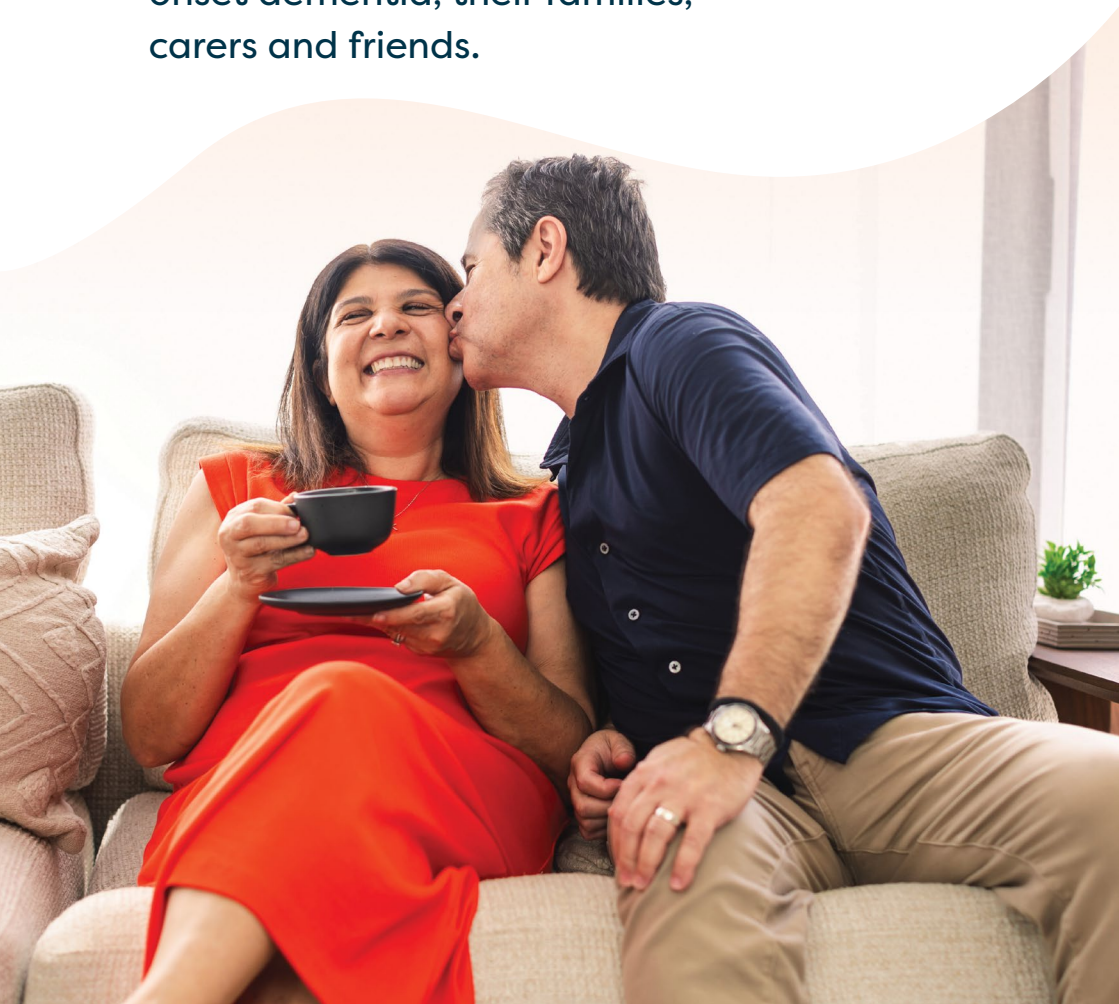
Dementia Australia®

The Younger Onset Dementia Guide

For people living with younger onset dementia, their families, carers and friends.



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Aboriginal and Torres Strait Islander people should be aware that this guide contains images of deceased persons.

Contents

Part 1

Part 2

Part 3

Part 4

Acknowledgements

Insignia Financial and the Insignia Community Foundation are pleased to partner with Dementia Australia through the provision of financial support for the development of the inaugural Younger Onset Dementia Guide in 2025.

ABOUT INSIGNIA FINANCIAL LTD

With origins dating back to 1846, today Insignia Financial is a leading Australian wealth manager. Insignia Financial provides financial advice, superannuation, wrap platforms and asset management services to members, financial advisors and corporate employers.

Further information about Insignia Financial can be found at **insigniafinancial.com.au**

About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated 433,300 Australians living with dementia, and the more than 1.7 million people involved in their care.

We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 40 years ago, today we are the national peak body for people living with dementia, their families and carers.

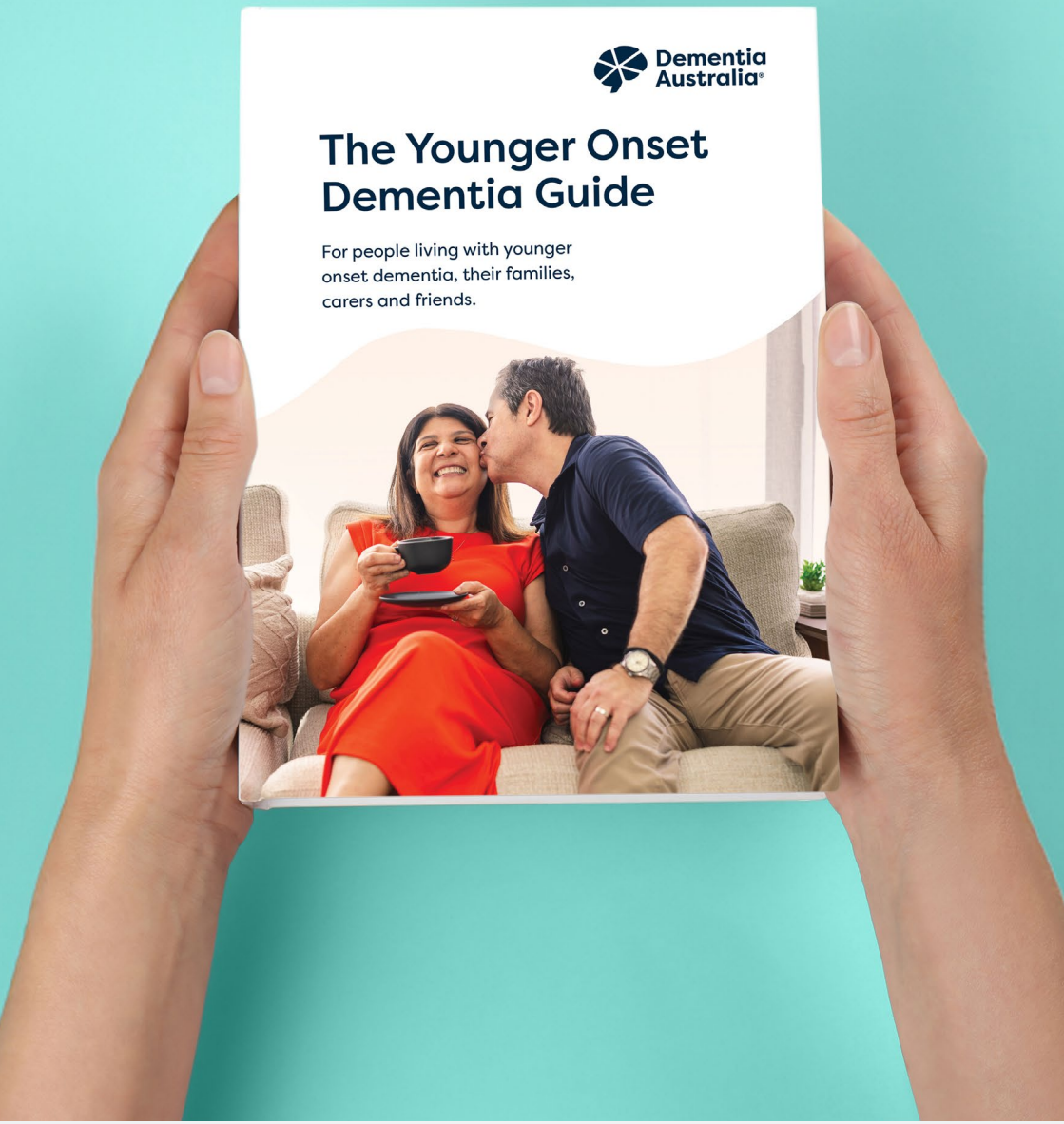
We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences.

We amplify the voices of people impacted by dementia through advocating and sharing stories, to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

To find out more about Dementia Australia, scan the QR code or visit **dementia.org.au**

About this guide



This guide is for anyone impacted by younger onset dementia. The information in this guide is divided into four colour-coded parts.

Part 1 **Sections 1–3** relate to understanding younger onset dementia and the impact on you emotionally, physically, socially and financially.

Part 2 **Sections 4–9** focus on supports, services and advice to help you live well with younger onset dementia and to manage the later stages.

Part 3 **Section 10–11** are designed for your family members and people helping to care for you, especially as your dementia progresses. It also offers ways to stay connected with Dementia Australia.

Part 4 **Section 12** offers useful tools: worksheets and checklists to help you live well and make plans.

This guide was developed in consultation with people living with younger onset dementia, their families and carers. We recognise that everyone's experience is different and advise that some readers may find some information in this guide distressing. If you need support, contact the **National Dementia Helpline** on **1800 100 500**.


Katie

Our message to you

If you have been diagnosed with younger onset dementia, you don't have to face this alone.

Every day, Dementia Australia supports people living with all forms of dementia, including younger onset dementia. We recognise that everyone's experience is unique and we respect your feelings.

There's a lot of information to take in and decisions to make, which can feel overwhelming.

That's why we created **The Younger Onset Dementia Guide** in consultation with people living with younger onset dementia, their families and carers. We've aimed to make the information in this guide as meaningful and relevant to your needs.

You are not alone. Support is available.

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

PART 1

Section 1

About dementia

About dementia

Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease.

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

Common symptoms include:

- memory loss
- challenges in planning or problem-solving
- 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 impaired judgement
- withdrawal from work or social activities
- changes in mood and personality.

Dementia is progressive. Symptoms may begin slowly or change more rapidly. They will become worse over time.

No two people will experience the symptoms of dementia in the same way. But it is important to know that, with planning and support, it is possible to live a meaningful, active life for many years after diagnosis.

Younger onset dementia

Younger onset dementia is the term used when you are under 65 years old and diagnosed with any type of dementia.

Aboriginal people tend to develop dementia at a younger age compared with non-Indigenous people.

If you are diagnosed with dementia under the age of 65, you will have some different needs to older people and may experience unique challenges due to your stage of life.

People living with younger onset dementia are often:

- physically strong and healthy
- supporting dependent children at home who are attending school or university
- still working and planning for retirement
- paying off a mortgage, with other financial commitments.

Younger people living with dementia may find it difficult to get a diagnosis because many people do not expect a younger person to have dementia and commonly mistake the symptoms of dementia for other health conditions.

Accessing services might also be hard because mainstream services that are designed for younger people may not understand how to support people with younger onset dementia.

Dementia Australia can help you manage a diagnosis and connect you to services that can support you and your family. Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline**

Who gets younger onset dementia?

Dementia can happen to anybody, and while it is rarer to develop it in your midlife, it is possible to develop symptoms in your 20s, 30s, 40s and 50s.

Researchers in dementia believe younger onset dementia depends on a combination of age, genes, health and risk factors. Dementia can be hereditary, but this is rarer than other forms.

