

Employment

This help sheet discusses decision making issues and advocacy for people with younger onset dementia who wish to continue working.

People diagnosed with younger onset dementia are often still employed at the time of their diagnosis. There are many decisions to make about employment including whether or not to tell the employer, what changes could be made to the workplace and how long to continue working.

The issues related to deciding whether or not to tell an employer about a diagnosis of younger onset dementia can be very complex. There are no set rules that will work for everyone. For many people it will depend on the extent to which symptoms affect their ability to do their job, the pace at which symptoms are progressing, and the support that may be required of (or that's likely to be offered by) the employer. Younger onset dementia may have no impact on a person's ability to do their work at the early stages, although it is likely to do so over time.

It is important for people with younger onset dementia to consider a number of options before making a decision about continuing with on-going employment and/or informing their employer.

Assessing the work situation

- Consider possible safety risks associated with dementia symptoms (for example, if operating machinery, being responsible for financial matters or driving work vehicles) and if there is a duty of care to inform an employer or clients receiving a service.
- Allow time to absorb the diagnosis and don't rush into any decisions.
- Fully review all aspects of the situation before telling an employer.
- Talk to family, health professionals and where appropriate, a union representative or anti-discrimination advocate about working conditions and health issues.
- Before considering resignation from employment, seek consultation and advice about employee entitlements and rights.

It may be useful to consider:

- Job satisfaction or work performance in the current role.
- Access to staff counselling.
- The number of years of service to the company.
- The nature of the work you do, and whether changes associated with younger onset dementia may affect others.
- The size of the company you work for and its ability to provide support.
- Relationships with peers and management.
- Whether it may be possible to change or reduce duties or put in place supports that may assist in carrying out the job.
- Available superannuation, death or disability insurance.
- The availability of an advocate when interacting with the employer.

Once the employer has been informed

- Regularly monitor the employment situation and the effect of dementia symptoms on work duties, particularly if symptoms are progressing.
- If there are any issues with work performance seek advice as to how to handle the negotiation process 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. Talk with the employer about possible changes, or with an advocate, union official or legal professional if you feel that your employer is unreasonably refusing to make adjustments.

Tips to minimise impacts on work

- Develop a routine structure for each work day. For example, have a set time each day to return phone calls; a set time for specific projects; and a set time for administrative tasks. This will help prevent activities from interfering with each other but also ensure that they don't get put off, adding to organisational difficulties and stress.
- Factor in break time at regular intervals throughout the day to prevent fatigue.
- If a task seems too difficult, or attention is declining – try not to push it, this may only make the situation worse. Try taking a break, then coming back to the task with a clearer mind.
- Use a diary or calendar to help keep track of appointments, tasks and projects.
- During meetings and work conversations take notes to maintain focus and to help with recall of information later.
- When working through a problem, try writing notes or developing a flow-chart.
- Try to minimise distractions, such as noise, email, phone calls (divert calls to message bank) and visual stimuli when concentrating on specific tasks.
- Try to deal with one task or problem at a time and complete it before moving onto the next.
- Set achievable goals with rewards for attaining each goal as a source of motivation.

Leaving the workforce before diagnosis

Some people may have lost their job or chosen to leave employment before a diagnosis of dementia was confirmed due to the impact of symptoms on their work performance or their confidence in carrying out their role. If this is the case, there might be potential for retrospective claims once a diagnosis is made if memory loss or other cognitive changes were a factor in the outcome.

- Review the 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.

- If there is a disability insurance benefit, check whether or not 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.

Leaving the workforce after diagnosis

The decision to leave the workforce should only occur after appropriate consultation has taken place with immediate family, advocates and the employer.

- Seek a medical or neuropsychological assessment to confirm the progression of the dementia and its impact on work capacity.
- The progression of younger onset dementia can be faster than dementia after the age of 65, so regular medical reviews regarding capacity to continue working are recommended.
- Consider using current sick leave entitlements when 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.
- After leaving the workforce, check that annual leave and long service leave is paid out at the correct amount.
- If there is a disability insurance benefit attached to superannuation, it may be better not to immediately resign from current employment. Most policies have a 3-6 month waiting time before an application can be made for a disability entitlement and it may be possible to take paid or unpaid leave in the interim. Resignation can occur after the acceptance of the disability application.
- If conflict arises during the termination process, use support networks such as family, unions, work place advocates, or other sources of legal support.

More information

For more help with employment and disability rights contact:

- Dementia Australia on **1800 100 500** or dementia.org.au
- JobAccess call **1800 464 800** or visit <http://jobaccess.gov.au>
- The Australian Human Rights Commission website humanrights.gov.au

Further Information

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**