



## Module 3:

# Why do we need a different approach in supporting people with FTD and their families/carers?

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## **Module 3: Why do we need a different approach in supporting people with FTD and their families/carers?**

Collaborators in the development of this toolkit, hope that this module may better inform policy makers, funding agencies and health and community service providers about the needs of people with FTD and their carers. We hope that the information in this section and the toolkit more generally may help provide ideas and evidence to support applications for further FTD program development and funding.

The authors of this toolkit are also happy to support and collaborate with any service providers who may wish to establish FTD specific programs. We would also like to be kept informed of any new services for people with FTD so we can pass on this information to the people with FTD and their carers whom we support.

This module will highlight the need to use a person centred problem solving approach to modifying traditional support services and care strategies for people with dementia. This approach will ensure a better response to the unique disabilities and needs of people with FTD and their carers. It will also help us to not lose sight of the person behind the FTD diagnosis.

### **FTD does not follow the same pathway as other forms of dementia**

Most literature on dementia is based on what we know about the usual progression of Alzheimer's disease. This means that most people understand dementia to progress from mild, to moderate and then severe disability. Hence most programs and services supporting people with dementia are established with this pathway in mind.

The frontal and temporal lobes handle the executive and language functions of the brain. When these brain regions are affected, many of the brain's communication, sorting and coordination functions are impacted. This means that disability, behaviour disturbance and risk can be more severe in earlier stages of FTD than in other forms of dementia.

The different rates and pathways of progression need to be considered in how we offer support and advice to people with FTD, to ensure we undertake earlier assessment of capacity, risk and consider earlier referrals to support services for people with FTD.

### **The need for different early intervention and support programs in FTD**

Most early interventions and support programs for people with dementia in Australia are currently based on supporting people with mild symptoms, limited disability and retained insight and communication abilities in the early stage of disease.



As we improve our capacity to diagnose and differentiate more types of dementia, it becomes more and more evident that early assessment and intervention programs for people with dementia need to shift from their current generic form, to a more person centred and disease specific approach.

Traditional early intervention programs for people with dementia, such as counselling, education and the current format of planned group support/activity programs, may not meet the needs of people with FTD in early stages. These may in fact set some people with FTD up for failure when they are already often struggling with communication issues, poor insight or behavioural symptoms. Interventions and programs need to better match the person's remaining abilities if they are to enhance quality of life and be of benefit to the person with FTD.

### **Is it possible to provide support groups and planned activity groups for people with FTD?**

Many health professionals and care workers running these programs in Australia may not be very familiar with the needs of the clients with FTD or how to modify their programs to better meet these needs.

Overseas, FTD specific groups are generally only run for people with early stage progressive non fluent aphasia and some people with FTD/MND or the Parkinson's plus syndromes such as PSP. This is because these are the types of FTD clients who have traditionally been thought to retain sufficient insight to benefit from these interventions.

People with bvFTD and Semantic dementia are generally not considered for these interventions, particularly those who lose insight early in the disease.

People with hyperactive or ritualistic behavioural presentations of FTD are often excluded or rejected from planned activity programs or social gatherings for people with dementia, because of a perceived inability to benefit or because their symptoms disrupt others in the group. However, it is possible that this may be more to do with how we currently offer early intervention programs and groups, rather than an actual incapacity to benefit from support or planned activities.

It is important to consider FTD as a focal dementia, meaning that more medial and posterior functions of the brain such as memory and visual/spatial skills may be relatively spared for much of the disease course. The regions and functions of the brain that are relatively spared in FTD as well as those structures which are impaired, are important to differentiate as they may hold keys to the types of support structures and early intervention programs that may be required by people with FTD.



For instance, instead of trying to get people with FTD to fit with general dementia activity programs, person centred assessment of abilities and interests beforehand, may provide opportunities to better match activity to abilities and preferences and set up more opportunity for success. This may create activity programs with improved staffing ratios or flexible programs that cater for more one on one supervision and support.

An FTD specific program may place more emphasis on short activities that require less concentration, activities that burn off excess energy and agitation with physical activity and more meaningful activities for a younger cohort. Similarly individualised assessment may find ways to engage individuals with symptoms of apathy.

### **Early intervention/support for people with Progressive Non Fluent Aphasia or Logopenic Aphasia**

People with language onset FTD such as logopenic aphasia and progressive non fluent aphasia may benefit from individualised communication strategy training and care planning with a speech pathologist. Carers would also receive education and support on appropriate communication techniques.

This could then be followed up with social gatherings that focus on practicing these new skills with other sufferers and carers who are similarly affected. This may improve symptoms of anxiety and depression by helping people with these deficits, (who often retain insight for longer,) feel less alone and isolated.

