



Section 4

Planning for the future

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

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

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

Web: dementia.org.au/the-dementia-guide



“

I like to do arts and work with my hands and that gives me a bit of peace and tranquil in my life. ”

Bruce, a Dementia Advocate who lives with younger onset dementia

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Section contents

Driving	51
Working	52
Legal matters	57
Financial management	58
Government support	60
Advance care planning	62



Scan the QR code to
find out more about Bruce's story

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

You might like to talk to family and friends about what is important to you. Talking to them will help them understand and respect your wishes in the future. Make decisions that fit in with your priorities and how you want to live.

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

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

Driving

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

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

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

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

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

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

Working

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

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

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

Before you talk to your employer

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

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

Telling your employer

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

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

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

Other options could be working reduced hours or retiring early.

Leaving work

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

If you have decided to finish work:

- Consider using any sick leave you have accrued before your employment ends. You are entitled to use this sick leave, as long as you provide a medical certificate.
- Talk to your insurance company, superannuation fund or financial planner. Ask about income protection and total and permanent disability insurance.

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

Getting advice and support

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

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

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

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

Legal matters

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

Will

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

Enduring power of attorney

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

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

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

Financial management

It is important to take the time to organise your finances. Gather essential information and documents together so they are easy to find. Consider that some information will be stored digitally, such as online banking and superannuation details.

In a safe place, keep the details of your:

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

It is advised to tell someone you trust where hard copies of documents are stored and also how to access your digital information.

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

Managing your money

- It may become difficult to remember PINs for debit or credit cards. Talk to your bank about alternatives, such as ‘tap and go’ cards and making payments using your mobile phone.
- You might like to arrange automatic payments for your bills. Set up direct debits to manage regular payments for phone or electricity bills.

Government support

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

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

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

Get your Companion Card

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

Present the card to a participating organisation. They will issue a second ticket for your companion at no charge.

Apply for your card online at **companioncard.gov.au**

Advance care planning

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

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

You can also appoint someone to make decisions on your behalf. This person can use your plan to guide their decisions.

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

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

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

Advocacy

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

In these instances, the **Older Persons Advocacy Network** (OPAN) may be able to assist.

Call **1800 700 600** or go to [**opan.org.au**](https://www.opan.org.au)