Call the National Dementia Helpline on 1800 100 500
Planning for the future

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"Planning is bringing the future into the present so that you can do something about it now."
Alan Lakein
Key points: Planning for the future

Following diagnosis, dedicate some time to making sure your financial and other affairs are in order. There are things you can do to make managing your money easier. Organising an enduring power of attorney will allow someone else, nominated by you, to make decisions about matters relating to your finances. An enduring power of attorney can also be appointed for other matters, including making medical decisions on your behalf, once you no longer have the capacity to do so.

You and your carer may be entitled to a range of benefits. If you have dementia you may be eligible for an aged or disability payment, dependent on your situation. Your carer may also be eligible for carer allowance and/or carer payment. You can contact Centrelink for advice on eligibility.

Now is the time to plan ahead and talk to others about your future. If you are able, try to do this as soon as you can. Make sure you have an up-to-date Will, so you can choose who inherits your money and possessions after you die.
To have a say in your future medical care, you can set up an advance care plan. Talk to your doctor or solicitor about this, or for more information visit [advancecareplanning.org.au](http://advancecareplanning.org.au)

If you drive, you must legally tell your local road and traffic authority about your diagnosis. You must also tell your vehicle insurance company. If you wish to continue driving, you can organise to sit a test that will determine your ability to do so safely.

If you are still working when you are diagnosed with dementia, you may choose to carry on doing so. Talk to your employer after taking advice on your rights, entitlements, working conditions and health issues. Advice is available from a range of places, including your doctor, the human resources department at your place of work, your trade union if you have one, a lawyer or anti-discrimination advocate.

If you stop working or reduce your hours, you may be eligible for some further benefits.
Financial matters

Once you have had a chance to adjust to your diagnosis, take some time to ensure your financial and legal affairs are in order, making sure all your essential documents can be found easily.

Things to think about include: details of your bank accounts, tax, benefits, pensions and superannuation, shares, trusts, mortgage or rent documents, insurance policies, powers of attorney and your Will.

It may become more difficult for you to make decisions or choices about financial or legal matters as time goes on, but there are lots of things you can do now to make sure you get to choose how you live now and in the future. Make these plans as early as you can with a trusted friend, family member or professional.

You may wish to elect different people to help you with different elements of this planning. Choose those who are likely to be able to offer you continued support as time goes on.

Direct debits

If they aren’t already in place, consider setting up direct debits for regular payments such as phone or power bills. That way they will get paid automatically.

Bank accounts

Think about your banking needs and how they might be impacted following your diagnosis. If you need or want somebody else to be able to manage your account, you can arrange an enduring power of attorney. Banks will require original copies of the enduring power of attorney, so it is helpful to talk to your branch manager and keep them informed about your decisions.

Talk to a financial advisor or solicitor about the best options for your circumstances. For some couples with joint accounts, setting up separate accounts during the later stages of dementia can make things simpler. Benefits and pensions, for example, can be paid directly into the account of the person living with dementia. In addition, any means-testing for benefits or aged care costs will be more straightforward, if the accounts are separate.
If you need or want somebody else to deal with your account, see Enduring power of attorney on page 85 for more information.

Debit and credit cards
If you have memory problems, you may find it difficult to remember PIN numbers for debit or credit cards. Talk to your bank about alternatives, such as a ‘chip and signature’ card.

Trusts
If you have property or savings, you might want to consider setting up a trust. This will ensure things are managed the way you have chosen, now and in the future. Seek advice from your solicitor, financial adviser and accountant.

For more information see Help Sheet, About dementia 7: Early planning. Available at dementia.org.au

Driving
People living with dementia can remain safe and competent drivers, particularly in the early stages of the condition. However, as dementia progresses it can have serious effects on memory, reactions, perception and the ability to perform tasks. At some point, all people with dementia will need to stop driving in order to reduce risk to themselves and others.

If you have a driving licence, the law says you must inform VicRoads promptly after being diagnosed with dementia. They can be contacted on 131 171.

Often, the doctor who gives a diagnosis of dementia will use their professional discretion to determine whether they need to notify VicRoads themselves from a duty of care perspective.

If you are interested in continuing to drive, you can undergo a medical review. This is likely to involve a driving test conducted by an occupational therapist. You must also tell your vehicle insurance company about your diagnosis.
For more information see Help Sheet, Information for people with dementia 4: Driving and dementia. Available at dementia.org.au

**Changed Conditions Ahead** is a guide by Dementia Australia and RACV for the carers, family members and friends of a person living with dementia who is driving. The kit can be downloaded at dementia.org.au/resources/dementia-and-driving

Many people with dementia choose to stop driving voluntarily, because they begin to feel less confident or find themselves becoming confused, even on familiar routes.

