

The Dementia Guide

For people living
with dementia, their
families and carers.

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About Dementia Australia

Dementia Australia supports people living with all types of dementia, and their families and carers. We provide support services, education and information, and advocate for greater community understanding of dementia. We have been proud to serve the Australian dementia community since 1983.

Our organisation helps people:

- access appropriate care and support
- maintain the best possible quality of life
- plan for their future.

Acknowledgements

This is the second edition of The Dementia Guide.

The Dementia Guide has been revised with the advice of the Dementia Australia Advisory Committee. This committee is made up of people living with dementia who are active advocates in their communities. It is the third of its kind in the world and the first in Australia.

The first edition was produced thanks to the advice and support of members of the advisory panel, who generously donated their time in developing this guide. The panel included:

- health, social and aged care professionals
- representatives from appropriate peak bodies
- government representatives
- people living with dementia, their families and carers.

This guide can be downloaded from dementia.org.au
Printed copies are available on request.

This publication contains information and general advice. It should not substitute personalised advice from a qualified professional.

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

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About this guide

This 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.

If you are living with dementia, The Dementia Guide will help you understand more about dementia and the treatments, support and services available. It includes information about living well with dementia and making plans for the future.

If you are a family member or friend of a person with dementia, this guide will help you to understand more about dementia, the support and services available, and information about providing support in a carer role.

You will find additional resources listed throughout this guide. There is also a checklist on page 127 to help you live well now and plan for the future. Keep this guide in an accessible place so you can refer to it when you need.

Our message to you

If you have been diagnosed with dementia, you do not have to face this alone.

Dementia Australia supports people living with dementia every day. We recognise that everyone's experience is different. And we respect the feelings you might have along the way.

This can be a time that feels overwhelming. There is a lot of information to take in and difficult decisions to make.

Which is why we created The Dementia Guide. This guide is a useful source of information, written specifically for people living with dementia.

It was developed in consultation with people living with dementia, their families and carers, making the information as relevant and meaningful as possible.

We hope that it reassures you that support is available. Most importantly, we hope it empowers you to look after your health and live well for as long as possible.

For more information or to ask a question, please call the National Dementia Helpline on **1800 100 500**. Our experienced staff are always ready to listen and offer support.

Sincerely,
Maree McCabe
CEO Dementia Australia



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Section 1

About dementia

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What is dementia?

Dementia is not one single disease. It is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is not a normal part of ageing.

Everyone experiences dementia differently. Your symptoms will depend on the cause of dementia and the parts of the brain affected.

Common symptoms include:

- memory loss
- challenges in planning or solving problems
- difficulty completing everyday tasks
- confusion about time or place
- trouble understanding visual images and spatial relationships
- difficulty speaking or writing
- misplacing things and losing the ability to retrace steps

- decreased or poor judgement
- withdrawal from work or social activities
- changes in mood and personality.

Dementia is generally progressive. Symptoms often begin slowly and become gradually worse over time.

It is important to remember that no two people experience dementia in the same way. People often lead active and fulfilling lives for many years after their diagnosis.

Who gets dementia?

Dementia can happen to anybody.

The risk of dementia increases with age



Over the age of 65,
dementia affects almost
one person in ten.



Over the age of 85,
dementia affects
three people in ten.

People under the age of 65 can experience
dementia, although it is less common.

Researchers in dementia now believe it depends on a combination of age, genes, health and lifestyle. Dementia can sometimes be hereditary, but this is quite rare.

What causes dementia?

There are many known types of dementia. Most people are diagnosed with one of four types.

Alzheimer's disease

Alzheimer's disease is the most common cause of dementia. This disease disrupts the brain's neurons. It affects how they work and communicate with each other. A decrease of important chemicals stops messages travelling normally through the brain.

You might experience:

- difficulties with short-term memory, especially recalling more recent events
- language and comprehension difficulties, such as problems finding the right word
- increasing disorientation in time, place and person
- problems becoming motivated and initiating tasks.

Vascular dementia

Vascular dementia occurs when there is reduced blood supply to the brain, causing cells to die. This can be the result of a stroke, narrowing of the arteries supplying blood to the brain, or bleeding in the brain.

You might experience:

- stepped progression of symptoms with periods of relative stability
- slowed motor speed
- impaired attention and short-term memory
- difficulty making decisions in response to a situation
- depression and apathy.

Lewy body disease

Lewy body disease causes tiny structures to develop inside brain cells. These structures disrupt the way the brain functions and can cause cells to die.

You might experience:

- fluctuating and sudden bouts of reduced alertness and/or confusion
- slowed movement, rigidity and tremors
- loss of facial expression
- difficulty with visual and spatial perception
- hallucinations
- poor abstract reasoning and judgement
- difficulty planning, reasoning, problem-solving and making decisions
- vivid dreaming with your body moving as you dream.

Lewy bodies are also found in people with Parkinson's disease. A person who has lived with Parkinson's disease for several years can develop Parkinson's disease dementia.

Frontotemporal dementia

Frontotemporal dementia causes progressive damage to the frontal and/or temporal lobes of the brain. It can also be called frontotemporal lobar degeneration. The symptoms of frontotemporal dementia depend on which areas of the brain are damaged.

The right and left frontal lobes impact your mood, social behaviour, attention, judgement, planning and self-control. When these lobes are affected first, it is called behavioural-variant frontotemporal dementia.

The temporal lobes on each side of the brain help us process what we hear and understand what we hear and see. When the temporal lobes are affected first, there is usually a loss of language

skills. There are two types of frontotemporal dementia where language is impaired—progressive nonfluent aphasia and semantic dementia.

You may experience:

- reduced intellectual abilities
- changes in personality, emotion and behaviour.

Other causes of dementia

A wide range of other conditions can also lead to dementia. These are rare, only accounting for about five per cent of all people with dementia.

Other diseases or causes include:

- Parkinson's disease
- corticobasal degeneration
- Creutzfeldt-Jakob disease
- HIV-related cognitive impairment
- Huntington's disease
- alcohol-related brain damage and Korsakoff's syndrome

- multiple sclerosis
- Niemann-Pick disease type C
- normal pressure hydrocephalus
- Progressive Supranuclear Palsy
- Chronic Traumatic Encephalopathy (from repeated head injuries)
- Down syndrome.

Mild cognitive impairment

People living with mild cognitive impairment often experience some loss of memory and a decline in other thinking skills, also known as cognitive abilities. This is not usually defined as dementia but as a minor neurocognitive disorder.

There is an increased risk of developing dementia. This may take many years, if it happens at all.

How does dementia affect younger people?

The term 'younger onset dementia' describes dementia in people under the age of 65. Younger people may develop any type of dementia, but Alzheimer's disease is the most common type.

Familial Alzheimer's disease

In some cases, younger onset dementia has a genetic link. This is called Familial Alzheimer's disease. It affects an extremely small number of people. Less than 100 people across Australia are likely to be affected at any one time.

Many of the symptoms experienced by younger and older people with dementia are similar. However, people with younger onset dementia can need different support as their life circumstances are different.

You may be strong and healthy, in full-time employment and raising a family. You may have a mortgage or other financial commitments, with plans to work until the age of 65.

