4 Living well

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Key points: Living well

If you’ve been diagnosed with dementia, there are lots of things you can do that will help you live as well as possible.

To help you cope with memory problems you could try using a large diary, perhaps keeping it next to a calendar clock. Also, try keeping important items, such as keys or glasses, together in the same place.

Try to make your home safer. Remove things that are easy to trip over and install assistive technologies such as carbon monoxide detectors and smoke alarms. You could also get automatic timers for plugs, lights and heaters.

Many people with dementia can continue to live on their own during the early stages of the disease, by making simple adjustments, taking extra safety precautions and calling on support from families, friends and others.

A diagnosis of dementia does not mean you should stop travelling, particularly if this is something you have always enjoyed. When people living with dementia are away from home, some careful planning will ensure the safety, comfort and enjoyment of everyone involved.

Try to stay active and social. This can help you retain skills and memory, as well as improving your self-esteem, sleep and wellbeing. Wherever possible, keep doing what you enjoy, even if you have to do it differently. Ask an occupational therapist (a health professional who supports people to maintain everyday skills) for advice on appropriate activities.

Having dementia doesn’t mean you should feel unwell. It is important to take steps to remain fit and healthy. Regular exercise and eating a balanced diet can help. If you smoke, try to stop.

Arrange regular check-ups with your doctor, as well as regular dental, eye and hearing checks. Get the annual flu vaccine and see your doctor promptly if you feel unwell.

Because dementia affects many parts of your brain, you may need to develop new ways of communicating with people. Simple modifications such as talking slowly, finding a quiet place to talk, and being more descriptive when you can’t remember a specific word will help you continue to communicate effectively.

Symptoms of dementia can affect relationships with family and friends. It is important to be open and honest about these changes, talk them through and ask for help wherever it is needed. Seeking counselling from a professional can help.
A positive outlook

"If you can’t change your fate, change your attitude." Amy Tan

Living with dementia is challenging and you may feel angry or frustrated about what is happening to you. Your plans for the future might change, but dementia doesn’t change who you are. It doesn’t mean that you need to stop doing the things you enjoy, but you might have to do them in a different way.

There are some practical things you can do to help you live as well as possible following a diagnosis of dementia. Focus on the things you can and want to do, and try not to become isolated. Keeping busy with activities you enjoy and staying socially connected with friends and family may help you to feel more confident.

To discover some examples of measures that have helped people with dementia to live happy and fulfilled lives, visit livingwellwithdementia.org.au

Coping with changes

The changes that occur with dementia can be frustrating, distressing and may undermine your confidence. You will probably notice changes in your abilities to do the things you usually do. When you or your family and friends notice these changes, it is time to adapt your daily routine.

Changes might include memory loss, problems with thinking and planning, difficulties communicating, confusion about time or place, sight and visual difficulties, apathy and withdrawal.

There are lots of practical things you can do to help you cope with these changes.

- Keep a notebook or large diary. Write down things you want to remember, such as names, phone numbers, social engagements or appointments. Keep the diary next to something you use a lot like the kettle or phone, so that you get used to referring to it.
- Consider writing down important ideas and information. This can provide a helpful memory aid. Written information can be easily shared with others.
- Consider positioning a whiteboard in a prominent place to record and display important information.
- Put labels or pictures on cupboards to remind you where things are.
- Reduce clutter around the home to make things easier to find.
- Place useful telephone numbers by the phone.
- If you find it helps, put a note on the door or by your bed to remind yourself to lock up at night.
- Ask your pharmacist about putting your pills in a dosage box or pack with the days of the week marked.
- Consider using a medication or pill box timer to help remind you when to take your medication.
• Keep a note of your address, family contact details and written instructions explaining how to get home, whenever you go out.
• Get support from family, friends and services in the community to help you keep doing the things that you want or need to be able to do.
• Make sure you continue to exercise, within your ability. This will improve the way you think and feel.
• Exercise your mind. Keep learning, thinking, and doing a variety of activities.
• Remain socially engaged.
• Make sure family and friends know to gently reassure you if you become confused about the time or place.
• Place way finding symbols and instructions on how to operate certain equipment around the home.
• Use contrasting colours. For instance, if your toilet bowl is white, consider a contrasting toilet seat to make sure it stands out.