Types of dementia that affect younger people

There are more than 150 different types of dementia that can affect people of any age. This section highlights the most common types that a younger person might be diagnosed with, as well as some of the rarer forms.

ALZHEIMER'S DISEASE

Alzheimer's disease is the most common cause of dementia. This disease disrupts the brain's neurons due to build-up of abnormal proteins, called plaques and tangles. These proteins affect how the neurons work and communicate with each other. A decrease of important chemicals stops messages travelling normally through the brain.

Common symptoms include:

- difficulties with short-term memory, especially recalling recent events
- language and comprehension difficulties, such as problems finding the right word

- trouble remembering the time, where you are and who people are
- difficulties with becoming motivated and starting tasks.

Memory loss is among the first symptoms noticed in older people with Alzheimer's disease, but is less likely in younger people with the condition.

Atypical Alzheimer's disease

These are rarer forms of Alzheimer's disease.

Posterior cortical atrophy	The first symptoms usually involve problems with understanding visual information. This can mean trouble reading or judging distances.
Logopenic aphasia	The first symptoms usually involve difficulties with language. This can mean problems with finding the right word or taking long pauses when speaking.
Behavioural/ dysexecutive Alzheimer's disease	The first symptoms usually involve difficulties with planning and decision-making, as well as navigating what is socially appropriate behaviour.

Familial Alzheimer's disease	Familial Alzheimer's disease is a rare form of Alzheimer's disease caused by genetic mutations that run in a family. The three genes found to mutate are: + PSEN1 (presenilin 1) + PSEN2 (presenilin 2) + APP (amyloid precursor protein). If you are affected by familial Alzheimer's disease, often you have a family history, typically knowing multiple relatives (including a parent), who developed Alzheimer's disease at a similar age.

DOWN SYNDROME AND DEMENTIA

It is estimated that around half of the people who have Down syndrome are likely to develop dementia at around 50 to 60 years of age.

Dementia in people with Down syndrome is usually, but not always, caused by Alzheimer's disease.

It is not well understood why people with Down syndrome are at an increased risk of Alzheimer's disease. It is thought to be linked to being born with an extra chromosome 21, leading to an overdevelopment of a protein that forms plaques on the brain.

While not everyone with Down syndrome will develop dementia, most people with Down syndrome experience structural changes in their brain by the age of 40.

VASCULAR DEMENTIA

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

Common symptoms include:

- slowed motor speed
- impaired attention and concentration problems
- difficulty planning and making decisions
- difficulty following instructions
- depression and apathy.

CADASIL

CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy) is a genetic form of vascular dementia caused by a mutation in the NOTCH3 gene. It is usually inherited from a parent who has passed on the mutated copy of the gene. This results in a rare disease of the blood vessels in the brain.

Common symptoms include:

- migraines
- repeated strokes
- progressive dementia
- seizures
- psychiatric symptoms.

LEWY BODY DEMENTIAS

This umbrella term describes two main types of dementia: dementia with Lewy bodies and Parkinson's disease dementia. In these forms of dementia, tiny structures called Lewy bodies develop inside brain cells.

Common symptoms include:

- hallucinations
- fluctuating levels of alertness, confusion or both
- features of Parkinson's disease (such as slowed movement, rigidity, shuffling walk, increased falls and tremors)
- difficulty with visual and spatial perception
- difficulty with abstract reasoning and judgement
- difficulty with planning, problem-solving and decision-making
- vivid dreaming, with body movement when dreaming.

Dementia with Lewy bodies

In dementia with Lewy bodies, the symptoms of dementia typically begin before the development of movement symptoms (which are characteristic of Parkinson's disease). Not everyone who has dementia with Lewy bodies will develop Parkinson's disease.

Parkinson's disease dementia

This is diagnosed when a person develops dementia symptoms sometime after a diagnosis of Parkinson's disease.

Frontotemporal dementia

Frontotemporal dementia causes progressive damage to the frontal or temporal lobes of the brain, or both. It is more commonly diagnosed in younger people than in older people.

There are several different types of frontotemporal dementia, which cause different symptoms. The main types of frontotemporal dementia are:

BEHAVIOURAL VARIANT FRONTOTEMPORAL DEMENTIA	
Early symptoms caused by this type	**Common symptoms**
Changes in personality, emotion and behaviour.	+ loss of inhibitions + loss of insight + losing interest in people or things (apathy) + loss of motivation + repeated use of phrases or gestures (compulsive behaviours) + impulsive behaviour.

PROGRESSIVE NON-FLUENT APHASIA	
Early symptoms caused by this type	**Common symptoms**
Changes in language and speech production.	+ difficulty understanding words and concepts + difficulty understanding complex sentences + slow, hesitant speech + difficulty speaking.

SEMANTIC DEMENTIA	
Early symptoms caused by this type	**Common symptoms**
Changes in language comprehension.	+ difficulty understanding the meaning of familiar words (for example, not understanding the word 'cup') + problems recognising familiar people or objects (for example, a bunch of keys is in the person's hand, but they do not know what the keys are used for) + difficulty finding the right word.

OTHER CAUSES OF DEMENTIA

A wide range of other conditions can also cause dementia. These are rare but can affect younger people. They include:

- alcohol-related brain damage, known as Wernicke's syndrome and Korsakoff's syndrome
- chronic traumatic encephalopathy (CTE) from repeated head injuries
- Creutzfeldt-Jakob disease
- corticobasal degeneration
- HIV-related cognitive impairment
- Huntington's disease
- Multiple sclerosis
- Niemann-Pick disease type C
- normal pressure hydrocephalus
- progressive supranuclear palsy.

MILD COGNITIVE IMPAIRMENT

Mild cognitive impairment is a condition that causes changes in memory and other cognitive functions, which cannot be explained by another condition. The changes are greater than usually expected from someone of a similar age.

Mild cognitive impairment increases the risk of developing dementia, but many people never progress to dementia and some even improve over time.

Regular check-ups with your doctor or a specialist, and a focus on tackling modifiable risk factors like diet, exercise and keeping your brain active, can be beneficial.

How younger onset dementia progresses

People with any form of dementia differ in the symptoms they have and how quickly or slowly their abilities change. Your abilities may change from day to day, or even within the same day.

Progression may happen rapidly, in a period of a few months, or slowly, across several years. While the progression of younger onset dementia can vary, the condition usually has three broad stages. Understanding these stages can help you be more prepared and plan for what might happen.

1

MILD OR EARLY-STAGE DEMENTIA

You might have some problems with thinking and remembering things but need minimal support.

2

MODERATE OR MIDDLE-STAGE DEMENTIA

You will need support to help you function at home and in the community. Cognitive changes are now more obvious and have a greater impact on your abilities and level of independence.

3

SEVERE OR LATE-STAGE DEMENTIA

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

While there is no cure for dementia, understanding how younger onset dementia progresses and making sure you have support at the right times means you can maintain your independence for as long as possible and live as well as you can. It also means that the people around you will know how they can support you and access support for themselves.

Section 2

Understanding the impact of younger onset dementia

Understanding the impact of younger onset dementia

A diagnosis of younger onset dementia can impact both you and your family in many ways. Being informed and prepared can help you decide how best to manage the condition and the challenges it brings.

Everyone's circumstances are different. Some things to consider can include:

- talking about your expectations of the future
- addressing changes in your relationships
- acknowledging your feelings of grief and loss.

Recognising your feelings

It's common to feel a wide range of emotions after a diagnosis of younger onset dementia.

You might feel:

- sadness
- anger
- frustration
- guilt
- resentment
- depression
- apathy
- shock
- anxiety
- loneliness
- confusion
- hope
- relief.

Physical reactions to the news of a diagnosis can include:

- headaches
- aches and pains
- exhaustion
- numbness
- changes in appetite
- changes in sleep
- illness
- low energy
- hair loss
- heart palpitations
- skin conditions.

Some of these symptoms can be signs of grief, but there may also be other causes. See your doctor to discuss all your symptoms.

Specific circumstances or situations may be a catalyst for bringing up strong emotions. For example, you might:

- experience sadness about what has changed
- feel overwhelmed by what a diagnosis means and how it may impact your future
- mourn changes in family dynamics, friendships and intimate partner relationships
- feel concerned about being unable to drive
- fear the loss of or changes in your employment
- grieve the loss of your work and social identity
- feel like you have lost the ability to provide for your family
- resent your need for increased support in day-to-day living
- feel upset about losing your independence.

The emotional and physical effects of grief and loss can also influence how you and the people around you respond. It is common to:

- stay as busy as possible
- try to anticipate another person's needs in a negative way
- drink, smoke or take drugs (more than usual)
- withdraw from friends, family or coworkers
- avoid responsibilities
- avoid things that are reminders of difficult feelings

- try to fix things, people or relationships
- take risks
- behave in an over-protective way
- be self-protective.

PROCESSING YOUR EMOTIONS

There is no right or wrong way to move through the challenging emotions you might be experiencing. There's no set time for how long it takes. Try to acknowledge how you are feeling, accept your feelings for what they are, and look at ways you can adapt to the new circumstances of your life.

This could include:

- adjusting your living environment to suit changing needs
- adjusting your expectations of yourself, others and how life will look
- connecting with others living with similar experiences
- maintaining connection with people and activities that you enjoy
- allowing others to provide support.

COPING STRATEGIES

When you are experiencing grief, it can be difficult to know how to cope or act.

Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline** to talk to someone who can help you process what you are feeling and connect you to supports that are right for you.

You could also consider using some recognised techniques to help you cope.

Try:

- breathing exercises
- taking a break. It doesn't need to be a holiday or something big or expensive. Take five to 10 minutes to sit with a hot drink, read a book or meditate
- scheduling and sticking to regular movement: daily exercise, stretching, walking, sport, yoga or walking the dog
- eating nourishing food
- staying connected: catching up with friends and family that support you, distract you or make you laugh
- participating in formal supports, such as joining a support group or accessing counselling
- planning something to look forward to. This can be small, such as a hobby you enjoy, or something more significant like a holiday with friends or family
- practising self-compassion: be kind to yourself
- accepting dementia as a new way of life. This may include being flexible and adapting your life and expectations, and living in the moment, day by day.


OCEAN SEA

Planning for a different future

We all have a vision of what our future will look like, and a diagnosis of younger onset dementia might make you feel like planning for the future is too difficult. However, if you give yourself some time to adjust and consider what is important to you, you may find your goals don't have to disappear. They might just look a little different.

In some cases, people living with younger onset dementia talk about the diagnosis as an opportunity to focus on what truly matters. It may be planning a special event or holiday, spending treasured time with friends and family or putting plans in place to manage the long-term health of your finances.

Whatever your goals, give yourself time to process what a diagnosis of dementia means to you and your vision of the future.

Navigating relationship changes

All relationships change over time, but a diagnosis of younger onset dementia can impact how you relate to the people around you, and how they relate to you.

You might experience changes in:

- your role in the lives of those around you
- how you feel about sex and intimacy
- your communication, behaviour and feelings
- how willingly you accept help and care from others
- the nature of your friendships
- your relationship with your children.

Your partner, children, or even your parents, might take a more active role in supporting you, personally and financially. Because these changes can be unsettling, a shift in dynamics or role reversals can strain relationships.

Communication is key. Choose a time when you and your family or friends feel calm or close and discuss how you feel with them. Always consider seeking additional support when it's needed.

Managing stress

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

By managing your stress levels, you can improve your concentration, strengthen your decision-making ability and enhance your quality of life. See Section 4, 'Living well', for strategies to help reduce stress.

