



An Australian Government Initiative

## **Module 6: FTD as a young onset dementia: special considerations**

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## Module 6: FTD as a young onset dementia: special considerations

Younger onset dementias such as frontotemporal dementia (FTD,) bring unique challenges to the affected individuals and their families. Whereas many people with Alzheimer's disease may be retired with grown children and even grandchildren at the time of disease onset, those with FTD may still be working and raising families when their symptoms first emerge.

In addition to coping with the changes affecting their loved ones, which may be particularly confusing to young children, the families of those with FTD may be burdened with unexpected financial strains and legal complications.

This module aims to outline some of the important considerations that may be relevant to individuals with younger onset dementias such as FTD and their carers. The information provided is not intended to be exhaustive, but should be useful in guiding families' thoughts about some important considerations related to younger onset dementia.

### Dementia in mid-life: Unique circumstances

When a condition such as FTD occurs during middle life, family members may find themselves caring for a partner with dementia, dependent children, and/or aging parents all at the same time. They may also begin to assume additional responsibility for household or family duties formerly managed by the person with dementia. It is important for these family members to recognise and accept their own limitations, and to seek assistance where possible. All family members – including those who assume the role of the primary care-giver – must learn to care for themselves in order to avoid physical and/or emotional “burn out,” which may lead to resentment of the person with dementia or reduced quality of care.

Helpful resources include:

- The *Carer wellbeing* section of this toolkit's *Module 3 – Managing frontotemporal dementia*
- *Frontotemporal Disorders: Information for Patients, Families, and Caregivers*: information booklet produced by the National Institute on Aging (United States) ([www.nia.nih.gov/Alzheimers/Publications/FTLD/](http://www.nia.nih.gov/Alzheimers/Publications/FTLD/)):



## The impact of FTD on relationships

Changes in the dynamics of personal relationships often accompany the onset of FTD, regardless of the age of onset. This can contribute to the emotional strain of caring for someone with this condition. Marital relationships in particular may suffer. Levels of intimacy in the relationship before the onset of the illness, as well as changes in intimacy which occur as a result of the illness, appear to relate to the amount of distress experienced by spousal carers [1]. Research suggests that younger caregivers may experience more burden than older caregivers [1]. Support groups specific to carers of people with FTD can provide a way for carers to share their experiences and to benefit from the advice offered by others in a similar situation (see *Module 3 – Managing the impacts of frontotemporal dementia*).

Changing relationships between children and a parent with younger onset dementia can be especially difficult to navigate, particularly when children are young and unable to understand the nature of the condition. Professional help and support groups may be of assistance, either by the provision of primary care and support, or through secondary consultation, such as providing support and expert advice to the school counsellor for example.

Relationships with extended families may also be impacted by the onset of FTD. Extended family members may know very little about FTD and may not have the benefit of contact with the diagnosing medical professionals who have provided explanations to immediate family members. Members of the extended family may find it especially difficult to communicate with the person with dementia if their contact with this person is limited.

Family members may also become anxious about the heritability of the condition. Primary caregivers may find it helpful to encourage extended family members to obtain information about the illness and review resources such as this toolkit.

Alzheimer's Australia has developed a number of helpful resources regarding relationship changes in the context of younger onset dementias such as FTD, including:

- *Managing the Impact of Change: a Younger Onset Dementia* tip sheet ([www.alzheimers.org.au/services/tip-sheets.aspx](http://www.alzheimers.org.au/services/tip-sheets.aspx))
- *Younger Onset Dementia: A practical guide*: describes relationship changes and coping styles ([www.alzheimers.org.au/services/further-reading-and-resources.aspx](http://www.alzheimers.org.au/services/further-reading-and-resources.aspx))
- *Emotional Impact*, Chapter 4 of *Exploring the Needs of Younger People with Dementia in Australia*: a report to the Australian Government Department of



Health and Ageing ([www.alzheimers.org.au/services/further-reading-and-resources.aspx](http://www.alzheimers.org.au/services/further-reading-and-resources.aspx))

- *Young people and dementia* help sheets: may help to answer the questions of young people about dementia and may help others explain dementia to them ([www.alzheimers.org.au/understanding-dementia/section-6-young-people-and-dementia.aspx](http://www.alzheimers.org.au/understanding-dementia/section-6-young-people-and-dementia.aspx))
- *In our own words: Younger Onset Dementia*: a collection of personal stories of Australians with younger onset dementia ([www.alzheimers.org.au/services/further-reading-and-resources.aspx](http://www.alzheimers.org.au/services/further-reading-and-resources.aspx))
- *Long & Lonely Road*: stories about living with younger onset dementia ([www.alzheimers.org.au/services/further-reading-and-resources.aspx](http://www.alzheimers.org.au/services/further-reading-and-resources.aspx))
  - *Alzheimer's Australia in each state and territory* also has extensive library resources, including books written specifically for children and teenagers. Video information is also available, as well as culturally diverse resources and information.
  - *Alzheimer's Australia* may also run frequent information sessions in each state for family members on topics such as “what is dementia”. Please refer to their website for session times and topics in your state.
  - *Alzheimer's Australia* runs Living with Memory Loss - Younger Onset Dementia programmes. Contact Helpline on 1800 100 500 for information on these sessions in your local state.