Younger people can find that they are misunderstood in the community. Often, people do not expect younger people to live with dementia.

How does dementia progress?

Despite some variations in dementia types and symptoms, dementia usually has a gradual onset of symptoms that worsen over time.

While the progression of dementia can vary, the disease usually has three stages. Understanding these stages can help you plan for potential challenges.

1

Mild or early-stage dementia

You might have some problems with memory but need minimal support.



2

Moderate or middle-stage dementia

You need support to help you function at home and in the community. Difficulties are now more obvious and have a greater impact on your abilities and dependency.



3

Severe or late-stage dementia

You are likely to be fully dependent on the care and supervision of others.

Unfortunately, dementia isn't reversible.

However, you may be able to maintain your independence and live well for many years. At each stage, there will be ways to make life better.



Section 2

Understanding your diagnosis

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Dementia can only be diagnosed with certain medical examinations.

This could involve:

- physical examinations to test sensory, movement, heart and lung function
- blood, urine and spinal fluid tests
- cognitive or neuropsychological tests to assess memory, language, attention and problem-solving
- scans to check brain structure and rule out anomalies
- psychiatric assessment to check for treatable disorders and manage symptoms that can occur alongside dementia.

Your general practitioner will likely refer you to different medical specialists for these examinations.

Recognising your feelings

It is normal to experience a range of emotions after your diagnosis.

You may feel:

- anger
- fear
- loss
- disbelief
- denial
- depression
- anxiety
- isolated
- a sense of relief.

It is important to recognise your emotions. This will help you adjust to your diagnosis.

Try to share your feelings with family and friends.

Writing your thoughts in a journal can be helpful.

You can also get help from:

- support groups for people with dementia
- your doctor or nurse
- trained counsellors.

Learn about support groups, counselling and other assistance following a diagnosis by calling the National Dementia Helpline on **1800 100 500**.

Learning more about dementia

Learning about dementia might be daunting or uncomfortable. But understanding the changes you may experience is an important step.

Learning more about dementia can help you:

- adjust to your diagnosis
- talk to your doctor about treatment and support
- identify your priorities and goals for the future
- access support and coping strategies
- make financial and legal plans
- make plans for your care over the coming years.

You do not need to learn everything at once. If you start feeling overwhelmed, give yourself time to get used to the new information.

Dementia Australia provides a range of resources online at dementia.org.au and education programs at dementia.org.au/education

You can also call **1800 100 500** for more information.

Telling people about your diagnosis

Sharing your feelings with family and friends can help you cope with your diagnosis and help them learn how to support you.

As your dementia progresses, the support of people who know and understand you will become increasingly important.

Some people start by sharing their diagnosis with close family and friends. Others choose to share the news with a broader group of people.

The people you tell may have a range of reactions. They may seem angry, afraid or surprised. They

may even seem relieved to have an explanation for your symptoms.

Try to be patient with any of these responses. They might need extra information or time before they become more supportive.

As your dementia progresses, this support will become more important. Some of your relationships might be tested, but others are likely to become stronger.

If you are struggling with talking about your diagnosis and need support to tell other people, you can call the National Dementia Helpline on **1800 100 500**.



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Healthcare team and treatments

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There is no known cure for dementia, but there are healthcare professionals, medications and other therapies that can help with some of the symptoms, including depression and anxiety. With the right support, people can live well with dementia for many years.

Throughout your dementia journey, you will receive treatment from different health professionals.

These can include:

- your general practitioner or family doctor
- medical specialists
- allied health professionals
- nurses.

Building your healthcare team

Working with your doctor

Developing a strong relationship with your doctor is an important step.

Your doctor can provide support, from diagnosis through to ongoing management and care. They can also refer you to specialist health professionals for your other care needs.

Your doctor and practice nurses need to get to know you. This will help them understand your dementia and recommend the best treatments. Be open and honest, and let them know if you do not understand something.

It can be helpful to have a family member or carer visit the doctor with you. They may offer other information about your needs, preferences and symptoms.

Make the most of your doctor visit

- Before your visit, write down a list of questions to ask.
- Book a long appointment so you have time to discuss things in detail.
- Take a list of the medications, vitamins and supplements you take.
- Keep a log of any changes you, your family and friends have noticed.
- Discuss your condition and document a dementia care plan.
- Ask about support services to help you live well.
- Take notes and ask for information to bring home with you.

Working with medical specialists

During the different stages of dementia, you may be treated by different medical professionals. Each will be relevant to different symptoms of the disease.

Your doctor may refer you to a specialist, such as a:

- **Geriatrician:** Specialising in diagnosing, treating and preventing disease in older adults (including dementia).
- **Psycho-geriatrician:** Specialising in diagnosing and treating mental and emotional disorders in older adults.
- **Neurologist:** Specialising in diagnosing and treating people with abnormalities of the brain and central nervous system.
- **Neuropsychiatrist:** Specialising in the behavioural and psychological effects of neurological diseases or injury to the brain.
- **Psychiatrist:** Specialising in diagnosing, treating and preventing mental illness and emotional problems.
- **Neuropsychologist:** Specialising in treating people with various types of nervous system disorders.

You should always feel comfortable with your medical team. If you are unhappy, ask your doctor for another referral. Do not worry about offending them. It is common to ask for a second opinion.

Working with allied health professionals

Allied health professionals form a vital part of your healthcare team.

They help you maintain your quality of life, independence, self-care and mobility. They also help reduce the risk of complications due to other conditions or injuries.

Allied health professionals work in both private and public healthcare settings. Speak to your doctor about accessing these services as part of your dementia care plan. At each stage of your dementia journey, you should discuss your changing needs with your doctor.

Contact your private health insurer to find out what services are included in your cover.

The people you might meet

- **Counsellor, psychologist or dementia consultant:** Helps you adjust to change and cope with difficult feelings.
- **Dietitian:** Provides advice for maintaining a healthy diet.
- **Diversional therapist:** Designs recreation programs based on your interests and abilities.
- **Music therapist:** Helps improve your health, functioning and wellbeing using music.
- **Neuropsychologist:** Provides ways to cope with behavioural changes as a result of changes to the brain and help in making a diagnosis.
- **Occupational therapist:** Assesses your abilities and provides support to help you stay independent.
- **Optometrist:** Checks your eyesight and monitors for any eye conditions.

- **Oral health worker:** Works with your dentist to keep your mouth, teeth and gums in good condition.
- **Podiatrist:** Maintains the health of your feet.
- **Physiotherapist or exercise physiologist:** Helps you improve your strength, balance and movement.
- **Social worker:** Supports you with handling money, finding services, and granting power of attorney.
- **Speech pathologist:** Helps you find ways to communicate with others if speaking has become difficult.

Understanding your treatment options

While there is no cure, there are drug treatment options to help improve some of the symptoms or reduce the rate of progression, depending on your dementia.

Learning about treatment options can help you to live as well as possible and maintain a good quality of life.

Some treatments can provide temporary improvement of symptoms.

Drug treatments

Certain drugs can improve some of the symptoms and reduce the rate of progression. The effectiveness of these drugs depends on your type of dementia.