Currently, aphasia support groups are mostly attended by people with aphasia secondary to stroke. However people with language onset FTD can be referred to these groups by diagnostic clinics. Refer to the aphasia association website for advice on local referral options <http://www.aphasia.org.au>

### **How is carer burden different in FTD?**

Carers of individuals with FTD are an often overlooked group. Importantly, carers are at risk of experiencing physical, emotional, and social difficulties while caring for someone with a condition such as FTD (Schulz and Martire 2004). The caregiver burden in FTD is greater than in other forms of dementia such as AD (Piguet, Hornberger et al. 2011), and is possibly related to the unique behavioural and cognitive symptoms of FTD.

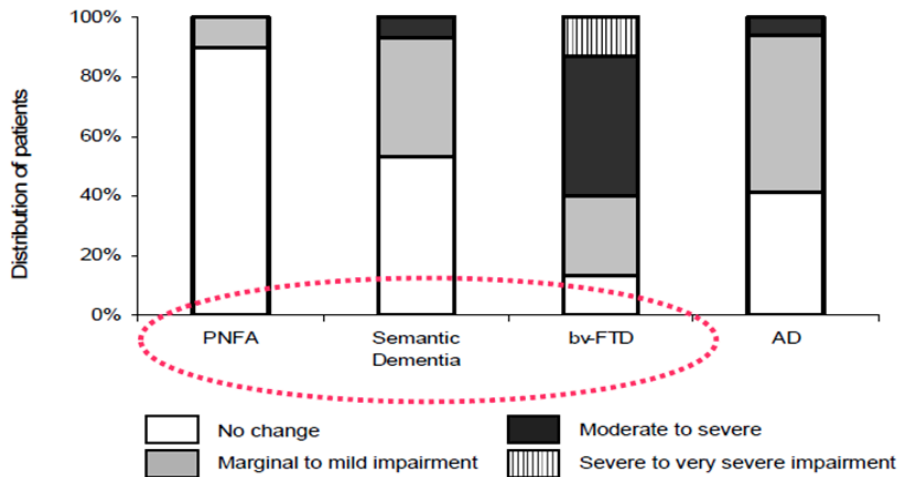
People with FTD often lose insight early in their disease process, creating significant barriers to the person accepting they have a problem, their willingness to seek diagnosis and to accept they need help and support. This greatly contributes to tensions in communication and care delivery as the person with FTD may resist support.



People with FTD will often lose decision making capacity and planning skills early and so carers of people with FTD tend to be supporting these functions for longer than in other types of dementia.

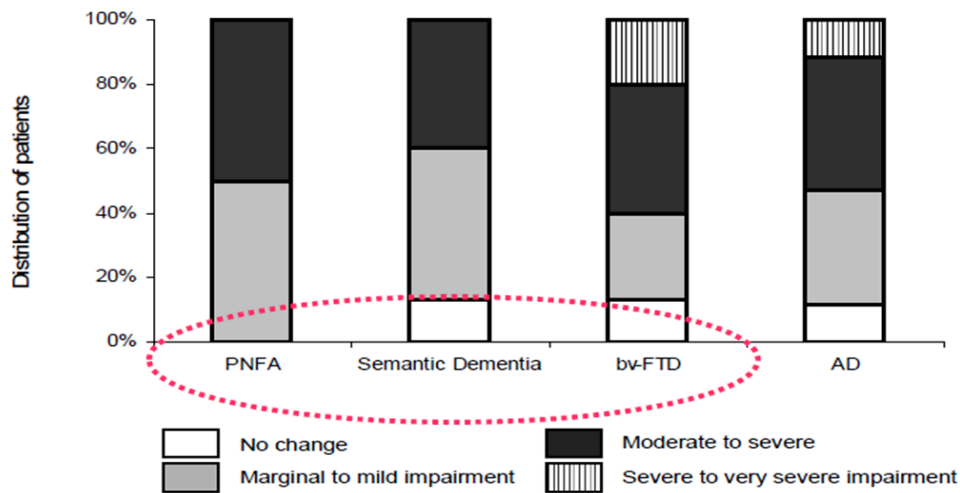
Studies conducted by Eneida Mioshi from Frontier’s FTD research group have also identified that people with some forms of FTD demonstrate higher rates of disability in earlier stage of disease than in Alzheimer’s disease as the graphs below demonstrate. Hence these carers may require assistance and linkage to support services earlier in the disease process, particularly if they are still working and supporting children or elderly parents as well.