Financial pressures can also greatly impact stress. Planning your finances and your future can help maintain financial independence, reduce financial stress and ensure you're prepared for the future.

See Section 3, 'Planning your finances and future', for information on how to assess, manage and plan finances. Getting financial counselling, advice and support can help put things into perspective.

Talking about your diagnosis

Sharing a diagnosis of dementia can be confronting. But it can also be a relief and help you cope more effectively.

The benefits of talking about your diagnosis include:

- Other people are accurately informed, reducing the chance of incorrect assumptions
- Others may have noticed changes in you, so discussing your diagnosis will help them understand how you are being impacted
- You can use it as a starting point with your employer to discuss strategies for making your job more manageable
- You can tell people how you would like them to support you
- It can help reduce misunderstandings and stigma that people around you might hold about dementia.

Changing or ceasing employment

A diagnosis of dementia does not always mean you need to stop work immediately. However, it may mean changes in tasks or adjusting your work hours.

Depending on your job, you may need to notify your employer of your diagnosis and how it impacts your capacity. This is particularly relevant if your job requires you to:

- have a high level of attention to detail or memory
- have personal responsibility for other people (for example, if you're a doctor or teacher)
- drive or operate machinery.

Start by talking with your doctor or specialist about your ability to work.

Steps to manage the impact of dementia at work

1. Develop a routine and structure
2. Take regular breaks
3. Use a diary, calendar or planner
4. Keep records by taking notes, making voice memos or recording video calls
5. Minimise distractions
6. Set achievable goals.

OTHER SUPPORTS

Dementia Australia provides a wide range of support that is designed for people living with younger onset dementia, as well as their families. Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline**

Your workplace may have support services, such as an **Employee Assistance Program**, a human resources department, or you could talk with your manager or colleagues.

JobAccess is an Australian Government national hub to support people with disabilities in the workplace and their employers. Visit **jobaccess.gov.au**

A range of services may be accessible through the **National Disability Insurance Scheme** (NDIS).
See Section 5 National Disability Insurance Scheme and younger onset dementia below for more information.

Australian Human Rights Commission can provide support to understand your rights. Visit **humanrights.gov.au**

Fair Work Australia may be able to help you understand your rights at work. Visit **fairwork.gov.au**

LONGER-TERM EMPLOYMENT CONSIDERATIONS

Here are some things to consider about your employment in the longer term:

- Some types of dementia can progress faster than others, so consider regular reviews regarding your capacity to continue working
- Get information about employee rights and entitlements
- Talk to union representatives or anti-discrimination advocates about working conditions and health issues
- Understand your employment conditions, including policies, entitlements or benefits related to sick leave, long service leave, disability entitlements, superannuation, income protection or other insurances that may have a disability component
- Review your superannuation policy to see if it includes a death or disability insurance benefit. See Section 3, 'Planning your finances and future' for more information.

REASONABLE WORKPLACE ADJUSTMENTS

Here's how your employer could make reasonable adjustments in your workplace:

- allocate tasks individually rather than all at once
- match tasks with your current abilities
- simplify work routines
- provide a quieter and less distracting workspace
- provide free time during the day to reduce the impact of fatigue on cognitive functioning

- provide assistive technology
- encourage the use of memory aids
- identify a colleague to buddy up with you
- provide positive visual and verbal encouragement to continue to work
- modify existing role, reducing responsibilities
- depending on financial situation, reduce hours or change roles.

Limiting or stopping driving

The type of dementia you have and the way it affects things like thinking, memory, movement (motor control), reaction times, vision and hearing will determine if you can continue to drive and for how long.

The law requires you to disclose to your state or territory licensing authority any medical conditions that could affect driving. There are serious consequences if you continue to

drive without notifying your licensing authority, or if you continue to drive after your licence has been cancelled or suspended. If you are in an accident, you could be charged with driving offences and insurance companies may not provide cover.

There is no definite point to say when someone is no longer legally able to drive: everyone's situation is different.

Here's what the process may look like:

1. Inform your licensing authority that you have a dementia diagnosis.
2. The licensing authority will ask you to see a doctor, who will assess your medical fitness to drive (this may be a different doctor from your usual one).
3. You may need a formal driving assessment with an occupational therapist.
4. Based on the outcomes of these assessments, the licensing authority will determine if you can continue to drive, or may place conditions on your licence.
5. You may need regular medical and driving tests.

The decision to stop driving can be hard. If you choose to stop driving or are no longer able to drive, consider other available transport options so you can remain as active and independent as possible.

Examples include:

- public transport
- community transport
- taxis or rideshare
- family and friends driving you. If you are eligible, they may be able to use the Australian Disability Parking Permit
- home delivery options
- using government-funded transport subsidies
- transport support through the NDIS (if you are eligible).

Contact your local council to find out what alternative transport options are available.

Section 3

Planning your finances and future

Planning your finances and future

Planning for the future is important for everyone, but it is particularly important if you're living with younger onset dementia. You may still be managing your career, family and other responsibilities, so consider making key decisions early, while you're still able to take an active role.

By planning ahead for things like medical care, financial security, legal matters and support systems, you can ensure your wishes are respected and that your future remains as secure and positive as possible.

Rebalance your plans and goals

Rebalancing your plans and goals after a diagnosis of younger onset dementia can feel overwhelming, but there is a lot you can do to reshape your situation.

RESET FINANCIAL PRIORITIES

Where to start

Identify and prioritise your most important financial and lifestyle goals, such as:

- ensuring your family's security
- covering healthcare needs and costs
- travel plans
- maintaining or changing your lifestyle.

Adjust financial goals to ensure they're realistic.

It's okay to scale back or adjust previous ambitions. You may also consider bringing forward other plans, such as travel.

You might need to stop working earlier than expected. Start planning, so you're ready for when your income changes.

RE-THINK WORK

Where to start

Explore opportunities for alternative ways of occupying yourself, such as:

- part-time employment
- further study
- getting involved in community social groups and activities
- contributing to causes you care about, like advocacy work, research, campaigns or fundraising activities.

Evaluate the potential impact on your income if you decide to reduce work hours, change roles or stop working.

Starting to plan

As your cognition changes, you may need to find different ways of managing your finances. Tasks that might require new strategies include:

- shopping for groceries and other items
- paying bills and knowing when payments are due
- banking activities, such as accessing accounts and services, reviewing bank transactions and statements, remembering personal identification numbers (PINs), passwords or information to access your accounts
- managing money, such as keeping track of transactions and daily spending, and keeping within credit card limits

- planning for the future, including sorting out important documents, making a will and appointing powers of attorney.

With some planning, you can implement the right strategies and supports to overcome these challenges.

Make a start by:

- assessing and simplifying your finances
- identifying your care costs
- building your support team
- preparing legal documents
- understanding your superannuation and insurance cover
- looking into government supports to know what you're entitled to claim and what the processes are.

Assessing and simplifying your finances

Start by gathering important information and documents in one place so everything is easy to find. You might have information on paper and stored digitally, or stored in online banking, superannuation or investment websites.

To help you simplify your finances, you could consider:

- consolidating your bank accounts
- setting up automatic payments for regular expenses and debts (such as mortgage payments, utility bills and personal loans) to minimise the risk of missed payments or incurring additional interest
- prioritising paying off high-interest debts first (such as credit cards, personal or car loans)

- consolidating or refinancing debts to reduce interest rates and monthly payments (consider the length of the loan term remaining)
- creating a budget to manage your fixed and variable expenses: see Section 12 Useful tools: worksheets and checklists
- starting to set aside emergency funds for future medical and care costs or unexpected expenses
- seeking financial advice to help with decision-making.

Identifying care costs

The more you prepare now for upfront, ongoing and future medical and care expenses, the better equipped you will be to meet those costs later, as your condition progresses.

UP-FRONT AND ONGOING COSTS

Up-front costs might include:

- scheduling regular check-ins with your General Practitioner to keep track of your health
- setting up assistive technology to help you manage your finances (like budget tools) and live as independently as possible (like scheduling apps, automated reminders, staying connected with friends and family)
- getting advice and help to make your home more dementia-friendly
- investing in new activities and experiences to stay active.

Ongoing costs might include:

- gap fees: when visiting a General Practitioner, there may be a gap between the charge and what Medicare covers
- gap or full fees for private health professionals not fully covered by Medicare or private health insurance, such as psychologists and physiotherapists
- complementary therapist fees, such as massage therapy or acupuncture
- prescription and over-the-counter medicines
- safety-related expenses, like equipment, safety services or home modifications
- private hospital excess fees
- respite service fees (for services that charge)
- transport costs
- membership or joining fees; for example, to access a gym or health club
- general socialising costs, like drinks, meals and gifts.

PAYING FOR CARE AND SERVICES

Financial resources you might be able to draw on include:

- Medicare subsidies
- private health insurance subsidies
- other private insurances, like income protection insurance or Total and Permanent Disability (TPD) insurance
- employee or retirement benefits

- personal assets
- Department of Veterans' Affairs payments
- Services Australia (Centrelink) payments
- subsidised community supports, such as Meals on Wheels, respite care and transport services
- funding through the National Disability Insurance Scheme (NDIS): see Section 5 National Disability Insurance Scheme and younger onset dementia.

Talk to a trusted financial advisor or family member about your situation.

Building your support team

Having a team of people to support you through different aspects of life (from healthcare to finances) can help ensure your decisions are well-informed. It can also reduce stress and optimise your quality of life.

Your support team might include:

YOUR FAMILY

Your family members may have a formal or an informal role in supporting your financial decisions. They might help you with decision-making or planning by offering you their opinion or advice, or you might appoint them formally to make decisions on your behalf. Read 'Preparing legal documents' later in this section for more information on legal decision-making.

YOUR HEALTHCARE TEAM

Your doctor and other medical specialists, including allied health professionals, can help you maintain your

independence for as long as possible, and discuss how to support you to keep making financial and other decisions.

YOUR LEGAL TEAM

Your lawyer or solicitor can assist with understanding and preparing legal documents to manage your finances, and your medical care needs and plans.

YOUR FINANCE TEAM

Various experts can offer perspectives to support your financial wellbeing.

A bank manager can help with account management, payment automation and ways to protect your money while ensuring you can access it when you need to.

An accountant can support your financial planning, investment adjustments, tax filing and estate planning.

A financial counsellor can provide free confidential information and advice to help work through debts or difficulty managing ongoing expenses. They can also support you with negotiations, counselling and emotional support. To get free information and advice from a financial counsellor, contact the **National Debt Helpline** on **1800 007 007** or visit **ndh.org.au**

A financial advisor or financial planner can provide advice about income replacement and help with planning for your future needs. The Australian Government's **Moneysmart** website has a register to help you find a financial advisor who can provide investment advice. Visit **moneysmart.gov.au/financial-advice/financial-advisers-register**

Section 12 of this guide, 'Useful tools: worksheets and checklists', contains worksheets to help you keep a record of

important documents and record your monthly income and expenses. It also includes a checklist of questions to consider when speaking with your financial team.

Preparing legal documents

Getting your legal documentation sorted early can help you feel more in control. Here are the things to consider when preparing legal documents, including who can help you make decisions, writing a will, and accessing superannuation and insurance.

DECISION-MAKING CAPACITY

If you've been diagnosed with younger onset dementia, you'll need to plan for what happens when you can no longer make decisions for yourself. This is known as "decision-making capacity" or simply "capacity".

As your dementia progresses, you might find that your ability to make decisions changes from day to day, or even hour to hour. It may be influenced by factors like:

- your physical health
- your emotional or psychological state
- your physical environment
- the time of day
- the type of decision you're making.

