

About you: Making employment decisions

This help sheet offers suggestions around making decisions about your work life.

If you are living with dementia and you are working, you will need to consider how dementia will affect your work life.

You may have already noticed the effects of dementia on your work, such as:

- difficulty communicating your thoughts to colleagues or clients
- difficulty concentrating
- forgetting meetings or appointments
- difficulty managing several tasks at once
- having difficulty with larger groups and possibly preferring to work alone
- losing confidence in your work abilities
- feeling uncertain about making important decisions.

With support, it is possible to keep working. Continuing this familiar routine helps some people feel better. Other people decide that it is best to stop working.

The key to making employment decisions is to take early control, plan and be realistic.

Planning your future

There are many decisions to make about your employment, including:

- whether to tell your employer
- if you decide to tell your employer, when you will do that
- whether there are safety risks to yourself or others if you continue working

- what changes could be made at your workplace to support you to continue working
- how long to continue working.

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

However, the issues related to deciding whether to tell an employer about a diagnosis can be complex. There are no set rules that will work for everyone.

Before you talk to your employer

Fully review all aspects of your work situation before telling an employer. Allow time to absorb the diagnosis and don't rush into any decisions.

Talk to family, health professionals and, where appropriate, a union representative or anti-discrimination advocate about working conditions and health issues.

Start by talking to your doctor about your ability to work. It may be useful to consider:

- if your symptoms affect your ability to do your job
- any safety risks associated with your dementia symptoms
- if there is a duty of care to inform an employer or clients receiving a service
- the pace at which your symptoms are progressing
- any support you might need to continue working, such as the support needed from your employer
- any options to change or reduce your duties
- your employer's capacity to provide support and what they are likely to offer
- your rights and entitlements in the workplace.

Speak with a union representative or an anti-discrimination advocate about any work-related concerns you have.

Assess your work situation

Reviewing your work situation will help determine if you resign or stay working for as long as possible.

It may be useful to consider:

- job satisfaction or work performance in the current role
- access to staff counselling
- how long you have worked for the company
- whether changes associated with dementia may affect others
- the ability of your employer to provide support
- relationships with peers and management
- the possibility to change or reduce your duties or put supports in place to help you carry out the job
- available superannuation, death or disability insurance
- using an advocate when interacting with the employer.

Getting guidance and support

From the start, seek guidance and support from:

- your doctor or medical specialist
- family and trusted friends
- your trade union or professional body
- Dementia Australia
- legal advisors
- a financial advisor
- counsellors or human resource officers in your workplace
- anti-discrimination advocates
- Centrelink.

These people can help you think things through and support you to make the decisions needed for the future.

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

Protecting your privacy and confidentiality

Organisations you talk to for guidance and support, including Dementia Australia, are required by law to respect your privacy. If you are concerned about the confidentiality of your personal or health information, ask to see the organisation's privacy policy.

Continuing to work

If you decide to keep working, here are some suggestions that might help:

- Talk to your employer about your diagnosis. This is a very big step for most people, so think about what to say and how much to tell. Using trusted family and friends for a rehearsal can be very helpful. You might want to take someone with you to help explain your situation.
- Discuss the possibility of changing aspects of your job that will make things easier for you.
- Think about who else in your workplace needs to know about your diagnosis. This could include clients as well as co-workers.
- It may help to have one or two trusted colleagues to be key supports in the workplace.
- Know your employment conditions, especially your sick leave and disability entitlements.
- Familiarise yourself with relevant anti-discrimination legislation.
- Continue to plan for the future and consider how you will decide when the time is right to leave work.
- If you are under 65, enquire about eligibility for funding from the National Disability Insurance Scheme (NDIS) to support you to continue to work. You can be supported through this process by calling the National Dementia Helpline.

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.

When an employer has been informed

- Your employer may request you to complete a medical test, to make sure you still can complete the tasks involved in your current role. Depending on the test results, your employer may ask you to consider a different role in the organisation.
- Regularly monitor your employment situation and the effect of dementia symptoms on work duties, particularly if your symptoms are progressing.
- If there are any concerns raised regarding your work performance, seek advice about how to negotiate adjustments to your work with your employer.