There are also a number of technological aids that can help you cope with changes.
• Reminder messages. Whenever you go in or out of the house, a recorded voice reminds you to pick up your keys or lock the front door.
• Calendar clocks. These show the date and the day of the week. Keeping the clock next to a diary or weekly planner can help you orientate yourself when checking appointments and other commitments. It can also be useful to keep a clock next to a medication dosage box for the same reason.
• Locator devices. These help you find frequently mislaid items such as keys. You attach a small electronic tag to the item, and you can then click a button on the locator device to make the tag beep.
• Automatic timers and switches. These will automatically turn off lights, irons and stoves if they have been left on too long.

For more information on technological aids that can help you, see Keeping safe at home on page 61.

Daily coping strategies

“Courage does not always roar. Sometimes courage is that quiet voice at the end of the day saying, “I will try again tomorrow.”

Mary Anne Radmacher

Things you once found easy like maintaining your schedule or managing your money may become increasingly difficult as your dementia progresses. Developing coping methods can reduce stress by making things as easy as possible and can help you remain engaged and active, and overcome challenges that inhibit your independence and wellbeing.

Identify

Make a list of tasks that have become more challenging, with a focus on the activities that are most important in your daily life.

Prioritise

Determine whether each task is necessary. For the more difficult and important tasks, consider asking for help from family and friends, or local service providers.

Strategise

Develop a regular daily routine and approach one task at a time.

Reduce stress

Living with dementia can be overwhelming and frustrating. Stress can further affect your health and ability to function. Taking steps to reduce stress can help improve your concentration, decision-making ability and overall quality of life.

To help reduce stress:
• identify sources of stress in your life and remove yourself from these situations whenever possible;
• establish boundaries and let others know what you are willing to tolerate and what you are not;
• take a break and find a quiet place to relax, if you’re in an environment that has too much noise or other stimulation;
• keep things straightforward by simplifying your routine and daily tasks to make them more manageable;
• consider asking for help with the tasks that become too difficult for you, or consider putting them off until later;
• break each task down into a step-by-step process. Give yourself plenty of time and take things at a slower pace if you need to;
• perform tasks with other people, for instance, cooking, shopping, housekeeping, exercising and paying bills.

Getting support
Support from family, friends and service providers in the community can help you keep doing the things that you want or need to do.

Make sure you let people around you know how they can help. If you can get support, you’ll have more energy to do the things you enjoy the most. You may be able to get some help with tasks around the house like cooking, cleaning, shopping or showering. There are support services available that can provide assistance.

Some useful ways to get information, support and referral to services include:

My Aged Care – a website and telephone service established by the Australian government to help you navigate the aged care system. Visit myagedcare.gov.au or call 1800 200 422.

The National Dementia Helpline – call 1800 100 500 to access support services and get advice on developing effective coping strategies.

Dementia-friendly environments
The physical environment can have a major impact on a person living with dementia. There are lots of practical things you can do to create an environment that will maximise your engagement and wellbeing at home:

• Improve lighting by replacing current globes with brighter ones, position seating such as chairs and couches by windows to take advantage of sunlight, and consider installing sensor lighting to reduce the risk of falls at night time.
• Ensure personal items and photos are on display to provide opportunities for reminiscence to reduce stress and anxiety.
• Place regularly used items in line of sight and group common items together to make them easier to find.
• Use labels to help locate and identify items.
• Make sure hot/cold indicators are clearly identified on taps, to avoid confusion.
• If you ever need to replace an appliance, make sure you do so with a familiar and recognisable model.
• Have distinctive coloured doors with contrasting door frames to help with orientation.

For more information see our series of Help Sheets, The environment and dementia, or refer to enablingenvironments.com.au for practical suggestions on each area of the home.

Keeping safe at home
Dementia can increase the risk of a person having an accident around the home, but there are measures you can take that will help keep you safe.

A broad range of assistive technologies and dementia-friendly products exists to improve the safety and wellbeing of people living with dementia, their families and carers by:
• reducing the risk of accidents in and around the home
• supporting independence and choice
• reducing premature entry into residential and hospital care
• reducing carer stress

The term ‘assistive technology’ refers to any device or system that allows an individual to safely perform a task they would otherwise be unable to undertake.

Assistive technology can range from high-tech solutions to simple equipment such as personal alarms and timers that switch off electrical items, calendar clocks, touch lamps and walking sticks.

These types of technologies can be easier to get used to if you adopt them early on, rather than introducing them after an emergency or crisis has already occurred, and in the more advanced stages of dementia.

Call the National Dementia Helpline on 1800 100 500
Alzheimer’s Australia provides advice on a range of assistive technology equipment suitable for dementia care. You can find out more by visiting bit.ly/vicassistivetech or calling the National Dementia Helpline on 1800 100 500.