You will also need to plan for who can make decisions for you when you are no longer able to make them yourself. You can appoint one or more people. You might start by discussing your wishes with family members and close friends.

DIFFERENT TYPES OF DECISION-MAKING

Everyone needs support at some point to make decisions. It may be that you need information in a certain format (e.g. in a letter instead of on a website), more time to decide, or support to communicate. You may need the support of someone (or multiple people) to help you make your own decisions, or you might decide to appoint someone to make decisions on your behalf. The types of support you need to make decisions may vary from decision-to-decision and at different times.

Supported decision-making

Supported decision-making describes a range of approaches, technologies, services, and processes that promote your right to make decisions. This may include providing information in a certain format, providing information at a time when you are best able to make decisions, giving you more time to make decisions, supporting you to communicate, or getting support from another person to help you make decisions.

Substitute decision-making

This describes the process of formally appointing a person or people to make decisions on your behalf if you are no longer able to make decisions on your own, even with support. Substitute decision-makers may be called different things, depending on the legal framework they are appointed under: power of attorney, guardian, nominee or representative are some names you might see referenced.

Your substitute decision-maker should consult with you as long as you're able. They should follow your written or verbal wishes once their legal appointment is active, which is usually when you are determined by law to have lost capacity to make decisions yourself, even with support.

Decision-makers you appoint for your financial matters are referred to differently from those who you appoint for personal and healthcare decisions. This may also vary between Australian states and territories (see Table 1a).

You might have a general power of attorney (which has a specific purpose and an end date) or an enduring power of attorney (which comes into effect when you no longer have decision-making capacity and doesn't have an end date).

If you have not legally appointed someone, each state and territory has different laws and terminology for appointing people or agencies to make decisions for you (see Table 1b).

If your decision-maker wants to dispute your wishes, or if someone else believes your decision-maker isn't acting in your best interest, they can apply to have the appointment reviewed by a Tribunal. Each state or territory has its own Tribunal (see Table 2).

Table 1a – Substitute decision-maker/s appointed by you by state and territory

State/territory	Financial decisions	Personal/healthcare decisions
Australian Capital Territory (ACT)	Enduring Power of Attorney (EPoA)	EPoA
New South Wales (NSW)	EPoA	Enduring Guardian

Northern Territory (NT)	Substitute decision-maker	Decision-maker under Advance Personal Plan
Queensland (QLD)	EPoA (Financial)	EPoA (Personal/Health)
South Australia (SA)	EPoA	Substitute decision-maker/s or Person Responsible
Tasmania (TAS)	EPoA	Enduring Guardian
Victoria (VIC)	EPoA (Financial)	Medical Treatment decision-maker
Western Australia (WA)	EPoA	Enduring Guardian

Table 1b – Substitute decision-maker/s appointed by a Tribunal by state and territory

State/territory	Financial decisions	Personal/healthcare decisions
ACT, NSW, NT	Financial Manager	Guardian
QLD, SA, TAS, VIC, WA	Administrator	n/a

Table 2 – Names of Boards and Tribunals by state and territory

State/territory	Name of Board or Tribunal for Guardianship or financial matters
ACT	Australian Capital Territory Civil and Administrative Tribunal (ACAT)
NSW	New South Wales Civil and Administrative Tribunal (NCAT)
NT	Northern Territory Civil and Administrative Tribunal (NTCAT)
QLD	Queensland Civil and Administrative Tribunal (QCAT)
SA	South Australian Civil and Administrative Tribunal (SACAT)
TAS	Tasmanian Civil and Administrative Tribunal (TasCAT)
VIC	Victorian Civil and Administrative Tribunal (VCAT)
WA	State Administrative Tribunal (SAT)

Choosing a decision-maker

Before choosing someone to make decisions for you, consider:

- Do they have integrity and will they act in your best interests?
- Do they understand what is important to you?
- Do they have the financial know-how to manage your affairs?
- Are they available and willing to take on this responsibility?

Choose someone who will respect your wishes, even under pressure from family or in emotional situations. For example, if you've said no to life-prolonging treatments when terminally ill, your appointed person needs to honour that, even if it's hard for others to accept.

ADVANCE CARE PLANNING

There will come a time when you won't be able to make decisions about your care. Advance care planning is the process of making decisions about what you want or don't want in the future.

The following suggestions may help you think about what you need to consider:

- current and future health preferences
- your spiritual or religious beliefs and how those beliefs might impact your later physical or medical care
- medical treatments and procedures you do or don't want to receive

- access to alternative treatments
- organ donation.

An Advance Care Plan is a legal document that a person with decision-making capacity makes about their future healthcare decisions. It might be a written legal document (which is signed by you and witnessed) or a written instruction (like a card in your wallet refusing a blood transfusion or resuscitation), depending on the type of directive you make and the state or territory in which you live.

Table 3 – Types of Advance Care Plans by state and territory

State/ territory	Advance care planning document	Document type
ACT	Health Direction Advance Care Plan Statement of Choices	Legal document Guiding document
NSW	Advance Care Directive	Legal document
NT	Advance Personal Plan	Legal document
QLD	Advance Health Directive Statement of Choices	Legal document Guiding document
SA	Advance Care Directive	Legal document
TAS	Advance Care Directive	Legal document

VIC	Advance Care Directive	Legal document
	Appointment of medical treatment decision-maker	Legal document
	Appointment of support person	Legal document
WA	Advance Health Directive	Legal document
	Values and Preferences form	Guiding document

For more information, visit the Advance Care Planning Australia website: **advancecareplanning.org.au**

WRITING A WILL

You're not required to have a will, but creating one lets you decide what happens to your personal belongings and assets after you die. A will allows you to leave your assets to specific people or organisations. If you have children, a will also allows you to arrange guardianship for them, if needed.

You can pay a lawyer or solicitor to write up your will, or it can be written by a Public Trustee (it's free if you meet the eligibility criteria). For a list of Public Trustees across Australian states and territories, visit the **Moneysmart** website at **moneysmart.gov.au/manage-your-money-in-retirement/get-help-in-retirement/wills-and-powers-of-attorney**

Laws regarding wills differ across states and territories, so it's important to understand the regulations affecting you.

When creating a will, it's essential to know what you own outright and what you may share ownership of with others. For instance, with property, you might have sole ownership, be joint tenants (where ownership automatically goes to the other party upon your death), or tenants in common (where you can leave your share to anyone you choose).

Wills don't expire, but they should be updated as your life circumstances change.

Think about who to choose as your executor. Their role is to:

- gather all your assets after you pass away
- pay off any outstanding debts, including funeral expenses
- distribute the remaining estate to the beneficiaries named in your will.

If you die without a will, you are considered to have died "intestate". As there is no executor, someone will need to make an application to the court to be appointed an Administrator so that your estate can be appropriately distributed. There are laws which determine who will benefit from the estate if you don't leave a will.

UNDERSTAND YOUR SUPERANNUATION

By law, employers must contribute a set percentage of your salary into a superannuation fund. This money is intended to fund your retirement and can't typically be accessed until you reach your "preservation age", which is usually between 55 and 60 years old, depending on when you were born.

With a younger onset dementia diagnosis, you may wish to access your superannuation funds early. Be aware though, that taking out your superannuation early could affect your:

- income protection, life insurance and total and permanent disability cover
- family tax benefit payments
- child support payments.

Before you apply, learn how this decision could affect your situation and seek independent financial advice. Services Australia has a Financial Information Service that offers free advice: **servicesaustralia.gov.au/financial-information-service**

There are several circumstances in which a person with dementia can access the money in their superannuation fund early. These include:

Compassionate grounds

If you want to apply for release of your superannuation on compassionate grounds, you must contact the **Australian Taxation Office** (ATO).

The terms for compassionate grounds are defined in the *Superannuation Industry (Supervision) Regulations 1994* and available on the ATO website: **ato.gov.au/individuals-and-families/super-for-individuals-and-families/super/withdrawing-and-using-your-super/early-access-to-super/access-on-compassionate-grounds**

This website also provides information about things to consider, eligibility criteria, how to apply and what to expect.

Severe financial hardship

In some situations, like severe financial hardship, you may be allowed to access your superannuation.

This is handled directly by your superannuation fund which will assess your application based on the criteria provided in the *Superannuation Industry (Supervision) Regulations 1994*.

For more information about early access to your superannuation based on severe financial hardship, visit the Services Australia website: **servicesaustralia.gov.au/who-can-access-their-superannuation-early?context=21971#sevfinhardship**

Note: Accessing your superannuation early could impact any payments you receive or the taxes you owe. Additionally, your superannuation fund may charge a fee for early withdrawal.

Nominating a beneficiary

When setting up your superannuation, you can nominate a beneficiary to receive your funds if you pass away. However, unless it's a binding nomination, your superannuation fund's trustees decide who gets the money, which could be one of your dependants, or it could be paid to your estate.

A binding death benefit nomination ensures your superannuation goes to your chosen beneficiary. Check if your fund allows this, as it typically needs to be renewed every three years. If you're unable to renew due to issues with capacity, some funds allow an Enduring Power of Attorney (EPoA) to renew it, so it's important to confirm this with your fund.

Under a non-binding nomination, you nominate a beneficiary, but the final decision is up to your superannuation fund provider.

If you're receiving a super pension, you can also set up a reversionary pension, allowing someone to continue receiving the pension after your death. Always consult your superannuation fund and seek independent financial advice.

Accessing insurance through your superannuation

It's important to review the insurance policies you have, including any that are part of your superannuation.

Most superannuation funds include default life insurance and Total Permanent Disability (TPD) cover. Some superannuation accounts may also include additional benefits such as death, terminal illness and income support, so check with your fund.

Since the rules for TPD and terminal illness cover vary between superannuation funds, check with your fund provider and familiarise yourself with their product disclosure statement.

Terminal illness

Terminal illness or death cover gives a lump sum payment to your dependants or the executor of your estate if you pass away. Death cover is typically available from age 15 to 70 and can be paid out early if you're diagnosed with a terminal illness.

With a terminal illness diagnosis, you can access your superannuation at any time, tax-free as a lump sum. However, any remaining balance after the certification period may be taxed upon withdrawal.

Total and permanent disability (TPD)

TPD cover provides a lump sum if you're totally and permanently disabled, replacing the income you would have earned. It's available from ages 15 to 65.

Since the definition of TPD varies between superannuation funds, check your fund's product disclosure statement to understand the details. To claim, you must meet the specific requirements of your superannuation fund's rules and insurance policy.

Note: If your superannuation fund doesn't allow early access for terminal illness, you may be able to transfer to one that does. Before deciding, seek independent financial advice.

Superannuation complaints

If your claim for TPD or terminal illness is rejected by your superannuation provider, you are able to ask the provider to review their decision, or you can contact the **Australian Financial Complaints Authority** (AFCA) to make a complaint by calling **1800 931 678** or submit an online complaint at **afca.org.au/about-afca/contact-us**

Other types of insurance

Here are some additional types of insurance policies you may have.

Personal insurance policies:

- **income protection insurance** provides monthly payments to replace a portion of income if you're unable to work due to illness or injury, including dementia
- **life insurance** provides a lump sum payment to your beneficiaries in the event of your death, ensuring financial support for family members or dependents

- **trauma insurance** pays a lump sum if you're diagnosed with a serious condition covered by the policy, which may include dementia
- **critical illness insurance** offers a lump sum payment if diagnosed with a specified critical illness. Some policies may include severe cognitive impairments like dementia.

