in nature and we recommend you seek professional advice in relation to any specific concerns or issues you may have.

While we strive to keep content accurate and up-to-date, information can change over time. For updates, please visit [dementia.org.au](https://dementia.org.au) or call the **National Dementia Helpline** on **1800 100 500**.

Web: [dementia.org.au/the-dementia-guide](https://dementia.org.au/the-dementia-guide)



“

**Bryan goes to the gym with me two or three times a week, he cycles for 10 minutes, does 20 sit-ups on an incline board, we do some strength training on weight machines, he rows for 10 to 15 minutes and then we walk for 10 minutes to cool down. ”**

Conny and Bryan, Dementia Advocates.  
Bryan lives with dementia.

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# Living well

### Section contents

Living with changes .....	66
Reducing stress .....	68
Maintaining communication .....	69
Navigating changed relationships .....	73
Living at home .....	76
Travelling safely .....	84
Staying healthy and active .....	86

There are lots of things you can do to live as well as possible with dementia.

Your abilities to perform daily routines and activities might change over time, but it does not mean you need to stop doing the things you enjoy. You just might have to do them differently.

It is important to stay engaged and look after your health. Small changes to your lifestyle can lead to better health and wellbeing.

## Living with changes

The changes that occur with dementia can include:

- memory loss
- problems with thinking and planning
- difficulties communicating
- difficulties carrying out routine daily activities such as cooking, banking and driving
- confusion about time or place
- sight and visual difficulties
- apathy and withdrawal.

If you or your family and friends notice these changes are affecting your quality of life, it is time to adapt your daily routine.

## **Ways to adjust to changes**

The changes you experience might be distressing or discouraging. But with support, you can keep doing the things you want or need to do.

- Continue to exercise and maintain a healthy diet, within your ability. This will improve the way you think and feel.
- Exercise your mind. Keep learning, thinking, and doing a variety of activities.
- Maintain your hobbies and pastimes as much as possible.
- Stay social.
- Continue to carry out tasks around the house, like cooking, cleaning, shopping and showering, asking for help if you need it.
- Access formal services to assist with your daily needs, such as My Aged Care government funded in-home care and support services, NDIS planned services or private services.

# Reducing stress

Living with dementia can sometimes be overwhelming and stressful. Stress can further affect your health and ability to function.

By lowering stress, you can improve your concentration, decision-making ability and quality of life.

## Ways to manage stress

- Identify any sources of stress. Remove yourself from these where possible.
- Establish clear boundaries. Let others know what you are willing to tolerate and what you are not.
- Simplify your daily routine.
- Break tasks into smaller steps. Give yourself plenty of time to do things at your own pace. Ask others to give you enough time.
- Ask for help with difficult tasks or put them off until later.

- If you are feeling overwhelmed, take a break in a quiet place to relax.
- Share the task with someone else to make it easier.

## Maintaining communication

Communication is a crucial way of letting people know what you think, feel or need. It is also important for maintaining your relationships with family and friends.

As dementia progresses, it can become difficult to express yourself. It can also become difficult to understand what others say.

You may need to develop new ways of communicating with people. Family and friends will also need to develop new ways of communicating with you.

Most people have good and bad days.

On bad days, you may:

- struggle to find the right words
- lose your train of thought
- repeat words, stories or questions
- get words confused or say them in the incorrect order
- have problems with reading, spelling or writing
- have problems understanding what other people are saying.

## **Helpful communication tips**

- Slow down and take more time to speak.
- Find a quiet place to talk where there is little distraction.
- Let people know when you are having difficulty speaking or understanding.
- Describe the person, place or thing if you cannot recall the name.



- Ask family and friends to prompt, remind or help you if you are struggling to find a word or repeating yourself.
- Give people feedback on how their communication style works for you.

## **When English is your second language**

If English is your second language, you might revert to your first language as the condition progresses. If this happens, you could:

- consider using interpreting technology (available on the Internet or smartphones) to facilitate conversation with family and friends unfamiliar with your first language
- become familiar with support services that cater to cultural diversity
- work with care givers who speak your first and second languages
- encourage family and friends to learn the basics of your first language.

It is important that your doctor understands your first language and cultural heritage.

You could also consider ways to communicate non-verbally, such as:

- the use of visual cues or picture cards
- body language and the use of gestures to help make yourself understood.

## **Dealing with isolation and loneliness**

People living with dementia can sometimes feel lonely and isolated from their community.

It is important to establish a routine that keeps you connected with family and friends.

You can also meet other people in the early stages of dementia. There are support groups and events for people living with dementia and their family and friends.

Call the **National Dementia Helpline** on **1800 100 500** to join a support group in your area.

# Navigating changed relationships

Symptoms of dementia can affect your relationships.

