



## **Employment support for people with Dementia**

### **When to talk to your employer?**

The risks of potential liability or injury as a result of declining cognition and resulting workplace errors need to be seriously considered. If changes or risks have become evident in workplace performance, then the person should explore whether they can take sick leave or paid/ unpaid leave until a diagnostic opinion can be sought.

Notifying an employer or resigning before a confirmed diagnosis is not advised since:

- There are many causes for cognitive changes and some are treatable/reversible
- In less scrupulous workplaces, telling your employer before a diagnosis is made, may also lead to reduced work hours or threats to ongoing employment, potentially adding the burden of legal disputes or unfair dismissal proceedings
- Potential loss of income benefits such as accrued leave
- Many income protection and total permanent disability policies will expire when employment or policy holder contributions cease. Resigning prior to notifying your insurer may cut off this potentially vital source of income support.

### **Weighing up your options...to work or not to work?**

Once the diagnosis has been confirmed, decisions can be made about working capacity and the best way forward in speaking to your employer. Each individual/family and their care team need to weigh up the risks versus benefits of continuing to work.

<b>Potential Benefits:</b>	<b>Potential Risks:</b>
<ul style="list-style-type: none"> <li>• Sense of role and purpose that is essential to wellbeing</li> <li>• Maintenance of normal routines</li> <li>• Positive outlet from emotional/relationship stressors that may have emerged as a result of diagnosis</li> <li>• Opportunity to continue an income stream for as long as possible</li> <li>• Opportunity to continue to accrue leave and entitlements</li> <li>• Promotes workplaces that are inclusive of people with dementia related disability</li> </ul>	<ul style="list-style-type: none"> <li>• Monitoring of workplace performance can be challenging; changes may not be detectable until an error occurs.</li> <li>• In some workplaces, errors may put the person or others at significant risk</li> <li>• There may be liability issues for the individual/employer, especially if work continues without disclosure of the diagnosis or without an OT assessment</li> <li>• The role may become overwhelming</li> <li>• The loss of certain capacities or changes to workplace roles may cause feelings of frustration/failure</li> <li>• Continuing to work may reduce quality time with family/friends or pursuing travel/retirement goals</li> </ul>

### **How to Access Work/Vocational Capacity Assessment?**

A Specialist Neurologist/Geriatrician/Psychiatrist or Neuropsychologist may be able to provide a general opinion about workplace capacity. This is a more straight forward decision when the symptoms are more advanced/obvious or where there have been quantifiable risks associated with the person working.

However it is important that we do not prematurely cut short the careers of people with dementia without first knowing more about their workplace, roles, and duties and how they match with the person's disabilities and remaining strengths.

In situations where the cognitive changes are more subtle, a more detailed Occupational Therapy workplace assessment is recommended. This will provide vital information about areas of cognitive and functional strength and disability that will help identify whether the person is safe to perform existing work roles. An OT workplace assessment may also provide opportunity to negotiate with an employer to see whether the persons could continue working, even if it is within different capacities/duties.

The following is a list of possible options for accessing workplace capacity assessment:

- Ask the diagnosing clinic for an opinion/ referral
- Ask your GP for an Allied Health Plan and referral to an Occupational Therapist for a workplace assessment.
- Your employer's Human Resources or Occupational Health and Safety Representative may be able to assist. In workplaces where there are positive employer/employee relationships, employers will often happily offer additional support and assistance. Most employers are also legally obliged to support employees within a fair work and equal opportunity employment framework
- If you have income protection or total and permanent disability insurance cover as part of your superannuation or in addition to your superannuation, your policy provider may also refer you for occupational workplace assessment before you are eligible to cease employment and make a claim

The following links can be used to help you/your family, your GP, your insurer or your employer to find an OT who can provide a workplace/vocational capacity assessment:

**Occupational Therapy Australia** has a search function on their website to help locate a specialist OT in your area.

<https://www.otaus.com.au/find-an-occupational-therapist>

**Community Rehab Services – Now called Disability Employment and Management Services**, may also be able to assist. A list of approved service providers is accessible via:

[https://www.dss.gov.au/sites/default/files/documents/12\\_2014/desdms\\_providers\\_by\\_esa\\_from\\_2\\_march\\_2015.pdf](https://www.dss.gov.au/sites/default/files/documents/12_2014/desdms_providers_by_esa_from_2_march_2015.pdf)

**P2Group** This private specialist service also works in collaboration with employers to negotiate return to work plans.

<http://p2group.com.au/>

## **Workplace Discrimination**

People with dementia are protected under workplace anti-discrimination laws and equal opportunity employment laws for people with disability. If you have been formally assessed as being able to work but experience discrimination, help is available:

- If you belong to a union or professional association, their representatives may help you negotiate with your employer to protect you from discrimination.
- If you experience discrimination by your workplace or unexplained redundancy/termination after notifying them of your condition and there is no human resource support available, **Fair Work Australia** may also provide support, advice and advocacy or put you in touch with a workplace lawyer <http://www.fairwork.gov.au/>
- Your specialist may be able to provide reports from any neuropsychological or work capacity assessments that may have been undertaken. These reports can be used as evidence to assist you to resolve any dispute.



## FTD Impacts on Employment and Income

A diagnosis of FTD has been shown to have significant impacts on household income and finances.