Government support and entitlements

You may be eligible for government benefits and support. Centrelink can provide you with advice about what to claim for.

One of these supports is the National Disability Insurance Scheme (NDIS). See Section 5 The National Disability Insurance Scheme and younger onset dementia for more information on how the NDIS might support you.

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

PART 2

Section 4

Living well

Living well

Aside from the legal and financial decisions you need to make, there are lots of other things you can do to live as well as possible with younger onset dementia. Your ability to perform daily routines and activities might change over time, but that doesn't mean you need to stop doing the things you enjoy. You just might have to do them differently.

Reducing stress

A younger onset dementia diagnosis is stressful so finding ways to minimise stress is important to your wellbeing.

Here are some ways you might manage stress:

- Identify sources of high stress for you. Plan ways of removing these or put strategies in place to minimise their impact
- Establish clear boundaries. Let others know what you are willing to tolerate and what you are not
- Simplify your daily routine
- Break tasks into smaller steps. Give yourself plenty of time to do things at your own pace
- Ask others to give you enough time. Ask for help with difficult tasks or schedule them for when you feel more able
- If you are feeling overwhelmed, take a break in a quiet place to regroup
- 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 more difficult to express yourself. It can also become difficult to understand what others are saying.

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.

COMMUNICATION TACTICS

Some things you can try might be to:

- slow down and take more time to speak
- find a quiet place to talk where there is minimal distraction or background noise
- let people know when you are having difficulty speaking or understanding
- ask family and friends to prompt, remind or help you if you are struggling to find a word or are 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 your dementia symptoms progress. If this happens, you could:

- consider using interpreting technology
- become familiar with support services that cater to cultural diversity
- find support workers who speak your first and second languages
- encourage family and friends to learn the basics of your first language.

It is important that your doctor understands your first language and cultural heritage. You could also consider ways to communicate non-verbally, such as using:

- visual cues; for example, using labels and signs
- body language and gestures to help make yourself understood
- communication cards — there are free bilingual communication cards available online from the Centre for Cultural Diversity in Ageing: **culturaldiversity.com.au/communication-cards**

Dealing with isolation and loneliness

People living with dementia can sometimes feel lonely and isolated from their community, friends and family. It is important to establish a routine that keeps you connected.

You can also be supported to meet other people who are living with younger onset dementia, who understand what you are going through. Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline** to find out if there are support groups in your area.

Navigating changed relationships

Symptoms of dementia can affect your relationships. You may experience a loss of independence when other people perform tasks with you, or on your behalf. Family members may start having conversations as if you are not in the room or make decisions and implement plans without your input.

You might feel angry or resentful at the change in dynamic with someone you are close to. You might also feel guilty relying on family and friends more than usual.

Talking to others and sharing your feelings may help you feel more connected to the people around you. It can also help your family and friends to understand how you are feeling and why the way they act or respond is important.

KEEPING RELATIONSHIPS POSITIVE

Here are some ways you can maintain positive relationships:

- Talk to family, friends and others about the support you want and how they can most appropriately 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 condition 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, know that they are frustrated with the condition, not you.

INTIMACY AND SEXUALITY

Dementia can affect sexual feelings and behaviour over time. You may feel uncertain, frustrated, or experience 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 the future, and let your partner 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 could include non-sexual touching or sharing special memories. Work with your partner to find something that satisfies you both.

Consent

Consent is important, whether you are being intimate with a new partner or have been married or together for a long time. The law states that sexual activity must never be initiated without clear consent from both partners.

A diagnosis of dementia does not mean that you automatically lose the capacity to consent to sex; however, there may be some times when you feel clearer about your feelings than others.

You can find some helpful resources and information at the **Dementia Australia Library**. Visit **dementia.org.au/library**

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 you or your partner physical or emotional distress.

Living at home

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

CREATING A DEMENTIA-FRIENDLY HOME

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

One of the ways you can do this is to improve lighting by:

- replacing current globes with brighter ones
- placing chairs and couches by sunlit windows
- installing sensor lighting to reduce the risk of falls at night-time.

Ensure there is sufficient space to move around by reducing clutter and removing potential trip hazards, such as loose electrical cords or rugs.

Display personal items and photos that help you feel grounded and safe.

You might accidentally lock yourself out of your home. Leave a set of house keys with a neighbour you trust, or fit a key safe outside your property with a spare key.

More tips for a dementia-friendly home

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

For more information about the range of services offered by Dementia Australia to help you continue living at home, call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline**

Planning for home-care support

Some people with younger onset dementia find their self-care, personal hygiene and household chores become more difficult to keep on top of. These changes can also increase your risk of malnutrition and dehydration.

Here are some things you can try:

- Organise to have your groceries delivered or arrange home-delivered meals
- Consider hiring a home maintenance service to help with windows and gutter-cleaning, smoke detector checks, leaking taps and light bulb changes
- Arrange for somebody to help with house cleaning, meals, transport and daily chores
- Arrange for help paying bills
- Set up a system for medication reminders, such as a Webster-pak®, arranged through your local pharmacy
- Explore options for how you may get around when dementia impacts your ability to drive
- Consider using public transport, taxis, ride share and community transport, as well as lifts from family and friends.

STAYING SAFE AT HOME

Some types of dementia can impact your visual or spatial perception. However, there are assistive technologies and products that can improve your safety.

These tools range from high-tech solutions to simple equipment. You might consider:

- personal alarms and timers that switch off electrical items
- calendar clocks
- touch lamps and night-lights
- handrails and safety ramps.

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

Here are some other ways to keep safe at home:

- 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. For more information, contact the National Equipment Database on **1300 885 886** or visit **askned.com.au**
- 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

- Talk to an occupational therapist. An occupational therapist can advise on ways to make your house safer through assistive technology and home modifications. An occupational therapist can be accessed through a referral from your doctor, **My Aged Care** (visit **myagedcare.gov.au**) or the **National Disability Insurance Scheme** (visit **ndis.gov.au**).

MINIMISING YOUR RISK OF FALLING

Usually, people with younger onset dementia are fit and strong. But depending on the type of dementia you have, you may come to experience changes in your balance or depth perception, which can lead to a higher risk of falling over and injuring yourself. Falling can be particularly dangerous if there is nobody around to help you.

You can reduce the risk of falling by:

- making sure your house is well lit
- removing trip hazards such as rugs
- fitting handrails on stairs or in the bathroom
- installing a personal alarm system
- seeking expert support from a physiotherapist or exercise physiologist to maintain or enhance your strength and mobility.

LIVING ALONE

If you are diagnosed with younger onset dementia and live by yourself, plan for when your dementia progresses and you can't manage on your own. Build a relationship with your doctor, healthcare professionals and service providers. Identify friends and family members who can play a supporting role.

Travelling safely

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

ENJOYING YOUR HOLIDAYS

Here are some tips to help you enjoy your holiday:

- Pick travel companions who understand your condition They can help with logistics
- Select travel options suited to your needs and ability
- Allow plenty of time for rest. Don't try to do too much
- Tell hotel, flight or cruise staff about your specific needs.

STAYING SAFE ON HOLIDAYS

Here are some tips to help you stay safe on your holiday:

- Plan trips that have 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
- Buy travel insurance if you have booked flights or hotels. Discuss your travel plans and health with the insurance company before taking out 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
- If you're travelling overseas, subscribe to **smartraveller.gov.au**

Staying healthy and active

Staying active and social can help you maintain your skills and memory.

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

LOOK AFTER YOUR HEALTH

With all the changes that are occurring, it can be difficult to keep on top of your regular health checks and health screens, such as pap smears, mammograms and prostate checks. Keep track of when these are due and set reminders to attend these appointments.

Not all the symptoms you might experience are caused by your dementia. Tell your doctor how you are feeling and what you are experiencing.

LOOK AFTER YOUR HEART

Your brain needs a healthy heart and blood vessels to keep it supplied with oxygen and nutrients. There are many ways to keep your heart healthy.

- If you smoke, try to stop. To help you quit, call **Quitline** on **13 78 48**
- Arrange regular check-ups with 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 good, quality sleep.

MAINTAIN FITNESS AND STRENGTH

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, don't 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
- participating in a sport
- attending a gym
- exercise classes.

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:

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

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) may be taken to support brain function. Speak to your doctor about your options.

You may be able to arrange for meal preparation assistance, or have healthy meals delivered to your home, through support from the NDIS.

LOOK AFTER YOUR BRAIN

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

You could try:

- reading
- singing
- dancing
- playing games or doing quizzes
- talking with others
- enrolling in a course
- doing crossword puzzles
- learning new skills.

LOOK AFTER YOUR HEARING

Get regular hearing tests and wear your hearing aids if needed.

MAINTAIN SOCIAL CONNECTIONS

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

You could:

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

Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline** to find groups in your local area or learn how to start one if there are none.


ndis
How the NDIS can help

Section 5

National Disability Insurance Scheme and younger onset dementia

National Disability Insurance Scheme and younger onset dementia

The National Disability Insurance Scheme (NDIS) is a scheme run by the National Disability Insurance Agency (NDIA). The NDIS provides support for people under 65 with a permanent and significant disability, including those with younger onset dementia. This means individuals diagnosed with dementia before the age of 65 may be eligible for NDIS funding to access support services and programs.

People assessed as eligible to access the NDIS are called "participants" and receive funding through an individualised plan based on their needs. This funding can be used to pay for supports and services to help in daily life, to help you coordinate your services, connect with community and to achieve goals.

People living with younger onset dementia who need help with everyday tasks may be eligible to receive NDIS support, for example to:

- complete difficult day-to-day tasks
- engage in hobbies or activities
- access the community
- get to appointments
- maintain personal care activities
- remain active and build on their strengths
- stay safe and independent at home
- maintain abilities or find new ways to do things

- find and plan supports that are right for them, such as through a support coordinator.

NDIS support is determined if a person can show evidence and demonstrate their need. Supports are only funded if they relate directly to the impact of approved disability (in this case, younger onset dementia). Some people have more than one disability and may be able to access additional support.

Applying to access the NDIS

To qualify as an NDIS participant, you must:

- be under 65 at the time of application
- be an Australian citizen or permanent resident
- live in Australia
- have a permanent condition that causes lifelong disability and be able to provide evidence of this (such as a confirmed diagnosis from your specialist).

To apply for NDIS access, you can call the **NDIS Helpline** on **1800 800 110**. They will talk to you about the requirements and refer you to a Local Area Coordinator who will meet you and discuss your needs. The Local Area Coordinator will explain what is needed to support your NDIS application. They can also submit an NDIS application on your behalf and introduce you to supports outside the NDIS.

Dementia Australia can help you understand the NDIS and what supports may be available to you. Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline**

NDIS Terminology

Here are some specific terms you may hear in relation the NDIS:

Participant	The person the plan is for.
NDIS plan	An individual NDIS plan with information about the person, their goals, needs and supports that the NDIS will fund.
Funded supports	Supports paid by the NDIS through a plan.
Provider	Someone who provides supports or services to help pursue goals in a plan.
Support Coordinator	A type of provider who connects you to appropriate service providers and explains how to use the NDIS-funded supports included in your plan.
Community Connections meeting	An initial meeting with your local area coordinator to discuss your goals and needs, and link you to community supports.
Local Area Coordinator (LAC)	Someone who works for NDIS partner organisations, and helps you understand and access NDIS supports.