Employers are legally obligated to make ‘reasonable adjustments’ to allow a person with a disability to do their work (cognitive impairment associated with dementia falls under national disability legislation). It is considered ‘indirect discrimination’ to refuse to make reasonable adjustments to enable a person with a disability to comply with workplace requirements. If you feel that your employer is unreasonably refusing to make adjustments, talk with your employer about possible changes, or with an advocate, union official or legal professional.

Tips for carrying out your job

Below are some tips that might help with tasks and projects:

- Develop a daily work routine, setting times for specific projects and tasks, to prevent jobs interrupting each other and to ensure they get done.
- Use a diary or calendar to track appointments, tasks and projects.
- Diarise regular breaks during the day to prevent fatigue.
- Try to deal with one task or problem at a time and complete it before moving on to the next.
- If a task seems difficult or you are finding it hard to focus, try to take a break and come back to it with a clearer mind.
- Take notes during meetings and conversations to maintain your focus and help you recall information later.
- When working through a problem, try writing notes or developing a flow chart.

- When concentrating on specific tasks, try to minimise noise, emails, notifications on your computer, phone calls and visual distractions.
- Motivate yourself by setting achievable goals and rewarding yourself when they are completed.

Reducing workplace pressures

You will need to track any effect your dementia symptoms have on your duties.

If you are having problems at work, they are quite likely to be a result of the changes associated with dementia. The changes are not something you can control, but you can control how you manage the situation.

Like anyone with a serious illness, you are entitled to special consideration in the workplace.

To reduce workplace pressures, you might consider requesting flexible working arrangements, such as changes to:

- working hours (less hours, or changes to start and finish times)
- patterns of work (split shifts, job sharing or duties)
- where you work (for example, working from home).

Sometimes simple strategies or changes in the environment can help.

Leaving the workforce

At some point you may decide to leave work. Try not to make a rushed decision.

Before you make any final decisions:

- Consult with immediate family, advocates, your doctor and your employer.
- Ensure you are fully aware of your benefits and entitlements.

Get good advice. This might include guidance from a financial counsellor, solicitor, your trade union or professional body, Centrelink and Dementia Australia.

Find out about:

- your superannuation policy and entitlements
- any sick leave entitlements. You are entitled to use this sick leave, if you provide a medical certificate.
- any long service leave entitlements
- disability or sickness benefits
- any income protection insurance or other insurances that may have a disability component. Talk to your insurance company, superannuation fund or financial planner. Ask about income protection and total and permanent disability insurance.
- any government benefits you might be eligible for after leaving work.

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

Leaving the workforce before diagnosis

Some people may lose their job or decide to leave work before a dementia diagnosis has been confirmed. This may be because of the impact of symptoms on their performance or their confidence in doing their job.

If memory loss or other cognitive changes were a factor in leaving the workforce, there may be potential for retrospective claims once a diagnosis is made.

You could:

- Review your superannuation policy (employer-related and private) to see if it includes a death or disability insurance benefit.
- Review the eligibility criteria for the disability insurance benefit. Check whether a retrospective claim can still be made.
- Review any written notes (employment history or medical history) for evidence of changes to behaviour, workplace performance, or capacity that may have resulted from the onset of dementia symptoms.

Tests and records prior to diagnosis may provide evidence that the onset of dementia symptoms was the cause of leaving work.

Where to get help

For more help with employment and disability rights contact:

- Dementia Australia
Call: **1800 100 500**
Visit: dementia.org.au
- JobAccess
Call **1800 464 800**
Visit: jobaccess.gov.au
- The National Disability Insurance Scheme
Call: **1800 800 110**
Visit: ndis.gov.au
- The Australian Human Rights Commission
Visit: humanrights.gov.au

Additional reading and resources

- Dementia Australia national library
Visit: dementia.org.au/library
- Dementia Australia support
Visit: dementia.org.au/support
- Dementia Australia education
Visit: dementia.org.au/education

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au