Here are some other measures you can take to keep yourself safe at home:

- Arrange for somebody to regularly check smoke alarms and carbon monoxide detectors.
- Ask your local fire service about a free home fire safety visit.
- An occupational therapist can give advice on items that could improve safety in the home.
- A physiotherapist can provide guidance on appropriate exercises that will reduce the risk of falls. Speak you your doctor for advice.

The Independent Living Centre in each state and territory provides information about smoke detectors, hot water services, temperature regulators and monitoring services. Advice is also available on home modifications and home design.

Contact numbers for Independent Living Centres can be obtained by calling the National Dementia Helpline on 1800 100 500, or by visiting ilcaustralia.org.au

Living alone with dementia

Many people with dementia continue to live on their own during the early stages of the disease. Making simple adjustments, taking extra safety precautions and calling on others for support can help enable this.

Safety

There are a number of safety issues to consider that, if addressed, will help you maintain your independence and allow you to live at home for longer.

Allied health clinicians can also provide support at home to help you maintain your quality of life, independence, self-care and mobility, while helping to reduce the risk of complications due to other conditions or injuries.

See Allied health clinicians on page 42.

Falls

Some people with dementia experience changes in their balance, which increases the risk of falls. Changes in your sensitivity to light, the contrast between colours, or depth perception might affect your navigation skills. Falls can be particularly dangerous if there is nobody around to assist.

- Help prevent falls by making sure the house is well lit, removing trip hazards such as rugs, and having handrails fitted on the stairs or in the bathroom.
- Keep a personal alarm with you at all times, so you can alert somebody if you fall.
- A physiotherapist can provide guidance on appropriate exercises that will reduce the risk of falls. Speak to your doctor for advice.

Accessing your property

It may be that memory loss causes you to become locked out of your home at some stage. Make sure you leave a set of house keys with a neighbor you trust, and keep their telephone number with you at all times. Alternatively, consider fitting a key-lock safe outside your property, with a spare key.

Looking after yourself

Changes in thinking might result in you paying less attention to your self-care, personal hygiene and household chores. Additionally, your risk of malnutrition or dehydration may increase.

Plan ahead to ensure your basic needs are met.

- Organise to have your groceries delivered, or arrange home delivered meals.
- Consider engaging a cleaning service.
- Arrange for family, friends or a paid worker to help you with housekeeping, meals, transportation and daily chores.
- Make arrangements for help with paying bills. You can give a trusted person the legal authority to handle money matters, or speak with your bank or service provider about automatic payments.
- Establish a system for medication reminders.
Isolation and loneliness
Establish a routine that encourages you to stay connected with family and friends. You can also take advantage of programs and services that involve other people in the early stages of dementia. Support groups and events organised specifically for people living with dementia and their family and friends do exist.

To find out more, call the National Dementia Helpline on 1800 100 500. You can also connect with other Australians in similar circumstances by joining the online forum at helpwithdementia.org.au.

Driving
At some point, everyone with a diagnosis of dementia will need to stop driving. This will reduce the risk to themselves and others due to a decline in their cognitive or sensory abilities. Giving up driving can be a big adjustment for anybody to make, but for a person who lives alone, this change can be even more significant.

Make sure you plan how you will get around once driving becomes an issue. Consider taxis, public transport and lifts from family and friends.

For more information, see Driving, page 81.

Health care services
People who live alone rely on their own perceptions of when they need care and support. A diagnosis of dementia means you might be less likely to recognise when you need to use health care services.

There is support available that will help you assess your health and care needs, and programs that can help you meet those needs. For more information, visit myagedcare.gov.au or call the National Dementia Helpline on 1800 100 500.

See Help Sheet, Information for people with dementia 05: Living alone. Available at fightdementia.org.au

Keeping safe when you travel
Just because you have been diagnosed with dementia does not mean that you can’t still experience the joys of travel. You may even have a list of places to visit while you are still able.

When people living with dementia are travelling away from home, some careful planning will ensure the safety, comfort and enjoyment of everyone involved.