### **Performance of basic activities of daily living such as showering, toileting etc**



Mioshi et al, 2007

### **Performance of Instrumental (community and domestic) activities of daily living such as cleaning, shopping, banking etc**



Mioshi et al, 2007

### The need for different support structures for family carers of people with FTD

Because most dementia literature and groups focus on disabilities of AD and vascular dementia as the most common types of dementia, this can become confusing and at times misleading to carers of people with FTD. They often start to question the dementia diagnosis because they can't relate the disabilities being described in these generic dementia groups, to the person they are supporting.

FTD specific carer support groups are still in their infancy in Australia but are well established overseas, particularly in the U.S and UK. Some of these models are described in Dr Tracey Wardill's Churchill Fellowship report:

[http://www-churchilltrust.com.au/site\\_media/fellows/WARDILL\\_Tracey\\_2008.pdf](http://www-churchilltrust.com.au/site_media/fellows/WARDILL_Tracey_2008.pdf)

In the experience of the Eastern Cognitive Disorders Clinic (Vic) and Frontier (NSW), who run FTD specific carer support groups, early interventions for family carers of people with FTD, need to focus on the disabilities associated with FTD and how to understand and cope with these. These carers are desperate to link with others who share similar experiences, not with people who are dealing with other disabilities.

Carers in these two FTD specific support groups, report that they find more compassion and understanding and feel less isolation when they finally link with other FTD carers and professionals who understand these conditions in more depth. This is consistent with carer support research which has found that increasing carer knowledge and skills, reduces the stress associated with care giving. (Schulz and Martire 2004)

Both ECDC and Frontier are currently formally evaluating their respective FTD carer support programs and this may help inform how to replicate more FTD specific dementia support programs across Australia.



*See FTD-specific groups listed at end of in module 2*

## **Why FTD Services can't be regionalised**

FTD is thought to be a rarer form of dementia because there are less people diagnosed with this condition in Australia than other forms of dementia. As diagnostic abilities improve, the prevalence of these conditions may in fact prove to be much greater than we currently think. Right now however, there are relatively small numbers of people diagnosed with FTD, spread across large geographical locations. This means we need to re-think how to deliver disease-specific programs that are accessible for people with FTD.

Specialist diagnostic clinics for FTD don't tend to put regional or geographical restrictions on access to their services for this reason. Other services wanting to support people with FTD need to follow this example if they are to provide access for sufficient numbers of people with FTD to warrant funding and providing disease-specific programs.

This may mean that there needs to be a shift away from local government area funded programs for people with FTD and a move toward several services such as planned activity group, day care and respite programs combining funding or establishing collaborative grant applications to provide FTD specific services across several regions.

## **Using technology to support FTD carers**

Because people with FTD and their families are generally younger and more internet savvy, the use of videoconferencing and the internet, may also help to provide access to support and advice for people with FTD in regional/remote areas. The U.S based website: [www.ftdsupport.com](http://www.ftdsupport.com) offers an international chat forum for FTD carers specifically.

Alzheimer's Australia Vic has also evaluated a pilot chat forum for people with younger onset dementia and their carers.

The Eastern Cognitive Disorders Clinic is currently working toward the establishment of an Australian chapter of the FTD Association and an Australian internet chat forum specifically for FTD carers. This chat forum is expected to go live in early 2012 and will be moderated by health professionals with specific knowledge and experience in supporting people with FTD, so that carers can post specific questions and requests for advice. Refer to the ECDC website for updates: [www.ecdc.org.au](http://www.ecdc.org.au)



## **FTD is not associated with primary memory problems**

Many support programs and behaviour management strategies aimed at helping people with early stages of dementia; focus on disabilities associated with Alzheimer's disease, which most commonly starts with memory loss. Because early FTD is not associated with a primary memory complaint, strategies and education focused on supplementing for memory loss are not going to be particularly useful or relevant to people with FTD.

Loss of insight and executive function will also make it difficult for the person with FTD to independently utilise memory strategies in any case, particularly when attention and concentration start to eventually affect memory processing.

## **The need to see frontal lobe dysfunction as a disturbance of adult brain functions**

A lot of literature on dementia discusses the importance on not 'infantilising' the person with dementia, or treating them like a child. However, those who support carers of people with FTD find it useful to teach carers about the context of frontal lobe development.

The frontal lobes of the brain are not fully developed until late adolescence/teenage years. Essentially the frontal lobes are what help us mature in to adult behaviour where we master our emotions, match actions with consequences, exercise forethought, judgement and planning.

Therefore helping carers understand frontal lobe dysfunction as a loss of these more advanced/adult brain functions, helps them to understand some of the behaviour they may observe, such as loss of emotional regulation, lack of social graces, increased self focus/centeredness and loss of empathy with the perspective of others.

Those who have raised teenagers will be able to relate to this behaviour. When they see its relationship to frontal lobe degeneration, they can be helped to understand why people with more frontal presentations of FTD may need external support and intervention to preserve dignity and safety.