You should talk to your doctor about drug options that may be available to you.

Questions to ask

- Are there any medications that can help me?
- Why are you offering me this medication?
- How will this medication help me?
- How do I take this medication?
- What happens if I miss a dose?
- Can I still take my other medication?
- Can I drink alcohol?

- Can I still drive my car?
- Will it impact my work?
- How can I reduce potential side effects?
- What changes should I tell you about?
- Are there other treatments I could try instead?
- Is there information I can take home with me?

Other treatments

Keeping the body and mind active is essential. Engaging in everyday activities, interests and social groups can be satisfying and fulfilling. Exercise and eating well are also beneficial and may even slow down changes in the brain.

Complementary therapies

Complementary therapies include a variety of treatments and practices that can support conventional medical treatments. These therapies may be described as being 'alternative', 'traditional' or 'holistic'. Complementary therapies can help promote wellbeing and improve your

quality of life, although the evidence to support their use is still being explored.

Therapies can include:

- natural products and supplements, including herbs, vitamins and minerals
- practices that involve manipulation of parts of the body, such as massage, chiropractic and osteopathy
- mind-body practices, including meditation, hypnotherapy, aromatherapy and music
- energy-based therapies like Reiki and Therapeutic Touch
- alternative medical systems, such as traditional Chinese medicine (including acupuncture and herbal medicine), Ayurvedic medicine, homeopathy and naturopathy.

Complementary therapies should not substitute the advice of your doctor. You should discuss potential complementary therapies with your doctor and your therapist should seek continued input from your doctor during treatment.

Treating depression and anxiety

People with dementia, their families and carers, may experience depression or anxiety. This is common in the early stages and again in later stages of living with dementia.

It is important to seek help. You should discuss treatment options with your doctor.

Drug treatments

Prescription drugs are one approach to treat depression and anxiety.

Antidepressant drugs work by correcting the levels of some chemicals in the brain. It can take several weeks to notice the benefits of taking an antidepressant.

Some people experience side effects to begin but these usually lessen after a week or two. Your doctor will help you find a drug and dosage that works best for you.

Non-drug treatments

Depression and anxiety can also be responsive to non-drug treatments or a combination of drug and non-drug treatments.

Non-drug treatments include:

- talk therapies, such as counselling
- reminiscence activities, where you recall past events
- life story work, where you record key moments of the past in a scrapbook or album.

Other things that can help with depression and anxiety include:

- keeping active
- engaging in enjoyable activities
- talking to friends and family
- maintaining a healthy diet
- reducing alcohol or caffeine.



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Planning for the future

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It is important to start thinking about the future in the weeks after your diagnosis.

You might like to talk to family and friends about your values and plans. Over time, you can make decisions that suit your priorities. Talking to your family and carers will help them understand and respect your wishes in the future.

Dementia affects people in different ways. Some people lose skills and abilities during the early stages. Other people might keep these for much longer.

Try to think about your future as soon as possible. It becomes harder to make these decisions as dementia progresses.

Driving

During the early stages of dementia, many people remain safe and competent drivers.

But as dementia progresses, it can affect your memory, reactions, perception and abilities. There will come a time when you will need to stop driving.

If you hold a driver's licence, the law requires you to tell your licensing authority about your diagnosis. You are also required to tell your vehicle insurer.

In some cases, your doctor may decide they have a duty of care to tell the licensing authority on your behalf.

If you want to continue driving, you will need a medical review. In some states, this involves a driving test with an occupational therapist. Many people choose to stop driving because they feel confused or less confident.

You might like to learn about other transport available in your area. Understanding your options can help you stay independent and active for longer.

Working

It is possible to keep working after a diagnosis of dementia. Continuing this familiar routine helps some people feel better. Other people decide that it is best to stop working.

Telling your employer

Deciding whether or when to tell your employer about your diagnosis can be difficult. It can depend on the extent to which symptoms affect your ability to do your job, as well as the support you may need from your employer.

Telling your employer can give you some protection under the law. If it is safe for you to work, your employer is legally required to make adjustments to help you keep working.

Once you have told your employer, you will need to track any effect your dementia symptoms have on your duties.

In some jobs, you may have to complete a medical test. This will confirm you still can complete the tasks involved in your current role. If not, your employer may ask you to consider a different role in the organisation.

Other options could be working reduced hours or retiring early.

In some jobs, you should tell your employer about your diagnosis immediately. This applies to jobs that involve driving or operating machinery. It may also be a legal or ethical rule of your contract.

Before you talk to your employer

Start by talking to your doctor about your ability to work. You can also think about:

- whether your symptoms affect your ability to do your job
- any safety risks associated with your dementia symptoms
- any support you might need to continue working
- any options to change or reduce your duties
- your employer's capacity to provide support
- your rights and entitlements in the workplace.

Leaving work

At some stage, you may choose to leave work or retire early. Before making this decision, you should talk to your family, your doctor and your employer.

If you have decided to finish work, you should consider:

- using any sick leave you have accrued before your employment ends. You are entitled to use this sick leave, as long as you provide a medical certificate
- talking to your insurance company, superannuation fund or financial planner. Ask about income protection and Total and Permanent Disability (TPD) insurance.

When you finish work, check that you receive the correct pay for any annual leave or long service leave owed.

Getting advice and support

When talking to your employer, you might like to have a support person with you. You could invite a family member, friend or colleague.

If you need advice about your rights, entitlements or working conditions, you can talk to:

- counsellors or human resource officers in your workplace
- your trade union
- a lawyer or anti-discrimination advocate.

Talk to your lawyer, superannuation advisor or Centrelink for superannuation or pensions advice.

Legal matters

It is helpful to talk to a solicitor soon after your diagnosis to update your legal affairs.

Will

A will lets you choose who will inherit your money and possessions after your death. As long as you understand the decisions you are making, you can make or change your will.

Enduring power of attorney

An enduring power of attorney appoints a trusted person (or people) to make decisions on your behalf. There are different types of powers of attorney, including supported, financial and medical.

You should prepare this document while you can still make these decisions.

You will need to give the financial or medical power of attorney to the relevant organisations. These include Medicare, your banks, Centrelink, and the Department of Veterans' Affairs.

Financial management

It is important to take the time to organise your finances. Gather essential information and documents together so they are easy to find.

In a safe place, keep the details of your:

- bank accounts
- insurance policies
- mortgage or rental contracts
- pensions and benefits
- powers of attorney
- superannuation
- shares
- tax returns
- trusts
- will.

Talk to a financial advisor, accountant or solicitor about your circumstances.

Managing your money

- Over time, it may become difficult to remember PINs for debit or credit cards. Talk to your bank about alternatives, such as a 'chip and signature' card.
- You might like to arrange automatic payments for your bills. Set up direct debits to manage regular payments for phone or electricity bills.

Government support

You may be eligible for government benefits and support. Some are means-tested, so your income and assets can affect your eligibility.

Centrelink can provide you with advice about what to claim for. If you find the forms confusing, Centrelink will be able to help you complete them.

Your carer may also be eligible to receive a payment or allowance.

Get your Companion Card

If you need carer support to attend activities or venues, you might be eligible for a Companion Card. A Companion Card is a great way to continue participating in leisure activities and events with the support of a carer, at little or no cost to you.