Key tips to get the most out of the NDIS

- You will need detailed reports from your specialist, doctor or allied health professional to prove eligibility for the NDIS. This could involve evidence of your diagnosis and a detailed report of how younger onset dementia impacts your day-to-day functioning
- Have a list of questions you want to ask the NDIS during the planning stages and have someone you trust to support you through the process
- Your NDIS plan is customised to your needs and choices. Clearly express your needs and be honest and realistic about what you can and cannot do
- For more information, call the **NDIS** on **1800 800 110** or visit **ndis.gov.au**
- For more Dementia Australia information about younger onset dementia and how the NDIS might be able to help, call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/ndis**

Section 6

Dementia Australia services

Dementia Australia services

Dementia Australia offers services to support:

- people living with all forms of dementia, including younger onset dementia
- people concerned about changes to memory, thinking or behaviour
- families and carers.

Our highly experienced and qualified dementia advisors provide information, support and education services to help you:

- understand your diagnosis
- learn more about your type of dementia
- adapt to changes in memory, thinking, behaviour and abilities
- plan for the future
- live a good quality of life.

We understand that every person and their experience of dementia is unique, and we take a very personalised approach in how we can support you.

Our dementia specialist team can talk with you about how we can best support you and your unique needs. You can participate in programs and services:

- as an individual
- as a carer
- as a couple or duo (your partner, friend or carer)
- as a family.

Services can be accessed in a variety of ways, including:

- face-to-face
- telephone
- online.

The best way to learn about our services and connect to them is to call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline**

Information services

DEMENTIA AUSTRALIA WEBSITE

Visit **dementia.org.au** for:

- information about Dementia Australia: who we are and what we do
- information about younger onset dementia: signs, symptoms, adapting to change and living well with dementia
- information, advice, commonsense approaches and practical strategies on issues commonly raised about younger onset dementia
- videos and links to apps on a range of topics about dementia
- information about education programs and information sessions
- ways to get involved in advocacy, fundraising and research.

DEMENTIA AUSTRALIA LIBRARY

The library service provides access to a comprehensive collection of print and digital resources about all forms of dementia, including younger onset dementia.

You can borrow books, articles, audio resources, ebooks and DVDs. Loaned items can be posted to you on request. Visit **dementia.org.au/library**

Support services

NATIONAL DEMENTIA HELPLINE

The National Dementia Helpline is a free telephone service available to anyone, 24 hours a day, seven days a week.

You can talk confidentially to dementia specialists about:

- cognitive changes and seeking a diagnosis
- understanding your diagnosis and the next steps to take
- the emotional impacts of younger onset dementia
- adapting to changes in memory, thinking, behaviour and physical abilities
- maintaining daily wellbeing and independence
- ways to connect with support programs and services to support you and your family.

Call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline**

If you need an interpreter, call the **Translating and Interpreting Service** on **131 450** or visit **tisnational.gov.au**

INDIVIDUAL SUPPORT

A specialised Dementia Australia team member will work with you, your family and your support network to understand your situation, offering information and support tailored to you.

Individual sessions will help you increase your understanding of dementia, plan support services and networks, develop personal and lifestyle strategies to help you live well and prepare and plan for any changes. You can also get information and support about the National Disability Insurance Scheme (NDIS).

INDIVIDUAL AND FAMILY SUPPORT COUNSELLING

A diagnosis of younger onset dementia can feel confronting and overwhelming. Counselling services for you and your family can support you in maintaining your emotional wellbeing by talking with a professional.

A counsellor can help you:

- work through feelings about your type of dementia and its symptoms
- share your emotions in private, with a partner or your family
- talk about changes to memory, thinking and behaviour and its impacts on family, culture and living arrangements
- plan for the future, by setting goals and seeking referrals for support.

FAMILY ENGAGEMENT COUNSELLING

This form of counselling is specifically designed for people living with younger onset dementia and their families. Families can access this type of support when experiencing concerns such as family conflict or difficulties with children adjusting to changes.

SUPPORT GROUPS

Dementia Australia coordinates support groups to connect people of similar ages and locations so that they can share experiences of living with dementia or supporting someone living with dementia. People are also supported to start their own support groups if there is not one in their area. Contact the National Dementia Helpline to find out what is available locally.

THE CONNECTING PEERS PROGRAM

One-to-one peer support is available to people living with younger onset dementia and those who support them.

This program pairs you with someone who is impacted in a similar way, to share experiences and learn from each other.

Education

Dementia Australia offers a broad range of information and education sessions, available face-to-face, online, or via pre-recorded webinars, to help build knowledge to support your wellbeing.

Our education services can help you:

- understand symptoms of younger onset dementia

- adapt your home environment to be dementia-friendly and dementia-enabling
- learn ways to respond to changes in memory, thinking, behaviour and communication
- identify supports and services to help you maintain independence and general wellbeing
- develop strategies to manage changes in abilities that affect daily life.

Dementia Advocates

Become a voice for people living with dementia. Dementia Advocates promote awareness and advise on decisions that impact services, supports and funding resources for people of all ages living with dementia. These include:

- government
- policy decisions
- legislation considerations
- supports and services offered.

There are several programs where people living with dementia of all ages are proactively involved in improving society's response to dementia. These include the Dementia-Friendly Communities projects, dementia alliances in local communities and Dementia Alliance International. For more information about these programs, call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au**

Section 7

Other supports and services

Other support and services

Financial support

The National Debt Helpline provides information and advice on how to get your finances back on track. It offers access to free financial counselling services to anyone experiencing financial issues. Call the **National Debt Helpline** on **1800 007 007** or visit **ndh.org.au**

Centrelink is a government agency where you may be eligible for financial assistance for living with a disability. Your support person may also be eligible for a carer's payment. Each payment is different and has different eligibility criteria. You can access Centrelink's financial information service for support with financial planning and management. Visit **servicesaustralia.gov.au/centrelink**

Legal aid

Agencies that offer legal information and advice are listed on the Australian Government Attorney-General's Department website: **ag.gov.au/legal-system/legal-assistance-services**

Find your state or territory legal aid commission at **nationallegalaid.org**

Help for financial or other abuse

National Legal Aid's Family Violence Law Help website offers information about domestic and family violence and the law in Australia. Visit **familyviolencelaw.gov.au** or call **1800 737 732**, 24 hours a day.

1800RESPECT provides confidential information, counselling and support on matters of domestic, family or sexual violence. Call **1800 737 732** or visit the website **1800respect.org.au**

Safe Steps provides information and support specifically for people with disabilities. Visit the Safe Steps website **safesteps.org.au/our-services/disability-support** or call **1800 015 188**, 24 hours a day.

Djirra is an organisation supporting Aboriginal and Torres Strait Islander people who are experiencing or have experienced family violence. It provides both legal and non-legal support. Visit **djirra.org.au/what-we-do/legal-services**

Guardian and administrator support

In most states and territories, a Guardianship Board or Tribunal can appoint a guardian or administrator if you're unable to make decisions. If there are issues managing your affairs, someone may apply to have one appointed to protect your interests. Visit the Australian Guardianship and Administration Council website at **agac.org.au**

Behaviour support

Dementia Support Australia provides specialised dementia support concerning changes in behaviour and other services. Visit **dementia.com.au**

Companion support

If you need support to attend events or activities, you might be eligible for a Companion Card, providing a second ticket for your companion at no charge. To apply, visit **dss.gov.au/supporting-carers/companion-card**

Transport services

A healthcare card or a companion card allows you to travel on public transport at a reduced price.

You may also be eligible for an Australian Disability Parking permit or taxi subsidies if you are unable to use public transport. Visit **dss.gov.au/disability-support-services/disability-parking-scheme**

Family support services

Dementia can bring extra challenges for families living with younger onset dementia, particularly those with dependent children.

Family engagement counselling	Delivered by Dementia Australia to support people living with younger onset dementia and their families on topics including family conflict, supporting children, decision-making and relationship adjustments. Contact the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline** for more information.
Relationships Australia	Provides relationship support services for individuals, families and communities, including counselling, groups and education. Visit **relationships.org.au**

Support for non-parent carers of children	Sometimes other family members take on the role of caring for children. Grandparents, legal guardians and other non-parent full-time carers of children are eligible for payments and services including the Grandparent Adviser Line, Child Care Subsidy, Family Tax Benefit and others. The Services Australia website has more information. Visit **servicesaustralia.gov.au/what-you-need-to-know-about-your-child-support-assessment?context=21911**
Parent helplines	Each state and territory provides telephone (and sometimes online) counselling and advice for parents, guardians and carers of children up to 18, to support family relationships and the wellbeing of children. Most are only the cost of a local call from anywhere within the state or territory. These services can help with support such as advice on how to talk to children and teenagers about challenging topics (such as a diagnosis of dementia and what it means for your family) in an age-appropriate way. Search 'parent helplines' online to find one that suits you.

Support for children

There are lots of services and supports available for children and young people.

Kids Helpline is a telephone and online counselling service for five to 25 year-olds, which provides support for any issue or challenge. Call **1800 551 800** or visit **kidshelpline.com.au**

Headspace provides webchat, email and online counselling support for 12- to 25-year-olds worried about their mental health or experiencing stress or isolation. Visit **headspace.org.au**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Section 8

Working with health professionals

Working with health professionals

Getting a younger onset dementia diagnosis can take a long time and may involve lots of different health professionals. Once you have been diagnosed, you may still need to see a team of health professionals who contribute to your care. Your doctor will be a key person, but depending on your needs, you may also see specialists and allied health professionals such as occupational therapists.

If you are living with younger onset dementia, look for health professionals who:

- will be a source of information and advice
- listen to you and your opinions
- explain things in a way you understand
- take the time to answer your questions
- help you feel comfortable.

Tips for managing your appointments

- Go prepared with questions
- Write things down and ask for information to take home with you
- Seek clarification
- Make appointments at the best time of day for you
- Take someone with you
- Request longer appointments
- Keep a log of any changes you, your family or friends have noticed.

Working with medical specialists

During the different stages of younger onset dementia, you may be treated by different medical professionals.

Each will be relevant to different symptoms of the condition. Your doctor may refer you to one or more of the following specialists:

Geriatrician	A specialist with comprehensive knowledge of dementia. Geriatricians take a holistic approach in helping you to manage your health needs in the context of dementia.
Neurologist	A specialist in diagnosing and treating people with abnormalities of the brain and central nervous system.
Neuropsychiatrist	A specialist in the behavioural and psychological effects of neurological diseases or injury to the brain.
Psychiatrist	A specialist in diagnosing, treating and preventing mental illness and emotional problems.
Neuropsychologist	A specialist who can help with early or differential diagnoses of dementia and offer strategies to support changed behaviours due to brain changes.

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 can 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 allied health services as part of your treatment plan. You should always discuss your changing needs with your doctor. If you have private health cover, contact your insurer to find out what health services are included.

You may also engage with a range of other healthcare professionals:

Community nurse	Provides health assessments, continence care, medication and wound management, or palliative care in the home.
Counsellor, psychologist or dementia consultant	Helps you to adjust to change and to recognise your feelings and emotions.
Dietitian	Provides advice for maintaining a healthy diet.

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.
Speech pathologist	Helps you find ways to communicate with others if speaking has become difficult. Will also perform swallowing assessments when required.

Understanding your treatment options

While there is no cure for dementia, there are some treatment options that may help alleviate some of the symptoms or slow the rate of progression, depending on your type of younger onset dementia.

Talk to your doctor about your specific circumstances and what medication treatments may be available to you. Your doctor may prescribe medications to manage other symptoms, including depression, anxiety or poor sleep.

Questions to ask your doctor about medications

- 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?

Treating depression and anxiety

People with younger onset dementia may experience depression or anxiety. Seek help if you are feeling depressed or anxious. You can discuss treatment options with your doctor.