Stopping driving can be a difficult adjustment, but there can be some benefits. These include reduced stress and saving money on insurance, fuel, registration and maintenance. These savings may be used to fund alternate transport (e.g. public transport and taxis, for which half price concession may be available. Ask your GP for more information).
Working

Some older adults and people diagnosed with younger onset dementia are often still employed at the time of their diagnosis. In many cases it is possible to continue working after a diagnosis of dementia. Some people find working helps them feel better physically and emotionally. Others might feel that stopping is for the best.

Likewise, many carers are still working and may require access to support and advice when it comes to balancing work and care. For more information see Support for carers on page 99.

Getting help

Consider taking advice on your rights, entitlements, working conditions and health issues before talking to your employer. Advice is available from a range of places, including your doctor, the Human Resources department at your place of work, your trade union if you have one, a lawyer or anti-discrimination advocate.

Assessing the work situation

Allow yourself time to absorb your diagnosis and don’t rush into making any decisions. Take time to thoroughly consider any possible implications of work-related decisions.

Things to consider include:

- the possible safety risks associated with dementia symptoms
- access to staff counselling
- the size of the company you work for and its ability to provide support
- your relationships with peers and management
- whether it may be possible to change or reduce duties, or put in place supports that may assist you in carrying out your role
Talking to your employer

Deciding whether or not you tell your employer about your diagnosis of younger onset dementia can be complex. For many people it will depend on the extent to which symptoms affect their ability to do their job, as well as the support that may be required from the employer.

You might feel anxious about telling your employer about your diagnosis, but doing so will help give you protection under the law. Once your employer knows, they are required to make ‘reasonable adjustments’ so that you can keep working, if you are able to do so safely.

In some occupations you are legally obliged to tell your employer about your diagnosis, so you will need to check your contract. If you drive or operate machinery as part of your job, you should let your employer know straight away.

It may be helpful to speak to the Human Resources advisor at your workplace, and have a support person including a family member, friend, colleague or advocate involved in any discussions.

Once your employer has been informed, regularly monitor the employment situation and the effect dementia symptoms are having on your work duties, particularly if your symptoms are progressing.

Leaving work

At some stage, you might decide to leave work or retire early. This decision should only be made after appropriate consultation has taken place with immediate family, advocates and your employer.

Use your current sick leave entitlements before leaving the workforce due to health reasons. An employee is entitled, on the production of a medical certificate, to utilise unused sick leave before resigning.

Before you leave the workforce, seek advice from your insurance company, superannuation fund or financial planner on entitlements such as Total and Permanent Disability (TPD) and income protection.
After leaving the workforce, check that any annual leave and long service leave has been paid out at the correct amount.

A lawyer, your superannuation advisor or Centrelink representative can offer advice about your superannuation and pension options. Contact details for Centrelink can be found at humanservices.gov.au/individuals/centrelink

If conflict arises during the termination process, use support networks such as family, unions, work place advocates, or other sources of legal support.

Medical testing

Depending on the nature of your work, some employers might require you to undergo a medical test. If you are found to be unable to perform the duties required in your existing role, you may be asked to consider changing to a different, more suitable role within the organisation. Alternatively, you might be asked to consider retirement, or working reduced hours.

For more information see Help Sheet, Information for people with dementia 10: Making employment decisions or Younger onset dementia 6: Employment. Available at dementia.org.au

Benefits

People with dementia and their carers may be entitled to a range of benefits. Some are means-tested, so they depend on income or assets, including savings. Accessing them can seem complicated, but there is support available through Centrelink who can advise on what to claim for and how to complete the forms.

Visit the Centrelink Payment and Service Finder online at humanservices.gov.au/individuals/centrelink to discover what benefits might be available to you. If you would prefer to speak to somebody over the phone, call 132 300 to discuss benefits for the person living with dementia or 132 717 to discuss carer benefits.
Carer payment and carer allowance

**Carer payment** is an income support payment for people who provide constant care at home to somebody with a severe disability, medical condition, or who is aged. To receive this, the carer must meet the Centrelink income and assets test.

**Carer allowance** is an income supplement for carers who provide additional daily care and attention. This allowance is not currently means-tested.

It is possible to receive one or both of these benefits. Speak to Centrelink for more information. Contact details can be found at humanservices.gov.au/individuals/centrelink

Companion Card

The Companion Card is issued to people with a significant, permanent disability, who can demonstrate they are unable to access most community activities and venues without attendant care support.