Present the card to a participating organisation. They will issue a second ticket for your companion at no charge. Apply for your card online at **companioncard.gov.au**

Advanced care planning

You should start to make plans for your future medical treatment and personal care. It is a good idea to talk to your family, friends and your healthcare team about your wishes.

A written advanced care plan documents the treatment and type of care you prefer.

You can also appoint someone to make decisions on your behalf with an enduring power of attorney. This person can use your plan to guide their decisions.

Over time, your preferences might change. You are likely to have many discussions about your care.

Remember to talk to your doctor so that you can make decisions based on good information. Your doctor can help you complete your plan.

Once you have a written advanced care plan, take it with you every time you go to the doctor or hospital.

Advocacy

At some point, you may need a professional to advocate on your behalf. This could be when you plan for the future or speak with healthcare, housing, welfare and financial service providers.

In these instances, the Older Persons Advocacy Network (OPAN) may be able to assist. Call **1800 700 600** or go to **opan.com.au**



Section 5

Living well

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

Your plans for the future might change, 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.

Coping with changes

The changes that occur with dementia can include:

- memory loss
- problems with thinking and planning
- difficulties communicating
- confusion about time or place
- sight and visual difficulties
- apathy and withdrawal.

When you or your family and friends notice these changes, it is time to adapt your daily routine.

Ways to cope with 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.

- Let people around you know how they can help. You may be able to get help with tasks around the house, like cooking, cleaning, shopping or showering.
- Access formal services to assist with your daily needs.
- 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.
- Stay social.
- Ask family and friends to reassure you if you become confused.

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 cope with 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 to make tasks more manageable.
- Break tasks into manageable 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.
- Do things together. 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 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 illness progresses. Caregivers may need to use visual cues or picture cards to help with communication. Body language and the use of gestures can also help make yourself understood.

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

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 plans for the future 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 you be more independent. 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.
- 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 to help locate and identify items.
- Make sure hot and cold indicators are marked on taps.
- Replace appliances (when needed) with familiar and recognisable models.
- Use distinctive coloured doors and contrasting door frames to help with orientation.

Accessing your property

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

You should also keep their telephone number with you at all times. 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. You can:

- organise to have your groceries delivered or arrange home-delivered meals
- consider hiring a cleaning service
- arrange for somebody to help with housekeeping, 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.

Make sure you plan how you will get around once driving becomes an issue. You may need to use taxis, public transport and lifts from family and friends.

Staying safe at home

Dementia can increase the risk of having an accident around the home. But there is a range of assistive technologies and products that can improve safety.

Assistive technology is any device or system that helps you safely do tasks you could not do otherwise. Assistive technology can:

- reduce the risk of accidents in and around the home
- support independence and choice
- 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
- walking sticks.

It is best if you can adopt these technologies early. 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 Independent Living Centre in your state or territory.

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 items to make your house safer.

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 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. They can refer you to services and supports to help you live at home for as long as possible.

Travelling safely

Living with dementia does not mean you cannot travel. With careful 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

- If you have other health issues, 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.
- Register overseas trips with the Department of Foreign Affairs and Trade. You can do this at smartraveller.gov.au

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 it differently. Engage in activities that keep your heart, body and mind active to look after your brain and improve your wellbeing.

Keep your heart healthy

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 leads to good health and will help you function best during the day.

Keep your body active

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.

For convenience, you may be able to have healthy meals delivered to your home (if you are over 65). Visit **myagedcare.gov.au** for more information.

Keep your mind active

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.



Section 6

Support for people with dementia

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You may not feel ready to ask for help, particularly if you have always been independent. But it can be useful and comforting to know about the information and support available.

Seeking support will help you live a good quality of life throughout the stages of your dementia. With the right support, you could delay going into residential care and live at home for as long as possible.

There are many care and support services available. Some services are free, but you may have to contribute to the costs of others. This may depend on your income and savings.

My Aged Care

My Aged Care is available to people aged 65 years and over. It helps people living with dementia apply for Commonwealth Government-funded services.

Services include:

- help at home

- social support
- respite care
- personal care
- transport
- residential aged care.

There are three types of government-funded support available.

- 1. Commonwealth Home Support Program (CHSP).** This is an entry-level care package. It suits people who need low-level support to keep living independently.
- 2. Home Care Package (HCP).** This package is for people who need many care and support services on an ongoing basis.
- 3. Residential Aged Care Support.** This package is for people who need help with everyday tasks, personal care and nursing care. This support is provided in an aged care residential facility.

My Aged Care will:

- assess your eligibility
- give you information about local services
- confirm co-funding costs.

Visit myagedcare.gov.au or call **1800 200 422**.

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is for people with younger onset dementia. It helps people with dementia under the age of 65 access services and support.

People living with younger onset dementia can apply for funding to support:

- their wellbeing
- independence
- participation in community life.

Funding can be used for:

- help in the home, including gardening, cleaning, maintenance, assistive technologies and building modifications
- support with daily activities
- support to maintain social relationships and to take part in activities and interest groups
- maintaining physical health and wellbeing
- coordination of supports.

The amount of support you receive is based on your specific needs, not your income and assets. The availability of NDIS funding also depends on your geographic location.

Visit [ndis.gov.au](https://www.ndis.gov.au) or call **1800 800 110**.

Support coordination and other services from Dementia Australia

If you are applying for an NDIS plan, you can request a support coordinator to help you manage your plan.

Dementia Australia is a registered NDIS service provider. We can help you engage with services and supports to help you live well. We can also help you to manage your plan.

Dementia Australia provides other services for people living with younger onset dementia.

Visit dementia.org.au or call the National Dementia Helpline on **1800 100 500**.

Local services

Your local council, or state or territory government, may also offer programs and support services, including:

- senior citizen groups and centres
- Planned Activity Group (PAG) programs
- help with shopping
- meal delivery
- home and garden maintenance
- home and personal care services
- respite care
- community transport
- accessible arts and recreational programs.



Section 7

Dementia Australia services

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Dementia Australia supports people living with all forms of dementia. We also support their families and carers.

Our registered supports and services are available through My Aged Care and the NDIS. We also offer supports and services that do not require you to be eligible for these schemes.

Our services cater to individuals, couples, families and groups. Services are available nationally and can be accessed in a variety of ways, including face-to-face, telephone or online.

Services are free or low-cost thanks to government funding and the generous donations of corporate partners and individuals.

Information services

Dementia Australia has a range of information for:

- people living with dementia
- family carers
- family members
- friends
- health professionals.

Visit the Dementia Australia website for:

- help sheets (available in 32 languages)
- books and resources from the online library
- videos and downloadable resources on a range of topics and forms of dementia.

We also operate a national library service. You can borrow books, journals and DVDs with detailed information about dementia. We post loaned items on request.

We have a range of online resources that can support you, your family and carers.

Dementia in my family website

Dementia in my family is for children and teenagers who know someone with dementia.

The website is full of colourful, interactive and age-appropriate content. It provides education about dementia using videos, games and quizzes. The website also shares experiences of other young people in similar circumstances.