## Employment and financial matters

The onset of FTD in mid-life may be accompanied by a significant financial burden for the family. If the person with dementia is still working when FTD is diagnosed, he or she will probably cease working earlier than anticipated. Financial implications may include loss of income, reduced access to pension plans, and/or changes in the family's ability to continue covering expenses such as private health care. Additional costs associated with medical expenses and respite or residential care may compound the difficulties associated with reduced income [1]. Spouses may be unable to continue working at their previous levels if they are needed to provide care in the home.

If the individual is able to continue working in the early stages of the disease, Commonwealth Rehabilitation Services (<http://www.crsaustralia.gov.au/index.htm>) may be able to assist in maintaining work [2]. Neuropsychological assessment and occupational therapy may be able to assist in providing information about areas of ability that are affected by the dementia and how to work around them [2].



In the event that financial assistance is required by the person with dementia and/or the person's family, options may include:

- Superannuation, with the possibility of early access due to medical condition
- Age Pension, Disability Support Pension, Sickness Allowance (via Centrelink)
- Carer Payments, Carer Allowance, Carer Supplement (via Centrelink)
- Bereavement payments, Bereavement Allowance, Widow Pension, Widow Allowance, (via Centrelink)
- Rent assistance (via Centrelink)
- Concession cards (via Centrelink)
- Income protection insurance
- Trade union arrangements

Professional financial advice should also be sought regarding the above possibilities.

Helpful information regarding planning for the future after receiving a diagnosis of dementia has been provided by Alzheimer's Australia in the following online documents:

- *I have dementia: Planning early*: information written for those with newly diagnosed dementia ([www.alzheimers.org.au/services/planning-early.aspx](http://www.alzheimers.org.au/services/planning-early.aspx))
- *Younger Onset Dementia: Employment and Younger Onset Dementia*: information written for caregivers ([www.alzheimers.org.au/services/employment-and-younger-onset-dementia.aspx#first](http://www.alzheimers.org.au/services/employment-and-younger-onset-dementia.aspx#first))

Centrelink has also provided a number of helpful online documents, including:

- *Caring for someone? A guide to your options and our services* ([www.centrelink.gov.au/internet/internet.nsf/filestores/cd001\\_1102\\_p/\\$file/cd001\\_1102en\\_p.pdf](http://www.centrelink.gov.au/internet/internet.nsf/filestores/cd001_1102_p/$file/cd001_1102en_p.pdf))
- *Carer Payment or Age Pension? Factsheet* ([www.centrelink.gov.au/internet/internet.nsf/publications/cd002.htm](http://www.centrelink.gov.au/internet/internet.nsf/publications/cd002.htm))



Finally, the Australian Government's Department of Health and Ageing also provides information regarding topics such as:

- *Managing Money*  
([www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-factsheet-managing-money](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-factsheet-managing-money))

## Legal matters

A number of legal matters may arise which families need to consider. Professional legal advice should be sought where appropriate

### *Decision making*

At some point in their illness, people with FTD will lose the capacity to make informed financial, legal, medical, and lifestyle decisions. The point at which this occurs will vary depending on the person's degree of cognitive impairment and insight into their difficulties.

- *Enduring Power of Attorney (EPOA)*: This is a legal document in which the person appoints another individual to make decisions on their behalf should they become unable to do so. In some states in Australia, separate EPOA documents are required for financial, medical, and lifestyle decision making. If an EPOA is not already in place, this should be arranged as soon as possible after diagnosis. The person with FTD may need to be formally assessed to determine whether they have the capacity to appoint an EPOA.
- *Guardianship and Administration Orders*: If a person is unable to appoint an EPA, in some circumstances it may be necessary to apply for a Guardian or Administrator to be appointed through the legal system. A Guardian can be appointed to make lifestyle or medical decisions on behalf of the person. An Administrator can be appointed to make financial decisions. Advice from a social worker, medical, or legal professional should be sought prior to making such applications.
- *Will*: This is a legal document containing instructions regarding how to distribute the estate of a deceased person. A Will must be completed, or changes made to an existing Will, while the person retains *testamentary capacity*. In order to have testamentary capacity the person must have an understanding of what a Will is, be aware of the extent of their estate, and be able to outline their chosen beneficiaries. A legal professional should be consulted for more details about testamentary capacity. The person with FTD may need to be formally assessed to determine their testamentary capacity prior to making or changing a



Will. A neuropsychologist would generally be the appropriate health professional to conduct an assessment of testamentary capacity.