- Pick your travel companions wisely. Make sure they are not only good company, but also understand your condition and are able to ease stress by looking after the logistical aspects of your trip.
- Reduce anxiety by selecting travel options based on your needs and abilities, while also considering comfort and safety.
- Allow plenty of time for rest in your schedule. Don’t try and do too much.
- If you are flying, taking a cruise or staying in a hotel, inform staff of any specific needs so they can be prepared to assist if necessary.
- If you have other health issues, plan trips where emergency health services and pharmacies are easily accessible.
- Be aware that changes in environment can trigger moments of confusion. Ensure your travel companions and other significant people (such as hotel staff) are also aware of this.
- Buy travel insurance if you have booked flights or hotels, to ensure you don’t lose out financially if things change. Call the insurance company before taking the policy, to get an understanding of any exclusions relating to a diagnosis of dementia.
- Create an itinerary that includes details of each place you will be staying and the dates you will be there. Give copies to family members, friends or your emergency contacts at home.
- Keep a list of your emergency contacts and telephone numbers with you at all times, in case you get lost.
- If you are travelling overseas, ensure your trip is registered with the Department of Foreign Affairs and Trade. You can do this through the smartraveller.gov.au website.
“As carer for my husband with dementia, I made sure we had time travelling together in our motorhome. By this time he was unable to drive and his mobility had declined, but he was able to enjoy the changing scenery, while being reassured that our living environment remained the same.”

For more information see Help Sheet, Caring for someone with dementia 8: Travelling. Available at fightdementia.org.au

Staying active

Keeping as active as possible – physically, mentally and socially – offers great benefits. It can help you meet new people, retain skills and memory, boost your self-esteem, improve the quality of your sleep and avoid depression.

You might find that activities take you longer than they used to. You may need to make changes to the way you do things, or have some support to do them. For example, if you enjoy cooking but are having trouble preparing a meal, you may still be able to do some elements of it, such as peeling the vegetables, setting the table or serving.

Try to adapt and make these changes, rather than giving up an activity that you enjoy altogether, or not pursuing an activity that could improve your wellbeing.

Keeping your mind active

You can exercise your mind by doing things you find challenging. Keep learning and thinking. Keeping your mind active can help you feel good and think more clearly. Try reading, singing, playing games, talking with others, doing crossword puzzles and learning new skills.
Remaining physically active

Physical activity is essential for keeping fit. It can also improve the way you think and feel.

National Physical Activity Guidelines recommend we do at least 30 minutes of physical activity every day. If this is difficult, start with less activity and increase it over time. People of all ages and abilities should do a few activities every day to improve fitness, strength, flexibility and balance. Examples include walking, dancing, Tai Chi, gardening, lawn bowls and exercise classes, including low intensity and water exercises.

For more information see Help Sheet, Information for people with dementia 7: Keeping involved and active. Available at fightdementia.org.au

Looking after your general health

Ensure you follow up any health concerns you may have with your doctor. Other conditions such as urinary tract or respiratory infections can make the symptoms of dementia more severe.

- Try to eat a balanced diet and drink plenty of fluids.
- Take regular physical exercise.
- If you enjoy having the occasional alcoholic drink, keep doing this (unless your doctor advises you not to).
- If you smoke, consider stopping.
- Get enough sleep.
- If you find yourself regularly feeling low, anxious or irritable, you may be depressed. This can be treated, so talk to somebody close to you and consider discussing it with your doctor.
- Have the flu vaccine each year and ask your doctor about the pneumonia vaccine for over-65s, if this is appropriate.

Maintaining a healthy diet

Eating well and staying hydrated will improve your overall health and energy levels so you can remain active. It can also help you to think better.

You need a variety of nutritious foods to stay healthy including vegetables, fruit, whole grains, lean protein (e.g. fish, beans, chicken) and low fat dairy. You should also limit some foods including sugary foods and drinks, high fat foods, salty foods and alcohol.

For convenience, you can arrange to have healthy meals delivered to your home. For information on how to arrange meal delivery, visit myagedcare.gov.au/help-home/meals

Nutritional supplements, such as Souvenaid, are also available. Speak to your doctor about your options.

Check-ups

Visiting your doctor regularly means any other health problems that could make the symptoms of your dementia more severe should get picked up quickly. This is especially important if you have diabetes, or heart or breathing problems.

In addition, have regular sight and hearing checks, dental check-ups, pay attention to foot care and make sure your shoes fit well.

For more information see Help Sheet, Information for people with dementia 3: Looking after yourself. Available at fightdementia.org.au
Effective communication

“If I occasionally lose track of what we’re talking about, give me the time to remember, and if I can’t, don’t be nervous, impatient or arrogant. Just know in your heart that the most important thing for me is to be with you.”  

_Sergio Cadena_

Because dementia affects many parts of your brain, you may need to develop new ways of communicating with people.

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

Most people have good days and bad days. On bad days, you may experience some of the following changes:

- struggling to find the right words or losing your train of thought.
- repeating words, stories or questions a number of times.
- getting words confused or saying them in the incorrect order.
- problems with spelling or writing.
- problems with understanding what other people are saying.