The card can be presented when booking or purchasing tickets, provided the cardholder requires attendant care support to participate in that particular activity. Participating organisations will then issue the cardholder with a second ticket for their companion at no charge.

This is a great way to encourage friends and family to accompany a person with dementia during leisure activities. It can also be used when paying for public transport.

For more information, visit companioncard.gov.au

Making decisions for the future

Everyone needs to make decisions from time to time about their health, care and finances. As dementia progresses, it will become harder for you to do this. If you are able to, think about your future, talk to others and plan ahead as soon as possible. You can make decisions and plans to ensure your future care and finances are handled in a way that reflects your wishes. These choices could range from how your money is managed to how you want to be cared for at the end of your life.
If you have dementia, the law protects your right to do the following:

- Make your own decisions and be involved in any decision making that affects you.
- Get support with making decisions about the future.
- Put plans in place in case you are unable to make decisions in the future.
- Appoint a person or people to make decisions in your best interests, if you are unable to.

**Wills**

Everyone should make a Will. It allows you to choose who inherits your money and your possessions after you die. Talk to a solicitor about making or updating your Will. If you are living with dementia, you can still make or change your Will, as long as you understand the decisions you are making and the implications of any changes. A solicitor can offer advice.

**Enduring power of attorney**

An enduring power of attorney is a legal document that allows an individual to appoint another person or people to make decisions for them regarding financial and personal matters.

There are various types of powers of attorney, including supported, financial and medical.

It is important to note that the person who makes the appointment must have the decision making capacity to do so, and trust the person or people they appoint to manage their affairs. The power then ‘endures’, meaning it continues once the person loses capacity to make decisions for themselves.

Visit the Office of the Public Advocate website at [publicadvocate.vic.gov.au](http://publicadvocate.vic.gov.au) or speak to your lawyer, accountant and/or financial advisor for more information on powers of attorney. The book ‘Take Control’ includes information on how to appoint powers of attorney, and is available in hard copy from Dementia Australia, the Office of the Public Advocate or online at [publicadvocate.vic.gov.au](http://publicadvocate.vic.gov.au)
Make sure you lodge financial or medical powers of attorney with all relevant bodies, including Medicare, your banks, Centrelink and the Department of Veterans’ Affairs.

**Advocacy**

Sometimes, an individual with dementia might need a professional to advocate on their behalf, particularly when it comes to planning for the future and liaising with health care, housing, welfare and financial service providers. In these instances, the following agencies may be able to assist.

- **The Office of the Public Advocate** 1300 309 337
- **Seniors Rights Victoria** 1300 368 821
- **The National Aged Care Advocacy Line** 1800 700 600
- **Elder Rights Advocacy** 03 9602 3066 or 1800 700 600

**Advance care planning**

Advance care planning is when a person discusses their preferences for future medical treatment and personal care with family, friends and medical professionals. Preferences might include the treatment and type of care they want.

These discussions should happen while the person still has capacity to make these kinds of decisions. Ideally, everybody should have a discussion about their future medical treatment, whether they have a diagnosis of dementia or not.

A written advance care plan helps people to accurately remember what you want and makes it easier to communicate these wishes to doctors and nurses who do not know you.

To make a written advance care plan, the person with dementia discusses and documents their wishes. These are known as advance care directives. They then appoint somebody to be their substitute decision maker by making an enduring power of attorney. The instructions (or advance care directives) within the plan can then be used by the appointed attorney to inform their decision-making.
Advance care planning usually involves ongoing discussions, as the wishes of a person might change as their circumstances change.

While the law does not require a lawyer to be involved with advance care planning, you should discuss it with your doctor to ensure your decisions are made based on good information. Your doctor can also help you complete the necessary document. Take a copy of your advance care plan with you every time you go to the doctor or to hospital.

**Start2Talk**

Start2Talk provides information and practical advance care planning worksheets that you can fill out.

For more information, visit [dementia.org.au/planning-ahead](http://dementia.org.au/planning-ahead)

**Advance Care Planning Australia**

The Advance Care Planning Australia website contains information about how to make an advance care plan, relevant to each state and territory.

For more information, visit [advancecareplanning.org.au](http://advancecareplanning.org.au)

**Things to consider**

- What are some of the things you would like help making decisions about?
- Who do you trust to make decisions on your behalf?
- What do you need to take care of now to ensure your wishes for the future are recognised?
- Have you taken care of powers of attorney, and made your advance care plan and will?
- What things are important to you about your future care?
- Do you know what financial assistance you are eligible for?
- If you drive, have you notified your local driving authority about your diagnosis?
- How will you know when it’s time to stop driving?