This does not infer that we advocate for people with FTD to be spoken to in baby talk or a condescending manner. People with FTD should still be treated as adults, with dignity and respect. Referring to frontal lobe functions as adult brain functions, is just a useful tool that can be used to help the carer comprehend and relate to what they are observing and to re-think their expectations of the person with FTD, particularly as the disease progresses.





## **People with FTD live in the present and less through reminiscence**

Strategies such as reminiscence therapy which is aimed at people with dementia, who have regressed in to longer term memory due to a loss of shorter term memory, may not always be as powerful for people with FTD.

Frontal lobe dysfunction will eventually significantly impair the person's ability to order thoughts and memories. Changes in emotional registration, language and loss of empathy may also mean that reminiscence may not always produce the same pleasurable reward for the person with FTD or their care giver as what can be expected in other forms of dementia.

People with FTD can tend to also be more impulsive and reactive to their immediate environments. We tend to describe people with FTD as being more 'environmentally cue driven.' Therefore those with extensive experience in supporting people with FTD have observed that as the disease progresses, reference to the past and future eventually declines and the person with FTD exists more and more in the present moment. In this context we need to focus on validating immediately expressed needs more than reminiscence.

There is also a much greater need to manage the environment to provide routine and structure as this is generally the way in which quality of life and the ability to cope can be enhanced. It is also necessary to remove environmental cues for unwanted behaviours because people with FTD tend to be more stimulus and impulse driven.

## **People with FTD require different respite/residential care and activity structures**

Because people with FTD often thrive on structure and routine, many carers observe an improvement in the person's ability to cope and behaviour once they are settled in to a regular respite or residential care routine.

However it is critical for respite/residential service providers to tailor one on one activities that consider the unique disabilities and remaining skills of the person with FTD. It is also important to ensure that services and activities are specific to the needs of someone who is likely to be younger and more physically fit (e.g. incorporate plenty of physical activity.)

The person with FTD will also require different communication strategies or more assistance to initiate and stay on task with personal care and leisure activity.

Care workers in these settings often over-estimate the abilities of the person with FTD because they tend to be younger and more mobile. It is important to distinguish that physical mobility is not always an accurate indicator of abilities in other cognitive domains.



## **Improving transitions in to respite and residential care**

Case managers and family carers can facilitate more successful transitions in to residential care and respite facilities, when they inform and prepare the receiving facility about the person's abilities and what works and doesn't work for that person in terms of strategies, activity and care. This is particularly true is supporting the transition of people with rare and poorly understood conditions such as FTD.

Life stories or respite passports are available from Alzheimer's Australia and DBMAS and may be a useful tool to assist with communicating these issues to the receiving facility.

## **Why does empowerment and decision making need to be considered differently for people with FTD?**

Most literature on dementia focuses on including the person with dementia in planning their future care objectives or putting their affairs in order. Whilst this is ideal, it is critical to consider that executive functions such as insight, judgement and planning will often become impaired in earlier stages of FTD than in other forms of dementia. People with language onset FTD may also provide unreliable responses to questions requiring their decision if they have expressive or receptive communication problems.

Therefore for people with FTD, it is critical that we assess decision making capacity as soon as possible to determine whether the person with FTD still retains ability to participate in major decisions such as medical care, finances and their care/support needs.

When the person with FTD is found to lack decision making capacity, carers often express anxiety regarding not involving the person with FTD fully in decision making. In many cases, reduced insight and emotional responses may in fact lesson the impact of news of diagnosis, prognosis, the need for RAC and other losses.

It can be reassuring for carers to understand that people with FTD who exhibit these disabilities, may not react with the level of grief to these circumstances that we'd expect.

In addition, it is important to consider that the person may become frustrated if we are asking them to make decisions that are too difficult for them to problem solve through or if their decisions are in opposition to what everyone else can see as safe or reasonable. Hence pursuing the person with FTD for decisions in these instances may result in more stress/harm than benefit.

Each case needs to be assessed on an individual basis as decision making capacities will vary between individuals and change as the disease progresses. Likewise, each decision will carry different weight in terms of importance and risk.

A neuropsychologist or medical specialist used to treating clients with dementia and FTD would be best placed to assess decision making capacity.



## **People with FTD are generally younger**

Most care services and care environments such as respite and residential aged care are more used to supporting people who are older and frail. Their exposure to dementia is more likely to be with people with Alzheimer's or vascular dementia. People with FTD are generally younger and more physically fit/able. In combination with common features of FTD such as reduced insight, disinhibition and impulsiveness, this can create significant care challenges for family, health professionals and care workers supporting people with FTD.

The implications of a younger onset dementia are discussed further in module 6.



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