Some approaches to consider when modifying how you communicate include:

- slowing down and taking more time to speak
- finding a quiet place to talk where you will not become distracted
- letting people know when you are finding it difficult to speak or understand
- describing the person, place or thing if you cannot recall its name.

Because the disease affects each person differently, try different combinations of these approaches until you find what works best for you.
Have a conversation with family and friends about whether you want to be prompted, reminded or helped if you are struggling to find a word or are repeating yourself. And make sure you provide feedback about how their communication style is working for you.

In cases where English is spoken as a second language, people with dementia may revert to their first language as their illness progresses. This may have an impact on future care, particularly if the person with dementia reverts to a language that is not familiar to the person or people caring for them.

In these instances, caregivers may need to start looking out for more visual cues, or use word/picture cards to aid communication. Non-verbal communication such as body language and use of gestures will become even more important.

It is vital that the person with dementia has a doctor who understands their first language and cultural heritage.

### Changed relationships

Symptoms of dementia, such as memory loss and changed behaviours, can affect relationships with family and friends.

When you share news of your diagnosis with family and friends, they will probably experience a range of emotions. See Responses to your diagnosis on page 35.

You may feel that you need to rely on family and friends more than you would like to. Unwanted help can feel overbearing or intrusive, leading to feelings of frustration, guilt or resentment.

**Remember – at some point in their lives, everybody will need help from others.**

Talk to your family and friends about what type of support you need and how they may be able to provide it. Accepting help will ensure you can remain independent for as long as possible, and accepting support from people close to you may help them to feel useful.

### Role changes

Many people with dementia will experience a sense of losing their independence, as their roles or responsibilities are passed on to somebody else. Others may find family members starting to have conversations as if they are not in the room, or making plans for the future without their presence or input.

Feelings of concern may result from the guilt associated with ‘burdening’ others with caregiving roles or the responsibilities you once managed.

Talking to others and sharing your feelings may help. Doing so will also help make your family and friends aware of how you are feeling and can help them modify their behaviour appropriately.

Alzheimer’s Australia Vic offers counselling for couples, families and groups. This can help during periods of change and adjustment. For more information, call the National Dementia Helpline on 1800 100 500 or visit fightdementia.org.au/vic

### Keeping your relationships positive

Learning to be completely open with your family and friends about how you are feeling can be difficult, but this is important to ensure you get the support you need.

Share your experiences of living with the disease with family and friends, and encourage them to share how they are feeling, too. Don’t let dementia become a topic that is ignored. Try to understand that your family and friends might sometimes want to talk about their feelings to other people and seek advice from external sources.

Be honest with each person in your life about how you would like your relationships to continue, and how you would like them to treat you. Make sure you focus your energy on your most supportive and comforting relationships, and show your gratitude to the people who are there for you.

If your family and friends sometimes become frustrated, try to remember they are frustrated with the disease and not with you.
**Intimacy and sexuality**

If you have a sexual partner, openness about sexual changes will help maintain closeness.

Dementia may affect sexual feelings and behaviour over time. Discuss your needs and expectations at each stage of the disease, including what you would like to happen in the future, and allow your partner to do the same. If you can be completely honest with each other, there is likely to be less confusion, blame, resentment, guilt or lowering of self-esteem.

You may experience uncertainty, frustration or reduced confidence because you are unable to do some of the things you were able to manage previously. This may lead to stress and changes in feelings towards your partner.

Remember, your partner may be experiencing some of these feelings as well. They may need to make adjustments if there is uncertainty about your levels of comfort with sexual contact or activities that you no longer enjoy.

Depression can lead to a loss of interest in sex, while some medications may have side effects that alter your sexual desire. As your dementia progresses, you may experience significant increases or decreases in your sexual expression and need for intimacy. Speak to your doctor if any of these changes are causing physical or emotional distress.

You may want to explore new methods of intimacy. This may include non-sexual touching or sharing special memories. Have an open dialogue with your partner and work together to find approaches that you both find satisfying and comfortable.

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**Things to consider**

- What are the important things in your life that you would like to continue doing?
- What would it take for you to continue living a happy, fulfilling life?
- What strategies might you or your family and friends be able to employ to enable this to happen?
- What would you like people to do when you are having problems communicating?
- What changes could you make to your home to create a more dementia-friendly environment?
- Have you booked regular check-ups with your doctor and dentist?
- Do you have a partner? If so, have you discussed the potential changes in your relationship with them? Would you consider counselling as a couple?
- How would you like to be supported by friends and family?