MEDICATION TREATMENTS

Prescription medications are one approach to treating depression and anxiety. Antidepressant medications 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 with, but these usually lessen after a week or two. It is important to keep your doctor informed about how you are feeling and how medications are affecting you. Your doctor can then help you find a medication and dosage that works best for you.

NON-MEDICATION TREATMENTS

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

Non-medication treatments include:

- keeping active: walking, jogging or more energetic exercises
- talk therapies, like counselling
- reminiscence activities, where you recall past events
- mindfulness activities, like meditation
- 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:

- engaging in enjoyable activities
- maintaining a healthy diet
- reducing alcohol and caffeine.

Lifestyle factors

Keeping the body and mind active are very important in helping you manage the impact of younger onset dementia.

Engaging in everyday activities, interests and social groups can be satisfying and fulfilling. Exercise and eating well can optimise your physical health, improve your mood 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 "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. It is recommended that you discuss the use of complementary therapies with your doctor or specialist before you start using them.

Some complementary therapies may not interact well with your current medications or could have an impact on other health issues you experience.

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 therapies, such as reiki and Therapeutic Touch
- alternative medical systems, such as traditional Chinese medicine (including acupuncture and herbal medicine), Ayurvedic medicine, homeopathy and naturopathy.

Section 9

Later stages of dementia

Later stages of dementia

How quickly younger onset dementia progresses varies from person to person, depending on the type of dementia they have and any other health conditions. If you have younger onset dementia, you will require increasing support as your condition progresses.

Understanding that dementia is a terminal condition can be very confronting. But talking about what you want in the later stages can be helpful for you and for your family.

It may be that you want to stay at home with additional supports.

You may also decide that you want to move to residential care (also called supported accommodation) when it is too challenging to remain in your home.

Residential care

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

Early planning for future residential care means you can make your wishes known before your dementia progresses. You may wish to help select somewhere to move to, so that when the time comes, your accommodation will feel more familiar and comfortable.

It can be hard to know when the right time to move to residential care is. 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.

At some stage, you may not realise you need additional care and support. Be guided by the people who you trust: your carers, family members or health professionals.

Contact the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au/helpline** if you want more information, support or advice on how to plan for the later stages of dementia.

Palliative care

Palliative care is specialised care and support for people with a life-limiting condition.

It focuses on planning for and then relieving a person's symptoms in the advanced stages of their condition. It can also provide emotional and practical support to family members and friends. People who deliver palliative care include:

- general practitioners (GPs)
- 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.

When the time is right, your palliative care will need to be organised by your family members, carer or health professional. This is why it is important that you have appointed an appropriate Enduring Power of Attorney or Enduring Guardian, and that you have actively been involved in advance care planning. See Section 3, 'Planning your finances and future' for more information on Advance Care Planning.

Visit the Palliative Care Australia website at **palliativecare.org.au** for state and territory office contact details, and further information.

SUPPORTING YOUR NEEDS IN THE LATER STAGES

In the advanced stages of dementia, palliative care can provide comfort and quality end of life support. This will be unique to you, but it could include:

- changing your body positioning
- taking care of your mouth and teeth
- assisting with difficulties in breathing
- taking care of your skin
- helping you with bowel management

- helping you with mobilisation
- making sure you have the spiritual and cultural care you want
- using music and aromatherapy
- using massage
- managing your pain.

MANAGING SYMPTOMS AND PAIN

How you manage your symptoms depends on the stage of your dementia and whether you have other medical conditions. Symptom management may not be easy to talk about, but it is important to discuss your wishes with your family or medical team so that everyone knows what you want. Ask yourself:

- How useful will the treatment be?
- What choice will promote the best comfort for me?
- Do I want life-prolonging services or interventions (for example, antibiotics, breathing support and resuscitation)?

Pain management is an important aspect of good quality care. There should be an ongoing approach to recording, assessing and managing your pain.

SUPPORTING YOUR DIET

Advanced dementia can lead to a reduced desire to eat. It can also make eating and swallowing difficult. Think about the point at which you may not be able to eat. What kind of nutritional support do you want?


lifeview

PART 3

Section 10

Support and information for carers and family members

Support and information for carers and family members

You may find yourself gradually taking on the role of "carer" to a person with younger onset dementia. This can often happen without making a conscious decision and you may not think of yourself as a carer.

The timing and nature of this change in role will depend on the person diagnosed with younger onset dementia and how they manage their condition. They may try to remain independent for as long as possible, or they might ask or rely on you to provide support in managing their symptoms. They might not be aware of the support they need.

As a family member or friend of someone living with younger onset dementia, you might:

- help the person with daily activities, like household chores, shopping, preparing meals, managing finances, appointments and taking medications
- help the person with physical tasks, like getting in and out of bed or walking
- provide personal care, like bathing, dressing and going to the toilet
- work with healthcare professionals and support agencies to meet the person's physical, psychological and social needs
- support the person when they experience changes to their mood, behaviour or psychological symptoms associated with dementia

- help the person stay involved with the hobbies, activities and interests they enjoyed before their diagnosis.

Whether you are a partner, child, relative or friend, if someone close to you is living with younger onset dementia, your relationship with them will change.

Look after your own health and wellbeing as much as possible and turn to others for support when you need it. This will not only ensure you provide the best care for the person with dementia but also for yourself.

Getting emotional support

Caring for someone with dementia can be rewarding. It can also be challenging, stressful, life-changing and at times, overwhelming.

You may have many different feelings over time, especially because the nature of your relationship with the person you support will change too.

There is no simple way to deal with these feelings, but it may help to know that the complex and varied emotions you feel are completely normal. You may want to share how you feel with a professional, a friend or family member, or someone at a carer support group.

Getting practical support

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

Friends and family	Try to involve family members and share responsibilities. This will take some of the pressure off you.
Community support	Connect with neighbours or groups you already have an association with. People may be happy to offer practical support, such as shopping, cooking a meal, or spending time with the person living with dementia.
Employer benefits	If you work, ask about carer's leave or other flexible working options.
Centrelink	Find out if you are eligible for any government benefits. Visit **servicesaustralia.gov.au/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 support specialists. Call **1800 100 500**.

Carer Gateway	Get practical information and resources specifically for carers. Visit **carergateway.gov.au** or call **1800 422 737**.
Carers Australia	A national service that works with all carers regardless of age or circumstances and supports carers through advocacy, policy and services. Visit **carersaustralia.com.au**

Support for young carers

Young carers are children and young people aged under 25 who care for a relative or friend. Many young carers assume adult level responsibility, and this can interfere with their education, training, employment and social development.

Here are some of the services that offer support for young carers:

Young Carers Network	Can help you find out about support services, access resources and share personal stories and opinions. Also offers annual one-off payments to help young carers (12-25) stay engaged in education. Visit **youngcarersnetwork.com.au**
Wellways	Provides information and advice for young carers. Visit **wellways.org/service-category/families-and-carers**

Carer Gateway	Offers a range of information, advice, carers support, as well as financial support for young carers. Visit **carergateway.gov.au/services-and-support** or call **1800 422 737**. You can request a call back.

Managing finances

Managing your finances can be complicated, and it can be even more so if you are involved in managing the finances of someone living with younger onset dementia.

The table below highlights some common challenges you might experience and gives recommended actions.

Challenge	Strategies
Stigma or discrimination that is directed to a person with dementia	Ask if there are specialised support teams to handle dementia-related issues. Advocate for staff training if needed.
Shifting to digital banking or other online services that can be accessed by you as well as the person with dementia	Ensure the person living with dementia feels in control of their finances. Help them manage digital banking or other online services, or request in-branch services.

Challenge	Strategies
Communication and cultural barriers	Help staff understand communication barriers the person living with dementia faces and ask for clear, respectful communication. Seek support for people living with dementia who need interpreter assistance.
Risk of financial abuse or exploitation	Talk to bank or financial institution staff about setting up automatic options to manage money safely, like setting withdrawal limits or arranging direct debits. Confirm the bank or financial institution has procedures to handle suspicious transactions, while ensuring customer privacy is protected.
Difficulties with power of attorney processes	Work to simplify setting up or recognising power of attorney, to ensure you can manage the person's finances when needed. Keep power of attorney documents in a secure but accessible place (like a safe or folder) and consider making digital copies. Ensure trusted people know where these are for quick access when needed.

MANAGING A BUDGET

Caring for someone with younger onset dementia also means understanding the impact on the person's finances and your own. Consider the following for budget management:

Reduced income	Plan for potential loss of income because: + the person living with dementia reduces their work hours or can no longer work + you may need to reduce your work hours to support them.
Increased care costs	Plan for medical, care services and transport expenses.
Insurance and benefits	Review the different types of benefits available, including insurance policies and government supports like NDIS.
Debts and bills	To minimise financial stress, manage debts and ensure bills are paid on time.
Plan for the future	Budget for unexpected and future expenses including support services or assisted living.

Section 12, 'Useful tools: worksheets and checklists' has a series of worksheets for tracking income, expenses, assets and documents.

PROTECTING AGAINST FINANCIAL ABUSE, EXPLOITATION AND SCAMS

Building a relationship with your bank or financial institution is important.

It can be hard for staff to recognise if someone has dementia and is challenged by managing their finances. As a carer, you may identify potential misuse of someone's accounts, financial abuse or exploitation faster than a financial institution.

Privacy laws can complicate matters, including limiting the ability to access accounts if legal financial delegations are not in place. Having a good relationship with the bank or financial institution makes it easier to spot unusual activity or potential financial abuse. It also allows staff to be more flexible and supportive, helping you navigate privacy laws and manage the person's finances more effectively.

Because their judgement may be impaired, a person with dementia is more vulnerable to scams. The Australian Government website **ScamWatch** provides information on scams, how to report them and protect someone in your care, or yourself. Visit **scamwatch.gov.au**.

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.

Here are some strategies to try:

- Make sure you try to eat a balanced diet, get enough sleep and make time for regular exercise and physical activity

- See your doctor regularly about your health
- If you need 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
- 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
- Take time to connect with how you are feeling and think about what you might need. You might make a call to a friend or enjoy a cup of tea or coffee
- Find out about social support 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.

Tips and advice to support a person with younger onset 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 them.

Learn to be creative and flexible with your caring strategies. Identify your strengths and the strengths of the person with younger onset dementia. This will help you see where you may need extra support. Always try to see the person and not just their dementia.

With time, dementia will affect a person's ability to carry out everyday tasks. Try to support and encourage the person you support to do as much as they can for themselves. When you help, 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 can't
- 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 want
- Be sensitive and offer encouragement
- Do things that are meaningful to both of you
- Include the person in conversations and activities as much as possible.

NUTRITION

Maintaining good nutrition for the person you care for is important, especially as their condition impacts their relationship with food. The person with dementia may:

- experience a loss of appetite
- forget how to chew or swallow
- not recognise food or drink
- develop an insatiable appetite
- develop a craving for sweets
- suffer from a dry mouth or mouth discomfort.

Tips to support good nutrition

- Stock up on healthy snacks that do not need preparation or cooking
- Try not to use patterned table settings or busy tablecloths. Keep to plain colours
- Allow time for the person to respond to food. Sometimes, showing them what to do can help them get started
- Serve only one plate of food at a time. Don't overload the plate
- Consider leaving food out so the person can snack through the day instead of eating at set mealtimes
- If they have swallowing issues, visit a speech therapist for appropriate strategies

+ Visit a dietitian 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 when speaking with them. Consider the impact of any distractions, such as noise, and try to eliminate noise if possible (for example, turn off televisions or radios). Go to cafes and other venues at quieter times
+ Consider using gestures, facial expressions and touch
+ Speak clearly and think about the words you use. If you are not understood, use simpler words or explain things differently. Try to 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, like hearing or eyesight problems, pain, or side effects of medication
- Give the person time to respond
- 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 over them.