Visit **dementiainmyfamily.org.au**

Help with dementia website

Help with dementia is a website that can help you, family members, friends and carers learn more about:

- the stages of dementia
- how and where to get help
- arranging counselling over email, video conference or phone
- connecting online with others going through the same experience.

Visit **helpwithdementia.org.au**

Living well with dementia website

The *Living well with dementia* website aims to inspire people with dementia to live a good quality of life. The site encourages you to:

- discover new hobbies and activities
- continue participating in activities you love
- keep your heart, body and mind well.

Visit **livingwellwithdementia.org.au**

Support services

National Dementia Helpline

The National Dementia Helpline is a free telephone service. You can talk to trained and experienced professionals about:

- practical advice and emotional support to manage the impact of dementia
- education and early intervention programs for you, your family and carers

- counselling and support groups for yourself, your family and carers
- accessing skilled dementia professionals
- local community and health services
- government support services
- resources for people from:
 - different cultural and linguistic backgrounds
 - Aboriginal and Torres Strait Islander communities.

Call the National Dementia Helpline on **1800 100 500**.

- If you need an interpreter, call the Translating and Interpreting Service on **131 450**.
- If you are deaf or have a hearing or speech impairment, call the National Relay Service on **133 677**.
- You can access the Helpline webchat at **dementia.org.au**
- You can access email support at **helpline@dementia.org.au**

Counselling

You may wish to talk to a professional about your dementia experience. They can offer support with:

- emotional reactions
- changed relationships
- planning for the future
- finding appropriate services
- living arrangements
- dealing with changes in behaviour, family and cultural reactions.

Professional counselling is available at all stages of your dementia journey. You can do it on your own, with your family or partner, or with your carer.

Counselling can help you:

- work through feelings about your diagnosis
- understand how to live well for as long as possible
- share your emotions with a partner or your family.

It can also help family members understand your dementia and the changes they may be seeing in you.

Call the National Dementia Helpline on **1800 100 500**.

Personalised and practical support

Dementia Australia provides a range of services to help you live well at home. Community support services include:

- dementia advisory service—receive personalised advice about the support, services and education programs available to you
- group social support
- individual social support
- personal care
- transport
- cognitive stimulation groups
- domestic help

- flexible respite
- centre-based respite
- cottage respite.

The community support services available to you depends on:

- your geographic location
- whether you are eligible for services through My Aged Care or the NDIS.

Community support services may also be available to you or your carer without a referral from My Aged Care and the NDIS if you meet eligibility criteria for state-based and local council services.

Call the National Dementia Helpline on **1800 100 500**.

NDIS support coordination for people living with younger onset dementia

If you are living with younger onset dementia and need help with your NDIS plan, we can help. Our Support Coordinators can help you implement your funded supports and services.

Dementia Australia is a registered NDIS service provider. We can connect you with community, government and private providers. We can also negotiate what providers offer you and how much it will cost out of your plan.

This service is for people living with dementia who have support coordination included under their NDIS plan.

Education services

Dementia Australia offers a range of education sessions and programs. These can help you, your family, and carers learn about the different stages of dementia.

Our education services can help you:

- better understand the symptoms and behaviours associated with the disease
- identify the supports and services you need
- prepare for and make changes in your daily life to live as well as you can
- share stories, concerns and emotions.

For more information about any of the programs or to book a session, visit **dementia.org.au/education**

Living with Dementia program

It can be helpful to meet and talk to people in similar circumstances.

The Living with Dementia program provides this opportunity, as well as education and support. You can attend the program alone or bring along a partner, relative or friend.

Topics include:

- symptoms and diagnosis
- research and drug treatments
- driving
- planning for the future
- living well with dementia
- community services
- legal issues.

For more information about any of the programs or to book a session, contact the National Dementia Helpline **1800 100 500**.

Sensitive content

Dementia Australia warns that the next two sections may be challenging or upsetting for some readers.

We provide this information to help you discuss and plan your future care needs with family and carers while you can still do so.



Section 8

Residential care

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Exploring residential care options can be difficult for everybody involved. You should be involved in discussions and decision-making, as much as possible.

We recommend early planning for future residential care. You can make your wishes known before your dementia progresses.

You may wish to help select the facility, so when the time comes you feel more familiar and comfortable.

Identifying the right time

If residential care is an option, it can be hard to know when it is the right time to move.

You may still be living independently in many ways. But there may also be times when your dementia puts your wellbeing at risk.

Every situation is different. To decide what is right for you, consider the following questions.

- Do you feel safe at home?
- Is memory loss, confusion or disorientation causing you problems?
- Has your mobility or coordination become limited?
- Do you need ongoing supervision to do things?
- Do you have needs that your carer, family or support services cannot provide?

If so, it may be time to consider moving to residential care.

It is possible you may not realise you need additional care and support. It is important to be guided by the people who you trust, such as your carers, family members or health professionals.

Choosing a residential care facility

Looking into residential care options can bring up many emotions. You may feel stress, sadness, relief, loneliness or guilt.

Sometimes families disagree or have concerns about the quality of care available.

It is important to discuss your changing needs with your doctor, carer or family member to ensure you receive the best care. Dementia Australia also offers advisory and counselling services that can help during this time.

Weighing up your options

When considering your options, it is a good idea to visit at least three aged care facilities. You can consider how they will meet your needs as your condition progresses.

Take a checklist that includes the things that are important to you and your family and friends. Your checklist might include some of the following things.

Activities and services

- ☐ Accessibility by public transport and car.
- ☐ Appropriate social and recreational activities.
- ☐ Outings and special events.
- ☐ Provision of extra services, such as hairdressing, podiatry and dental.
- ☐ Vacancies and waiting lists.

Care and medical support

- ☐ Welcoming and informative staff.
- ☐ Positive staff interactions with residents and family.
- ☐ Care staff with appropriate dementia training.
- ☐ Provision of appropriate medical care.
- ☐ Appropriate overnight staffing levels.
- ☐ Option to keep your existing doctor.

Comfort

- ☐ A clean and homely environment.
- ☐ Respect for privacy and personal space.

- ☐ Comfortable bedrooms with personal belongings.
- ☐ Pets are welcome to visit.
- ☐ Ambiance of communal areas and garden.
- ☐ A dementia-friendly environment, e.g. clear signs and paths to the toilets.
- ☐ Good-quality, varied meals served in suitable dining facilities.
- ☐ Consultation on food preferences and dietary requirements.
- ☐ Respect for cultural and spiritual beliefs and emotional needs.

Family support

- ☐ Close location to family and friends.
- ☐ Families are welcome to stay for meals.
- ☐ Option for family and friends to continue playing a caring role.
- ☐ Flexible visiting hours.
- ☐ A committee for residents and relatives.

Trialling residential respite care

Before making a decision, you can try one or more short stays in a residential respite care facility.

This will give you a chance to become familiar with the facility. This may make the eventual transition into full-time care easier.

It will also give your carer a break. Regular respite might help them continue caring for you at home longer.

Understanding fees and costs

The Australian Government funds some of the costs of residential aged care facilities. But you may also have to make a financial contribution.

If you are over 65, your My Aged Care funding will depend on your financial circumstances and can vary between facilities.