You may experience a loss of independence when a carer or family members step in to perform tasks with you, or on your behalf. Family members may start having conversations as if you are not in the room or make decisions and implement plans without your input.

It is common to feel guilty relying on family and friends more than usual and unwanted help can feel intrusive and overbearing.

Talking to others and sharing your feelings may help. It can also help your family and friends understand how you are feeling so they can modify their behaviour appropriately.

Accepting help can be difficult but the right support will mean you can live independently for as long as possible.

## **Keeping relationships positive**

- Talk to family, friends and others about the support you need and how they can provide it.
- Focus your energy on your most supportive and comforting relationships. Let people know they are valuable to you.
- Share your experience living with the disease. And encourage others to share their feelings too.
- Accept that family and friends may want to discuss their feelings with other people.
- If people become frustrated, remember they are frustrated with the disease, not you.

## **Intimacy and sexuality**

Dementia can affect sexual feelings and behaviour over time.

You may feel uncertain, frustrated or a loss of confidence. This can lead to changes in feelings towards your partner.

There might be things you cannot do any more.

Being open about sexual changes will help you stay close. It also leads to less confusion, blame, resentment, guilt or lowering of self-esteem.

Discuss your needs and expectations for now, and in the future. It is important to allow your partner to do the same. You may need to make changes to find sexual contact or activities that you both enjoy.

You can also explore new methods of intimacy. This includes non-sexual touching or sharing special memories. Work with your partner to find something that satisfies you both.

### **Depression and intimacy**

Depression can lead to a loss of interest in sex. Some medications can also have side effects that change your sexual desire.

As your dementia progresses, you may feel more or less need for sexual expression and intimacy. Speak to your doctor if any of these changes cause physical or emotional distress.

# Living at home

A well-designed home can help support your independence. The right supports and practical modifications can maintain your abilities around the house.

## Creating a dementia-friendly home

Some changes to your home can help you feel more safe and secure.

- Improve lighting by:
  - replacing current globes with brighter ones
  - placing chairs and couches by sunlit windows
  - installing sensor lighting to reduce the risk of falls at night-time.
- Ensure there is sufficient space to move around by reducing clutter and removing potential hazards such as loose electrical cords or rugs.
- Display personal items and photos. This helps prompt reminiscence and can reduce stress and anxiety.

- Place regularly used items in your line of sight.
- Group common items together so they are easier to find.
- Use labels or picture cards to help locate and identify items.
- Make sure hot and cold indicators are marked on taps.
- Replace appliances (when needed) with the same or similar models that are familiar to operate.
- Use distinctive coloured doors and contrasting door frames to help with orientation.

### **Accessing your property**

At some stage, you may accidentally lock yourself out of your home. Make sure you leave a set of house keys with a neighbour you trust.

Or you could fit a key-lock safe outside your property with a spare key.

## Planning for support

Some people with dementia find their self-care, personal hygiene and household chores start to decline. These changes can also increase the risk of malnutrition and dehydration.

It is important to plan so that you meet your basic needs. Listed below are some things you can try:

- Organise to have your groceries delivered or arrange home-delivered meals.
- Consider hiring a home maintenance service to help with windows and gutter-cleaning, smoke detector checks, leaking taps and light bulb changes.
- Arrange for somebody to help with house cleaning, meals, transportation and daily chores.
- Arrange for help paying bills. You can give a trusted person the legal authority to handle money matters. You can also speak with your bank or service provider about automatic payments.



- Set up a system for medication reminders, such as a Webster-pak<sup>®</sup> arranged through your local chemist.
- Explore options for how you may get around when dementia impacts your ability to drive. Consider using public transport, taxis, Uber, and community transport, as well as lifts from family and friends.

## **Staying safe at home**

Dementia can increase the risk of having an accident around the home but there are assistive technologies and products that can improve safety.

Assistive technology can:

- reduce the risk of falls and accidents in and around the home
- support independence
- reduce premature entry into residential and hospital care
- reduce carer stress.

Assistive technology ranges from high-tech solutions to simple equipment. Some simple solutions include:

- personal alarms and timers that switch off electrical items
- calendar clocks
- touch lamps and night lights
- hand rails and safety ramps
- walking sticks where they have been prescribed and correctly set up by a health professional.

It is best if you can assess your home safety and introduce safety solutions early, as some technologies and equipment need to be assessed by an allied health professional. This gives you time to learn how to use them, rather than in an emergency or at a more advanced stage of your dementia.

Here are some other ways to keep safe at home.

**1. Check smoke alarms and carbon monoxide detectors.**

Arrange for somebody to check these detectors regularly. Get advice on smoke detectors, hot water services, temperature regulators and monitoring services. Contact the **National Equipment Database** on **1300 885 886**.

**2. Identify fire and safety hazards in and around the home.**

Ask your local fire service about a free home fire safety visit. If they identify any hazards, you can take steps to remove them.