### **Employment Impacts**

FTD related disabilities and associated behavioural or communication changes, generally impact the person's capacity to continue active employment quite early in the disease process. Eventually the primary family carer's capacity to work is also impacted as the person with FTD requires closer supervision and support. Even in people diagnosed in their 60's, a diagnosis of FTD may force an earlier than anticipated cessation of employment impacting savings for retirement.

### **Behavioural Impacts**

The disabilities associated with FTD can also lead to poor financial decision making and or excessive spending behaviour. It is not uncommon for carers to present to diagnostic services reporting significant legal and financial hardship due to FTD associated behavioural changes.

### **Costs of Care**

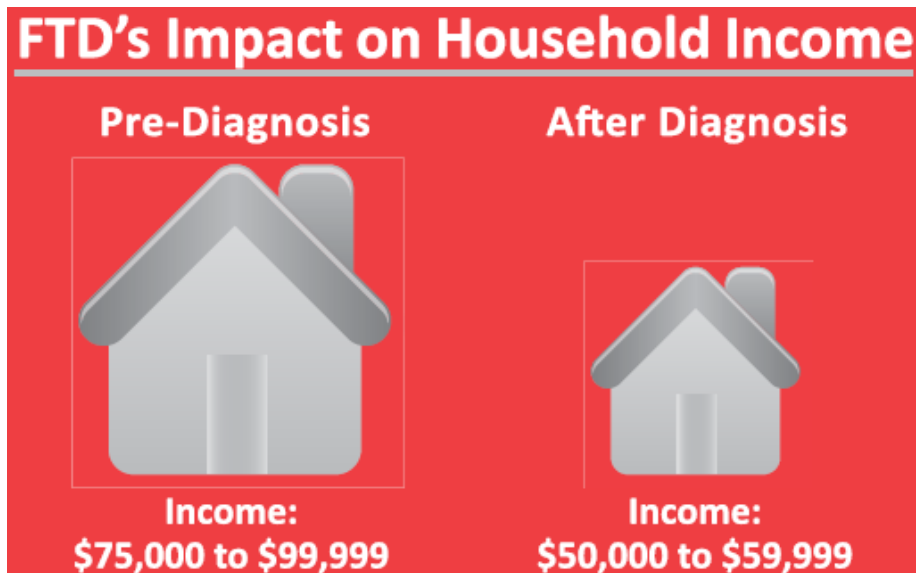
FTD is commonly associated with significant disruption to behaviour. Impulsivity can also lead to significant risks for the person with and their family. For this reason, people with FTD have higher rates of hospitalisation for injuries associated with misadventure or for psychiatric care to manage behavioural symptoms. They also generally require earlier access to community support, higher level care packages and more resources in terms of day care and respite. They also tend to enter residential care much earlier than people with Alzheimer's Disease

### **Study of Socio-economic Impacts of FTD**

A yet to be published study of over 700 FTD family caregivers conducted in 2016 by the Emory University and Association for Frontotemporal degeneration in the US, has reported the following early findings:

- 12 months post diagnosis, only 74% of carers in this study were able to maintain full time work
- 37% of carers had to cease employment altogether due to their caring responsibilities.
- Nearly  $\frac{1}{4}$  of all carers had missed work days due to personal illness or caring responsibilities
- The costs of caring for someone with FTD were also found to be 2-3 times greater than the costs of caring for someone with Alzheimer's Disease

- 58.8% of carers reported income impacts as a result of poor financial decision making, compulsive spending/gambling or impulsive behaviours leading to legal consequence/cost.
- 38.8% reported that they could just make ends meet and 12.6% carers reported that they could not make ends meet



Source: <https://www.theaftd.org/wp-content/uploads/2016/12/AFTD-Newsletter-Fall-2016-1.pdf>

The support and welfare systems in Australia are quite different to those in the US and so these study results are not directly comparable. However there are anecdotal reports from Australian families affected by FTD that indicate many of the same financial stressors.

This burden is much greater for families affected by younger onset FTD (before age 65).

### Case Example:

#### Australian Carer for her 47 year old husband who has behavioural variant FTD (December 2016)

*"After a 6 month hospitalisation to work on a plan and medication regime that would make my husband's behavioural symptoms more manageable, and one residential care eviction, we finally found a residential care facility locally that agreed to take him but only with support from the local mental health services and my entire network of friends and family providing around the clock support. I was unable to work due to this and was still supporting two kids.*

*Yet Centrelink took away my carer payment as soon as he went in to care. When I complained, all they could offer me was New Start at \$581 per fortnight. My husband gets a disability pension of \$877 per fortnight. His care and medication costs \$2200 per month and we have 2 kids under 18 still living at home. His Super is gone. I don't know how I am going to make ends meet. I'm paying all this money for care, yet the facility is ill equipped to cope and if I don't spend my days with him, they'll kick him out.*

*There are no other options on offer yeti feel like I'm being penalised. The worst of it is that FTD has already robbed me of my husband. He no longer responds to me, I am separated by illness, yet my assets and financial future is still tied to him. We can't even get a divorce to keep my family financially afloat because he can't consent."*

The Eastern Cognitive Disorders Clinic has representatives on the Board of the Australian FTD Association (AFTDA). This organisation aims to raise awareness and lobby for system reforms which will better support families affected by FTD in the future. See [www.theftd.org.au](http://www.theftd.org.au) for more information.

For advice on how to reduce the financial impacts of FTD or any form of dementia, please refer to our financial advice and support resource on our website.