Aged care fees may include:

- a basic daily fee
- a means-tested care fee
- an accommodation payment
- fees for extra or optional services.

Fees are based on an assessment of your income and assets by Centrelink or the Department of Veterans' Affairs.

My Aged Care provides information on organising residential care. They can help you estimate bonds and fees using a Residential Care Fee Estimator.

You can also get advice from a financial specialist in aged care or an accountant.

To learn more about eligibility, fees and costs for residential aged care funding through My Aged Care, visit **myagedcare.gov.au**

Getting financial assistance

For people aged 65 years and over

If you are aged 65 years and over, you could receive financial assistance to enter a government-funded residential care facility.

You will need to have an Aged Care Assessment (ACAS) first. This assessment is free of charge. It is usually conducted in your home (or hospital). You can involve family members, carers or close friends.

The assessment will:

- determine the level of care you need
- recommend appropriate types of residential care
- provide details of suitable facilities
- provide a written statement of eligibility to show residential care facilities.

Your doctor can refer you for an assessment. You can also request an assessment by calling My Aged Care on **1800 200 422**.

Private residential care services are also available. These do not require an Aged Care Assessment.

For people with younger onset dementia

If you are living with younger onset dementia and would like to be assessed for funding to live in a residential care environment, you will need to refer to the National Disability Insurance Scheme (NDIS). You can find out if funding is available for you to move out of home and into a group care environment.

Private residential care services are also available and do not require an assessment.

Making the move

Applying to facilities

You can apply to many facilities at the same time. All applications are private.

Ask to be placed on a waiting list. This will give you extra time to consider if it is the right time to move.

Stay in regular contact with the facility while you are on the waiting list. This will let them know you are still interested. And if you need to move urgently, let the facility know.

Receiving an offer

When a place becomes available, they will contact you to see if you are still interested and when you can move in. Things can move quickly, so you need to be ready. Generally, you will have seven days to move in.

Charges may apply from the date of your acceptance, including those required by the Australian government.

The facility will provide you with a Resident Agreement. This outlines the services, fees, rights and responsibilities. Make sure you understand everything before signing the agreement.

Moving into one care facility doesn't mean you have to stay there forever. It is possible to move from one facility to another.

Getting familiar

The care staff at your chosen facility will gather information about who you are before you move in. This information might include your:

- personal preferences
- interests
- life and family history
- medical conditions
- food likes and dislikes
- social and activity preferences.

The staff will then draft a care plan for you. Let them get to know you as much as possible. This will help them provide the best care.

Settling into your new home

Moving into a new home is never easy. When you move into a facility, think about:

- putting labels on all personal belongings.
This will help you know what items belong to you, as well as find any that go missing

- choosing personal items and furniture to go into your room. This adds familiar touches to make your room feel more like home
- having a pharmacist or doctor review all medications and give these details to the staff.

Managing visits from family and friends

Seeing your family and friends can bring up a range of emotions. As your dementia progresses, it can become even more difficult.

But there are things you can all do to make visits meaningful and enjoyable.

Things your friends and family might like to do when they visit

- Get to know the care staff by name. They can introduce themselves or follow a regular ritual for visits.
- Bring a magazine or newspaper with them. They can read out interesting articles or do a quiz with you.

- Bring old photos or postcards to help stimulate memories.
- Write a letter with you to your mutual friends or family. This can help nourish and maintain your relationships.
- Use hugs, neck massages and handholding to replace or complement conversation.
- Make a life book. This is a wonderful way of validating your life journey and remembering accomplishments.
- Request a private space during visits to let you be more intimate.
- If allowed by the facility, bring an animal or your pet with them.
- Bring a supportive friend with them for moral support.

If a visit does not go as planned, do not worry. We all have high and low energy days, and you or your friend or family member may have felt tired that day.

It is still important for you to spend time together. No matter what that looks like.

Keeping in touch

Transitioning into care can be challenging and confusing for all involved. Remember, it takes time to settle into a new environment. Your friends and family will also have to deal with the change on a practical and emotional level.

Encourage your friends and family to stay in touch by sending you cards and notes. Every time you look at the card, you will feel their support.

Protecting your quality of care

If you, your family or friends are concerned about the care you are receiving, let your facility manager know immediately.

You can also contact:

- the Older Persons Advocacy Network on **1800 700 600**
- the Aged Care Quality and Safety Commission on **1800 951 822** or at **agedcarequality.gov.au**

You can complain by calling **1800 550 552** or by visiting **agedcarequality.gov.au/making-complaint**



Section 9

Later stages of dementia

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Most people in the later stages of dementia will need total care. It can be difficult to accept this final stage of the disease, but planning can make it a little easier.

Advanced care planning allows you to express your care preferences at a time when you are still able. Advanced care plans can be oral or written.

It can be a positive and empowering process to go through soon after your diagnosis. You can let people know your wishes in case decisions need to be made on your behalf in the future.

Your family and carers can then honour your values and choices. It helps to reduce their worry and stress when it comes to treatment in times of crisis.

Understanding palliative care

Palliative care is specialised care and support for people with a terminal condition.

It focuses on relieving a person's symptoms in the advanced stages of their disease. It can also provide emotional and practical support to family members and carers.

People who deliver palliative care include:

- general practitioners
- specialist doctors, such as oncologists, cardiologists, neurologists and respiratory physicians
- nurses
- allied health professionals, such as pharmacists, occupational therapists and physiotherapists
- social workers
- grief and bereavement counsellors
- pastoral care workers.

Supporting your needs with palliative care

Providing personal comfort

There are active ways that palliative care can provide comfort. This can include:

- changing body positioning

- mouth care
- assisting with difficulties in breathing
- skincare
- bowel management
- mobilisation.

Managing symptoms

How your symptoms are managed depends on the stage of your dementia and whether you have other medical conditions.

With symptoms management, there can be difficult decisions to make. Your family and carers will need to consider your wishes and values. They should also consider the following questions.

- How useful will the treatment be?
- What choice will promote the best comfort?

Managing pain

Pain management is an important aspect of good quality care. There should be an ongoing,

systematic approach to recording, assessing and managing your pain.

Supporting nutrition and hydration

Advanced dementia can lead to a reduced desire to eat. It can also make eating and swallowing difficult. There is no evidence that artificial nutrition or hydration helps prolong life or provides a peaceful death.

Managing antibiotics

Decisions about taking antibiotics need to be made in context and on an individual basis.

When the time is right, your palliative care will need to be organised by your family members, carer or health professional.

Visit **palliativecare.org.au** for state office contact details and further information.



Section 10

Checklist

This section offers a checklist of things to help you to live well now and make plans for the future.

In the first month

- ☐ Learn more about your diagnosis. This includes:
 - the type of dementia you have
 - what drug and non-drug treatments are available
 - what health professionals might be involved in your care.
- ☐ Book an education session with Dementia Australia. You can learn about dementia and how to live well for as long as possible.