**3. Talk to an occupational therapist.**

An occupational therapist can advise on ways to make your house safer through assistive technology and home modifications. An occupational therapist can be accessed through a referral from your doctor, My Aged Care or the National Disability Insurance Scheme.

## Preventing falls

Some people with dementia experience changes in their balance. This can increase your risk of a fall. Falls can be particularly dangerous if there is nobody around to help you.

You can help prevent falls by:

- making sure your house is well lit
- removing trip hazards such as rugs
- fitting handrails on stairs or in the bathroom.

A personal alarm is a technology option to alert somebody if you fall.

A physiotherapist or exercise physiologist can give you exercises to help reduce your risk of falls. You can contact one directly, through My Aged Care or the NDIS or speak to your doctor for advice.

## Living alone

Many people with dementia continue to live on their own during the early stages of the disease. If you live alone, it can be difficult to recognise when you need to use healthcare services.

It is important to build a relationship with your doctor, health professionals and service providers, such as My Aged Care or the National Disability Insurance Scheme (NDIS). They can refer you to services and supports to help you live at home safely for as long as possible.

# Travelling safely

Living with dementia does not mean you cannot travel. With planning, you can have a safe, comfortable and enjoyable experience.

Here are some tips to help you enjoy your holiday.

- Pick travel companions who understand your condition. They can help look after logistics.
- Select travel options suited to your needs and abilities.
- Allow plenty of time for rest. Do not try to do too much.
- Tell hotel, flight or cruise staff about your specific needs. They can then be prepared to assist, if necessary.

## Staying safe on holidays

- Plan trips with easy access to emergency health services and pharmacies.
- Changes in your environment can sometimes trigger moments of confusion. Make sure your travel companions and holiday staff are aware of this.
- Consider buying travel insurance if you have booked flights or hotels. Discuss your travel plans and health with the insurance company before taking the policy. There may be some exclusions that relate to dementia.
- Give copies of your itinerary to family members, friends or an emergency contact at home.
- Keep a list of emergency contacts and telephone numbers with you at all times.
- If travelling overseas, subscribe to **[smartraveller.gov.au](https://www.smartraveller.gov.au)** to receive travel advice updates for your destination.

# Staying healthy and active

Staying active and social can help your skills and memory. It can also improve your self-esteem, sleep and wellbeing.

Wherever possible, keep doing what you enjoy, even if you have to do things differently. Engage in activities that keep your heart, body and mind active to look after your brain and improve your wellbeing.

## Look after your heart

Your brain needs a healthy heart and blood vessels to keep it supplied with oxygen and nutrients.

There are many ways to keep your heart healthy.

- If you smoke, try to stop. To help you quit, call Quitline on **137 848**.
- Arrange regular check-ups with your doctor. This includes regular dental, eye, hearing and foot health checks.



- Get the flu vaccine each year. If appropriate, ask your doctor about the pneumonia vaccine for over-65s.
- If you regularly feel low, anxious or irritable, you may have depression. Depression is treatable. Take the first step by talking to your doctor.
- Follow up any health concerns with your doctor. This is especially important if you have diabetes, or heart or breathing problems.
- Get enough sleep. Good quality sleep is important for good health and will help you function best during the day.

## **Look after your body**

It is important to take steps to remain fit and healthy.

Thirty minutes of physical activity each day can improve the way you think and feel. If this seems difficult, do not worry. You can start with less activity and increase it over time.

There are activities to suit every age and ability.

You could try:

- walking
- dancing
- Tai Chi
- gardening
- lawn bowls
- exercise classes, including low-intensity and water exercises.

## **Maintain a healthy diet**

Eating well and staying hydrated keeps you healthy and energised. It will help you remain active and think better.

You need a variety of nutritious foods to stay healthy. These include:

- vegetables
- fruit
- whole grains
- lean proteins, such as fish, beans and chicken
- low-fat dairy.

Sugary foods and drinks, high-fat foods, salty foods and alcohol should be limited.

Nutritional supplements, such as Souvenaid (for people living with mild Alzheimer's disease), can be taken to support brain function. Speak to your doctor about your options.

You may be able to arrange for meal preparation assistance or have healthy meals delivered to your home, through support from My Aged Care or the National Disability Insurance Scheme.

## **Look after your mind**

You can exercise your mind by doing things you find challenging. Keeping your mind active can help you feel good and think more clearly.

You could try:

- reading
- singing
- playing games

- talking with others
- doing crossword puzzles
- learning new skills.

## **Maintain social connections**

Staying socially connected improves quality of life by providing a sense of belonging and connectedness.

You could:

- join groups or clubs
- maintain contact with friends and family
- continue to attend your place of worship
- participate in volunteer activities.