When communicating with a person with dementia, 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
- Introduce exercise routines, programs or outdoor activities
- Try different things until you find what works for you both.

CHANGES IN BEHAVIOUR

People living with dementia can sometimes behave differently than they used to. Keep in mind this is not deliberate and try not to take it personally. Some common changes in behaviour are:

- repetition: asking the same question or repeating an action
- restlessness, including pacing or fidgeting
- lack of inhibition, including saying or doing something that is not appropriate
- night-time waking or sleeplessness
- increased agitation or confusion at particular times
- following you around or calling out to check where you are
- putting things in unusual places and then forgetting where they are
- suspicion, including thinking someone has taken their belongings when they cannot recall where they have put them
- hoarding or hiding things
- aggression or anger
- overreaction
- apathy, poor motivation and inability to initiate activities.

Tips for responding to changes in behaviour

- 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
- Try distracting the person from what is upsetting them. You could try changing the conversation, having something to eat or going for a walk together
- Engage in the activities they enjoy
- Try aromatherapy, massage, music or dance therapy, or contact with animals
- Try talking therapies, reminiscing with the person or doing life-story work.

Changes in behaviour can be stressful for family members as well as for the person living with dementia.

Try to understand why the person's behaviour might have changed. Keep a record of when you notice changes so that you can understand whether there may be a trigger. If the changes are significant or you are having trouble coping with them, seek professional 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 a care home.

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 changes in behaviour. They can link carers with appropriate support networks.

For more information about the **Dementia Behaviour Management Advisory Service**, call **1800 699 799** or visit **dementia.com.au/dbmas**

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.

PERMANENT RESIDENTIAL CARE

If you're caring for someone with younger onset dementia, you may need to make the decision to move them to residential care. This can be a very difficult decision, and it's normal to feel a mix of emotions, such as loss, guilt and even relief. That's normal. Be kind to yourself and make sure you get the support you need.

It can also be a stressful and challenging process, particularly if the move into residential care happens quickly; for example, after a hospital admission.

It's worth planning and researching your options ahead of time, as this can reduce stress and help you to make the best decision.

For more information about residential care, visit **dementia.org.au/living-dementia/care-options/residential-care**

GRIEF AND BEREAVEMENT

When a person you care about is dying or has died, you may experience a wide range of feelings. Everyone has different reactions. You might feel:

- sadness
- a sense of loss
- shock and pain
- disbelief and an inability to accept the situation
- relief, both for the person with dementia and for yourself
- guilt
- anger

- resentment
- lack of purpose now that your caring role has ended.

Grieving is not always about experiencing negative emotions. You may also feel joy or happiness. 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 death, you may feel shocked and vulnerable, so:

- try to avoid making any major decisions
- acknowledge your feelings
- arrange for support around emotional events, such as birthdays or anniversaries
- talk to your doctor if you feel overwhelmed, depressed or physically unwell.

Getting back on your feet

It can be hard to move on with your life after your caring responsibilities change or the person you love has died. 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. Don't try to rush the process
- Accept help. Other people can support you and let you express your feelings, reflect and talk.

Sharing your experience

Sharing your feelings among family and friends can be beneficial for everyone.

- Reflect on 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 don't give up. Your confidence will gradually return.

Section 11

Staying connected

Staying connected

Dementia Australia has lots of ways you can stay up-to-date with information and services available to you.

Sign up to our monthly eNews and our social media channels to receive updates on research and resources, hear stories from people impacted by dementia, and find out what you can do to improve the lives of people living with dementia, their families and carers. Visit **dementia.org.au/e-news**

Social media

Find Dementia Australia on the following social media channels:

facebook.com/DementiaAustralia

instagram.com/Dementia_Australia

linkedin.com/company/dementiaaustralia

x.com/DementiaAus

Podcast

Scan the QR code to listen to and find out more about Dementia Australia's Hold the Moment podcast or visit: **dementia.org.au/podcast**

Dementia Australia Library

The Dementia Australia Library is the largest publicly accessible dementia library in the world, providing a free and comprehensive collection of print and digital resources. Find out more at **dementia.org.au**

Dementia-Friendly Communities

Many areas have committed to ensuring their local community is dementia-friendly. Any community can be a Dementia-Friendly Community: one where people living with dementia are integral in creating spaces that understand, respect, support and empower them.

Find out what is available in your community by contacting the **National Dementia Helpline** on **1800 100 500** or visiting **dementia.org.au/dementia-friendly-communities**

PART 4

Section 12

Useful tools: worksheets and checklists

This section offers worksheets and checklists to help you to live well now and make plans. For a more detailed online budget planner check out the Moneysmart Budget planner: **moneysmart.gov.au/budgeting/budget-planner**

Useful tools: worksheets and checklists

Financial planning worksheet 1: Current income

Income type	Yes/no	Institution details (name, address, contact)
Work salary		
Bonuses or overtime		
Income from savings/ investments		
Centrelink benefits		
Department of Veterans' Affairs		
Child support		
Other income (for example, rental property)		

	BSB and account number	Owner/s details	Other details	Amount received per month

Financial planning worksheet 2: Expenses

Expense item	Yes/ no	Institution details (name, address, contact)
Debts		
Mortgage/rent payment		
Car payment (loan/lease)		
Credit card		
Personal loan		
Student loan		
Other		
Fixed		
Property/council rates		
Utilities:		
gas		
electricity		
phone		
internet		
water		
Car:		
registration		
licence		

	Account number	Other details	Payment due date	Payment amount per month

Expense item	Yes/ no	Institution details (name, address, contact)
Child support payments		
Health insurance		
Pet or other insurance premiums		
Subscriptions/memberships		
Other		
Variable		
Groceries		
Medical:		
medicines		
dental		
eye care		
other		
Personal:		
personal care items		
clothing/shoes		

	Account number	Other details	Payment due date	Payment amount per month

Expense item	Yes/ no	Institution details (name, address, contact)
accessories		
education (for example school uniforms, books)		
sports/hobbies		
other		
Transport/vehicle:		
petrol		
parking/tolls		
public transport		
taxis		
airfares		
other		
Entertainment/dining out		
Unexpected costs (for example emergencies, car repairs, fines, incidental home modifications)		
Other		

	Account number	Other details	Payment due date	Payment amount per month

Financial planning worksheet 3: Current assets/investments

Asset type	Yes/no	Institution details (Name, address, contact)	BSB and Account number
Term deposits/ savings balance			
Property (estimated value)			
Superannuation balance			
Shares			
Bonds			
Mutual funds			
Trust fund			
Other (for example, cryptocurrencies)			

	Owner/s details	Document location	Other details	Current value
			Total estimated asset value	

Financial planning worksheet 4: Legal documents and other information

Legal documents	Yes/no	Owner	Document location
Driver's licence			
Passport			
Residency/ citizenship details			
Marriage certificate			
Centrelink details			
Will			
Power of Attorney (financial)			
Enduring Guardian (healthcare)			
Car registration			
Birth certificate			
Property deeds			

	Any additional details	Notes

Other	Details (for example institution and account details)	Location	Notes
Safety deposit box			
Password manager app			

Planning your finances checklists

Here are some questions to consider and ask your financial team:

Banking	✔
Account simplification and general support	
Can I consolidate my bank accounts to make it easier to manage my finances and reduce confusion?	
Can I make my partner a joint signatory on my accounts?	
How do I arrange “authority to operate” or “third party authority” for trusted individuals?	
Is there a staff member or specialised team at this branch, call centre or service that is knowledgeable about dementia and can assist me?	
Account access and payment management	
How can I set up or simplify online or phone banking access?	
Can I request face-to-face banking services if I find digital platforms difficult to use?	
Can I set up automatic payments for regular expenses?	

Banking continued	✔
Documents	
Can I send a copy of my certified power of attorney document electronically or do I need to come into a branch?	
How does the bank store power of attorney documents and are they accessible across all branches or only at the branch where they were submitted?	
What steps do I need to take to ensure the power of attorney is recorded on all relevant accounts?	
How will the bank verify the power of attorney in future transactions, and what is the process if I need to make changes or updates?	
Fraud prevention	
What protocols do you have to safeguard people living with dementia or cognitive decline?	
What security measures, such as transaction alerts, can be set up to protect me from fraud?	
Notes or further questions	

Accountant	✔
Can you help ensure my tax returns are filed accurately and on time, and identify any potential tax credits or deductions I'm eligible for?	
How might changes in my income or expenses affect my overall tax liability?	
Are there any tax-advantaged accounts or financial products that can help cover these costs?	
If I access my superannuation early how could this impact any payments that I receive or taxes that I have to pay?	

Financial counsellor/advisor	✔
Can you help assess my current debts and develop a plan to manage or reduce them, especially if my income is impacted?	
Is it possible to consolidate or refinance my debts to lower the interest rates and monthly payments?	
What other options do you recommend for managing and reducing debts, especially high-interest ones, such as credit card, personal or car loans?	
How can I start setting aside emergency funds for future medical or care expenses?	

Financial counsellor/advisor continued	✔
What government or financial assistance programs might I be eligible for and how do I apply for them?	
Can we review my current income streams, such as pensions, benefits or investments, and plan for any potential changes?	
How can I adjust my retirement plan based on my current financial situation and any anticipated future needs, such as bringing forward travel or lifestyle goals?	

Planning your future checklists

Call the **National Dementia Helpline** on **1800 100 500** to book an appointment with a Dementia Australia specialist. They can provide information and recommend supports for your specific situation.	
In the month following diagnosis	✔
Learn more about your diagnosis, including:	
+ the type of dementia you have	
+ what drug and non-drug treatments are available	
+ health professionals who might be involved in your care.	

Explore Dementia Australia's website for information and details of upcoming education sessions. Visit **dementia.org.au/get-support/dementia-information-and-education-sessions**

Join the Dementia Australia Library service: visit **dementia.org.au/library**

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 counsellors.

Write a list of services and supports to improve your quality of life and to help you:

+ live well at home
+ keep healthy and active
+ remain engaged in activities and hobbies.

In the next six months	✔
Connect with others in similar situations. Dementia Australia runs group programs, social and peer support for people living with dementia, carers and families.	
Assess your home environment. Make modifications to keep safe and help adapt to changes to your memory and thinking.	
Assess your wellbeing. Look after yourself and keep your heart, body and mind active. Include exercise and healthy eating in your daily routine.	
Organise regular check-ups with your doctor, dentist, optician and podiatrist. Ask each practitioner for written advice or consider having someone go with you to appointments, to take notes and ask questions.	
Make plans for your future. Consider any legal and financial matters, advance care directives, and medical and healthcare wishes.	
Apply for a Companion Card to continue participating with carer support (at little or no cost) in leisure activities and events.	

In the future	✔
Begin discussions regarding future living arrangements.	
Consider changing utilities and other accounts into a partner's name for ease of access.	
Consider removing your name from the electoral roll with the Australian Electoral Commission.	

Dementia Australia®

National Dementia Helpline

1800 100 500

How we can help

Visit our website or speak to our team for:

- information and advice on dementia, including signs and symptoms
- information resources, available in many languages
- practical support and counselling
- assistance to find supports and services in your community.

Find us online
dementia.org.au