- ❑ Talk to family and friends about how you are feeling. Contact Dementia Australia if you, your partner or your family want to talk with trained dementia professionals.
- ❑ Write a list of services and supports that could help improve your quality of life. Think about things that could help you:
 - live at home
 - keep healthy and active
 - remain engaged in activities and hobbies.
- ❑ Register with My Aged Care or the National Disability Insurance Scheme (NDIS) to learn if you can apply for funding to pay for the services and supports you need.
- ❑ If you drive, tell your licensing authority and your car insurer about your diagnosis. If you need to stop driving, look at other transport options. This will help you remain active and connected with your family and community.

- ☐ If you work, look at your legal and financial options before reducing your hours or leaving work. If you or your carer need to stop working, ask Centrelink about available benefits.

Over the next six months

- ☐ Connect with and learn from other people living with dementia. Dementia Australia runs education programs and support groups for people with dementia, their carers, and families.
- ☐ Assess your home environment. Make modifications to help you cope with changes to your memory and thinking and keep you safe.
- ☐ Assess your wellbeing. Keep your heart, body and mind active to look after yourself. Introduce exercise and healthy eating into your daily routine.

- ❑ Organise regular check-ups with your doctor, dentist, optician and podiatrist.
- ❑ Make plans for your future. Consider any legal and financial matters, advanced care directives, and medical and healthcare wishes.
- ❑ Start to plan for when you may no longer be able to live at home. Research your options and eligibility for residential aged care. This might include:
 - having a My Aged Care comprehensive assessment
 - attending a Dementia Australia information session about residential aged care
 - speaking with a dementia counsellor about your feelings and change in circumstances.



Section 11

Support and information for carers

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When someone in your family is diagnosed with dementia, they may approach living with dementia in different ways.

Some people seek to remain independent for as long as possible. Others will seek the support of another person to help them manage their symptoms and maintain a level of independence. Some people may not be aware of the support they need.

You may find yourself gradually taking on the role of ‘carer’. It can often happen without making a conscious decision to do so.

As a family member or friend of someone living with dementia, you may provide a range of care, including:

- helping the person stay involved with the hobbies, activities and interests they enjoyed before their diagnosis
- working with healthcare professionals and support agencies to meet the person’s physical, psychological and social needs

- helping the person with daily activities, such as household chores, shopping, preparing meals, managing finances, appointments and taking medications
- providing personal care, such as bathing, dressing and going to the toilet
- supporting the person when they experience changes to their behaviour or psychological symptoms associated with dementia
- helping the person with physical tasks, such as getting in and out of bed or walking.

If someone close to you is living with dementia, do not underestimate the impact this can have on you. Whether you are the partner, child, relative or friend, your relationship will change.

It is important to look after your health and wellbeing and turn to others for support when you need it. This will ensure you provide the best care for the person with dementia, for as long as you are able.

Getting emotional support

You may be experiencing a range of emotions, including loss, guilt and anger. You may feel grief for the loss of who a person once was.

You may also feel a sense of fulfilment from being able to support the person with dementia.

Experiencing any of these feelings is normal. You may want to share how you feel with a professional, a friend or family member, or someone at a carer support group.

At Dementia Australia, we have trained counsellors, support groups and education programs for carers. Call the National Dementia Helpline on **1800 100 500**.

Getting practical support

Caring for a person with dementia can become more demanding over time. Getting help can make it easier for you to provide the best support.

There are many sources of support:

- **Friends and family:** Try to involve family members and share responsibilities. This will take some of the pressure off you.
- **Employer benefits:** If you work, ask about carer's leave or other flexible working options.
- **Government benefits:** If you stop working, find out if you are eligible for any government benefits through Centrelink.
- **Carer support groups:** Talk to others going through similar experiences. You can share practical tips and get emotional support. Ask Dementia Australia about groups in your area.
- **National Dementia Helpline:** Get information and support from trained Dementia Advisers. Call **1800 100 500**.
- **Carer Gateway:** Get practical information and resources specifically for carers. Visit **carergateway.gov.au** or call **1800 422 737**.

Person-centred care

Person-centred care for people living with dementia means offering care that:

- treats the person with dignity and respect
- promotes their rights
- understands their individual history, lifestyle, culture, likes and dislikes
- sees things from their perspective
- provides a positive social environment that nurtures their relationships in the community.

These principles help embrace the uniqueness of every person, regardless of their disease. It is important to see the person and not just their dementia.

You and the person with dementia should be part of developing their care plans. As a partner, family member or friend, your understanding of the person is invaluable.

Looking after your health and wellbeing

As a carer, it can be easy to put the other person's needs first and ignore your own. Looking after yourself is vital for your health and wellbeing.

- Make sure you eat a balanced diet and make time for regular exercise and physical activity.
- See your doctor regularly about your health.
- If you have to move or lift the person you are caring for, seek advice from your doctor or an allied health professional to reduce your risk of injury.
- If you regularly feel sad or anxious, talk to your doctor as early as possible. These can be signs of depression.
- Make sure you have some regular time to relax or do something for yourself. Meet with friends, go on an outing or take a short break.
- Find out about Planned Activity Groups or respite support for the person you care for.

This will allow you to take time for yourself, knowing that they are being well looked after.

Supporting a person with dementia

Every carer experience is different. Much of how you care for a person living with dementia will come naturally. It will be based on instinct and the unique relationship you share with that person.

Learn to be creative and flexible with your caring strategies. Identify your strengths and the strengths of the person you care for. This will help you see where you may need extra support.

Always try to see the person and not just their dementia.

Become a Dementia Friend

For people living with dementia, performing daily tasks and maintaining social networks can sometimes be challenging. This is why building communities in which people living with dementia feel understood, accepted, and included, is so important.

Businesses, organisations, groups, and individuals can all play a vital role in creating dementia-friendly communities.

By becoming a Dementia Friend, you can learn what it is like to live with dementia, and how you can help those living with this condition maintain connections with those around them. Find out more at dementiafriendly.org.au/register

Everyday care

With time, dementia will affect a person's ability to carry out everyday tasks. Try to support and encourage them to do as much as they can for themselves.

When you help out, try to do things with them, not for them. This helps the person keep their independence, confidence and self-esteem.

Tips to support ability

- Focus on what a person can do rather than what they cannot.
- Be flexible and patient if they find it hard to remember or concentrate on things.

- Put yourself in their shoes. Try to understand how they might be feeling and the care they may want.
- Be sensitive and offer encouragement.
- Give them meaningful things to do, from everyday chores to leisure activities.
- Include the person in conversations and activities as much as possible.

Nutrition

Maintaining good nutrition for the person you care for can present challenges. The person with dementia may:

- experience a loss of appetite
- forget how to chew or swallow
- fail to recognise food or drink
- develop an insatiable appetite
- develop a craving for sweets
- suffer from dry mouth or mouth discomfort.

Tips to support good nutrition

- Plan for meals to be social occasions, whenever possible.
- Stock up on healthy snacks that do not need preparation or cooking.
- Do not use complicated table settings.
- Allow time for the memory to respond to food.
- Serve only one plate of food at a time.
- If there are swallowing issues, visit a speech therapist for appropriate strategies.
- Visit a dietician or doctor for extra advice on maintaining good nutrition.

Communication

The way dementia affects a person's communication will vary. Many people struggle to find the right words or follow a conversation.