Further information about such legal considerations can be found on the Alzheimer's Australia website under:

- *Legal Planning and Dementia: an Alzheimer's Australia position paper*  
([www.alzheimers.org.au/research-publications/alzheimers-australia-numbered-publications.aspx](http://www.alzheimers.org.au/research-publications/alzheimers-australia-numbered-publications.aspx))
- *Younger Onset Dementia: A practical guide*  
([www.alzheimers.org.au/services/further-reading-and-resources.aspx](http://www.alzheimers.org.au/services/further-reading-and-resources.aspx))
- *Early planning and younger onset dementia*  
([www.alzheimers.org.au/services/early-planning-and-younger-onset-dementia.aspx](http://www.alzheimers.org.au/services/early-planning-and-younger-onset-dementia.aspx))
- *Legal and Financial Issues: a Younger Onset Dementia tip sheet*  
([www.alzheimers.org.au/services/tip-sheets.aspx](http://www.alzheimers.org.au/services/tip-sheets.aspx))



## ***Driving***

A person with a diagnosis of FTD may be required to undergo a driving assessment to determine their safety to remain on the roads. As a result of cognitive and behavioural impairments, driving by the person with dementia may be deemed unsafe.

These assessments often create stress and anxiety, as a driving license gives enormous independence. It may also be very difficult for a spouse, child, or partner who is dependent on the person with FTD for transport. It is not uncommon for these carers to underestimate their loved one's driving impairment. For this reason, it is recommended that all people with significant cognitive impairment have an occupational therapist driving assessment performed with a licensed examiner. Often people are able to continue driving, but may need annual assessments.

***Each State and Territory has its own guidelines which must be followed.*** It should be noted that these assessments are not covered by Medicare, and the costs will need to be borne by the driver. The State and Territory authorities regard a driving license as privilege, not a right. Your doctor can assess your medical fitness to drive, but not your driving skills. Given the devastating consequences of motor vehicle accidents, these decisions are best made by specialists such as occupation therapists who have been qualified to assess an individual's driving capacity.

There have been precedents set, in which Doctors who had assessed people with dementia as safe to drive, were later found responsible when those people went on to have road accidents. It is also possible that insurers may refuse to pay out on claims if the person's dementia diagnosis was discovered and they had not undergone a recent driving assessment. For this reason, Doctors are encouraged to now refer on for specialist assessment to avoid possible legal/financial ramifications.

Examples of driving forms and other information are also provided below, and are available on your licensing authority's website. For example, in Victoria, Vic Roads have a number of forms that can be downloaded and submitted via post or email to:

Vic Roads Medical Review  
PO Box 2504  
Kew, VIC 3101  
Phone: 13 11 71  
Fax: 03 9854 2307  
Email: [medicalreview@roads.vic.gov.au](mailto:medicalreview@roads.vic.gov.au)





- *Vic Roads Licencing, Medical, and Exemption forms:*  
[www.vicroads.vic.gov.au/Home/Licences/FeesFormsAndFAQs/LicensingForms](http://www.vicroads.vic.gov.au/Home/Licences/FeesFormsAndFAQs/LicensingForms)
- *Vic Roads information regarding medical conditions and driving:*  
[www.vicroads.vic.gov.au/Home/Licences/MedicalConditions/MedicalConditionsAndDriving.htm](http://www.vicroads.vic.gov.au/Home/Licences/MedicalConditions/MedicalConditionsAndDriving.htm)
- *Vic Roads Guide to Occupational Therapy Driver Assessment:*  
[www.vicroads.vic.gov.au](http://www.vicroads.vic.gov.au)

Further information can be found on the Alzheimer's Australia website under *Dementia and Driving* ([www.alzheimers.org.au/research-publications/driving-and-dementia.aspx](http://www.alzheimers.org.au/research-publications/driving-and-dementia.aspx)).



### **Summary**

Younger onset dementias such as FTD, often presents unique challenges to persons with dementia and their caregivers. These may arise in relation to family circumstances, employment, financial affairs, and legal matters. It is helpful for families to begin considering these issues early in the course of the illness, while the person with dementia may possibly retain the capacity to participate in making important decisions.

Information and assistance is available for those with younger onset dementia and their families. In addition to publically available information, professional advice should always be sought. Appropriate supports are vital in assisting patients and their families cope with the challenges posed by younger onset dementia.

### **References**

1. Harvey, R.J., et al., *Young onset dementia: Epidemiology, clinical symptoms, family burden, support and outcome*. <http://home.kosha.net/~h1415c/report.pdf>, 1998.
2. Hodges, J.R., et al., *Younger onset dementia: A practical guide*. Quality Dementia Care Series. **Alzheimer's Australia**.