This can be upsetting and frustrating for you and the person with dementia. But there are things you can do to better understand each other.

Tips to support communication

- Make eye contact. Try to listen carefully, even when you are busy.
- Make sure you have the full attention of the person. Consider the impact of any distractions, such as noise.
- Use gestures, facial expressions and touch, if it feels right.
- Speak clearly and think about the words you use. If you are not understood, use simpler words or explain things differently.
- Remain calm and use positive language.
- Stick to one topic and ask questions that are simple and easy to understand.
- Consider other factors that might affect communication. These include hearing or eyesight problems, pain, or side effects of medication.
- Give time for responses. Repeat yourself if needed.

- Deal with misunderstandings and mistakes by using humour. Laughing together can ease tension. Make sure it is appropriate by judging how the person responds.
- Involve the person in group conversations and avoid talking across them.

Try not to:

- give too many choices
- argue or confront
- talk down to the person
- talk about the person as if they are not there
- ask questions that depend on remembering too much
- give information too far in advance.

Interests

Interests and hobbies can help a person living with dementia enjoy the best quality of life. You can help maintain their interests by choosing activities you both enjoy.

Tips to maintain activity

- Tap into past interests and hobbies.
- Build on the person's strengths, focusing on what they can still do.
- Listen to music, dance, play with animals and look at old photos.
- Consider some gentle exercise or outdoor activities.
- Try different things until you find what works for you both.

Coping with changes in behaviour

People living with dementia can sometimes behave differently from how they used to. Keep in mind this is not deliberate and try not to take it personally.

Some examples of changed behaviours are:

- aggression
- overreaction
- hoarding

- repetition, such as asking the same question or repeating an action
- restlessness, such as pacing or fidgeting
- lack of inhibition, such as inappropriate behaviour in public
- night-time waking, sleeplessness and 'sundowning' (increased agitation or confusion in the late afternoon and early evening)
- following you around or calling out to check where you are
- putting things in unusual places and then forgetting where they are
- suspicion, e.g. thinking someone has taken their belongings when they cannot recall where they have put them
- apathy, poor motivation and ability to initiate activities.

Managing changed behaviours

- Try to think from the perspective of the person with dementia and offer reassurance.

- Work out if there is a problem so that you can try to resolve it.
- Avoid correcting or contradicting the person with dementia.
- Try distracting the person. You can change the conversation, have something to eat or go for a walk together.
- Engage in the activities they enjoyed before their diagnosis. This will help them remain engaged and feel valued.
- Try aromatherapy, massage, music or dance therapy, or contact with animals.
- Try talking therapies, reminiscing with the person or doing life story work.

As their dementia progresses, these behaviours may change. Other unusual behaviours may also emerge. Family members can often find this distressing, as can the person with dementia.

Try to understand why the person's behaviour has changed. A sudden change is unlikely to be due to the progression of dementia, which is typically slow.

A curable physical or medical issue is more likely to be the cause. It is important to see your doctor for a medical assessment when behaviours change.

If there are no physical causes, it could mean the person has an unmet need. Keep a record of when the behaviours are happening to help you understand them or spot any triggers.

If these issues persist or cause distress, talk to a professional. Behavioural changes are very common, and many things can help.

Dementia Behaviour Management Advisory Service

The Dementia Behaviour Management Advisory Service is a nationwide service funded by the Australian government.

This service provides clinical support to carers of people living with dementia, where behavioural and psychological symptoms are impacting their care. This can be care provided at home or in an aged care facility.

Clinicians conduct individual assessments and care planning to help carers in their roles. They also assist carers to identify triggers and develop strategies to prevent or minimise difficult behaviour. They can link carers with appropriate support networks.

For more information, visit dementia.com.au or call **1800 699 799**.

Respite care

Access to respite can help you to have a break and look after yourself so that you can continue to provide care at home for as long as possible. Different respite options are available to people in care relationships. These include:

- flexible respite
- in-home respite
- day centres
- overnight cottage respite
- residential respite.

Managing grief and bereavement

When a person with dementia is dying or has died, family members and friends may experience a range of feelings.

Everyone has different reactions. Some people grieve the loss of that person, even if they did not wish for them to go on living with dementia. Some people find they have grieved too much already to have strong feelings at the time.

You may experience:

- sadness, for what could have been or for what you have lost
- shock and pain
- disbelief and an inability to accept the situation
- guilt
- relief, both for the person with dementia and for yourself
- anger and resentment

- lack of purpose now that your caring role has gone.

What you feel and how long you feel it for will vary from person to person. There are no rules for grieving. We all react in our own way and in our own time.

Following a loss, you may feel shocked and vulnerable

- Try to avoid making any major decisions.
- Accept that you may feel sad or upset at times.
- Arrange for support around emotional events, such as birthdays or anniversaries.
- Talk to your doctor about any feelings of depression or physical illness.

Remember, it will take time to adjust to your loss. If you are finding it difficult, it may be useful to talk to a professional.

Speak to your doctor or call the National Dementia Helpline on **1800 100 500**.

Getting back on your feet

It can be hard to move on with your life after your caring responsibilities change or you lose a loved one. But the time will come when you are ready to re-establish your own life and move forward.

- Take your time. The length of time needed to adjust varies from person to person.
- Be patient. Do not try to rush the process.
- Accept help. Other people can support you and let you express your feelings, reflect and talk.

Share your experience

Sharing your feelings among family and friends can help you work through your grief.

- Remember the person. Talk about earlier times before dementia affected them.
- Celebrate the person with family and friends. Many people find this helpful on birthdays or anniversaries.

- Re-establish your social networks. Start to see old friends again or look at making new friends.
- Keep trying. You may not feel confident at first. It can be difficult to make decisions, talk about ordinary things or cope with social gatherings. But do not give up. Your confidence will gradually return.

Stay connected

You are not alone. We are here to help.

Dementia Australia has office locations across metropolitan and regional Australia. We also provide outreach services to remote areas. Our services can be delivered face-to-face, by telephone or online, depending on your needs and situation.

You can receive the latest news and developments from Dementia Australia with our monthly eNews. Email membership@dementia.org.au to sign up.

Find us on social media:

Facebook facebook.com/DementiaAustralia

Instagram instagram.com/Dementia_Australia

Twitter twitter.com/DementiaAus

Become a member

Dementia Australia membership is open to anyone concerned about dementia. As a member, you can play a role in the continued growth and future development of our organisation.

For more information on membership, visit dementia.org.au/membership or call the National Dementia Helpline on **1800 100 500**.

Lifeview

Lifeview is a family focused community, providing care and wellness in a supported social environment, where residents live well through engagement, warm hospitality and lifestyle choices.

Lifeview's philosophy of care is based around one of choice, freedom and dignity of risk.

A Rainbow Tick accredited organisation, Lifeview's delivery of residential aged care reflects contemporary international and Australian best practice models of holistic, person-directed care. We promote quality of life, health, wellbeing and the independence of each resident, including those living with dementia.

Lifeview's staff are trained in best practice dementia care, facilitating growth, meaningful engagement and improved wellbeing. Resident quality of life is as important as their quality of care.





This guide is proudly
supported by Lifeview