Module 4:
Assessing the impact of frontotemporal dementia

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Module 4: Assessing the impact of frontotemporal dementia

Module 1 and 2 have already highlighted the unique features of FTD and challenges in diagnosing FTD, which require specifically designed assessment tools. Just as many screening tools for dementia can’t diagnose the specific disabilities of FTD, management strategies which were developed for people with Alzheimer’s and other types of dementia, may not always be suitable for people with FTD.

This module is intended as a resource for health care professionals, care workers and family carers/friends who are managing the impact of frontotemporal dementia (FTD) on the individual.

It focuses on person-centred assessment and practical communication and management strategies that will identify and meet care and support needs in order to prevent or minimise behavioural and psychological symptoms of FTD (BPSFTD).

The need to evaluate the success of the strategies we use will also be addressed, as all care givers have an ethical imperative to ensure that interventions are doing good and not also doing harm.

The following modules 4 and 5 bring together the information on FTD contained in modules 1 and 2 and apply it in practical ways to the assessment and care of persons with FTD in the acute, community or residential care settings. This information is also intended to empower family carers and others by informing them about the process of planning care so that those who wish to can apply these principles in their own care giving or contribute to the process with their health service/care support team.

The impacts of FTD for health professionals/care workers

As health service providers we may provide care at many different points along the person’s journey with FTD.

Prior to diagnosis we may find ourselves suspecting and screening for the possibility of FTD for the purpose of referral to medical practitioners or specialised clinics.

We may meet the person in an accident and emergency department, given that the physical impact of a movement disorder, lack of insight or disinhibition increase the risk of accidents and incidents. The person may present in acute or community care as someone whose lack of insight or reasoning skills makes managing a chronic or newly diagnosed health condition such as diabetes difficult. In residential aged care (RAC), the unique disabilities caused by FTD can severely compromise the person’s well-being if not understood by care staff.

After diagnosis we may be trying to assist the person with FTD and their families to cope, reduce risks and maintain health and quality of life.
After diagnosis it will be the responsibility of health service providers such as nurses, social workers and case managers to not only be able to accurately assess the person's needs and strengths but also to teach and inform families and direct care workers about this condition.

The management of FTD is a new and evolving area. Many healthcare professionals in Australia and at international centres have developed expertise in the management of this condition in recent years, but there remains only a small evidence base from which to draw clear FTD-specific management recommendations. This module, therefore, may be updated in the future as further research and information becomes available.

**FTD: Some Guiding Principles for Care Provision**

Before becoming specific about assessment and care provision, it is useful to highlight some general themes or ways of thinking that will assist in guiding your care.

- The behavioural and psychological symptoms of FTD can fluctuate greatly, even across the course of a day, depending on variables such as environment and fatigue. This means that the results of assessment or use of strategies may be different at different times of day. It is therefore useful to continue problem-solving and trying different strategies until suitable techniques are identified.

- We are dealing with a progressive condition; the goal posts are always moving and we need to be constantly vigilant.

- There are a number of potential ‘danger periods’ for symptom emergence or exacerbation. These include times of transition into care or hospital, times when the person is immersed in an unfamiliar environment and times when the person is over- or under-stimulated. People with FTD are often ‘routine-bound’ and dependent on stable environmental conditions; when removed from comfortable conditions they may display a “de-compensation” in behaviour. Minimizing disruption to routine is often helpful.

- Cognitive impairments themselves are not modifiable. This is particularly true in people with FTD who have limited insight into their condition. Thus, the primary interventions should focus on psychosocial and environmental adjustments, improved communication, reliance on remaining strengths, and informing carers to enable them to adjust expectations and their own behaviours. When individuals do retain insight (e.g., in early PNFA), techniques should be adjusted accordingly.

- Professional assessment and advice is valuable in the management of FTD. Carers may be able to problem-solve on their own and may even cope effectively for a relatively long period of time, but as the FTD progresses there is no substitute for the advice of specialists who understand the complexities of the presenting symptoms.
• Specialists may include a neurologist, neuro-psychiatrist, cognitive nurse, speech pathologist, occupational therapist, and/or psychologist. A social worker or case manager may also be able to provide specialist advice in regard to financial and practical care and support options.

• When care is no longer within the scope of our knowledge, expertise or practice then we have an ethical duty to seek specialist assistance. Specialists FTD clinics have been highlighted in other modules.

Health Professionals and Care workers: Using FTD Assessment Tools to Plan Care

The point has been made in Modules One and Two, that existing and recommended multidisciplinary cognitive assessment tools such as the Mini Mental State Examination (MMSE) or the residential care Psychogeriatric Assessment Scale (PAS,) will not adequately assess the possibility or extent of FTD symptoms. An accurate assessment is critical to quality care[1].


This section will discuss the use of two dedicated and validated FTD assessment tools, Addenbrooke’s Cognitive Examination (ACE-R), a tool developed by the Cambridge FTD research group, and the Frontal Behavioural Inventory (FBI). Both tools can be found on-line at the Australian Dementia Collaborative Research Centres website www.dementia-assessment.com.au/frontotemporal. Both tools also come with on-line instruction guides and it is important, as with any assessment tool, to read the guide and feel competent to use the tool. The Cambridge Behavioural Inventory is an alternative to the FBI and can be found on the Frontier website. www.ftdrg.org.au.

The ACE-R is a useful tool in that it includes the MMSE tests of registration, recall, concentration, basic language and writing skills. However, it importantly also features more in-depth tasks and questions that establish the presence of the FTD symptoms of verbal fluency, naming, recognition and perceptual ability. A care provider's motivation in using such a tool is generally to identify aspects of cognitive function that can no longer be relied upon, and having identified those deficits, to plan care that assists the person compensate for them.

However, we must also view these tools as providing information about personal strengths. The individual items in a cognitive assessment are capable of telling us much about what is still working for the person, and these strengths can be used by us when planning care.

For example, lack of concentration will mean that verbal instruction will be quickly ‘forgotten’ and lengthy explanations will be more likely to irritate than assist. Frequently repeated and simple verbal prompts, on the other hand, may enable the person to independently complete a task if they retain some motivation and the requisite visuospatial skills.
Behavioural assessment tools are different from cognitive assessments. They focus less on the cognitive impairments and more on the personal behavioural outcomes of the impairments and the behavioural reactions of the person to a set of circumstances or events.

A behavioural assessment tool will generally guide either a family carer or health service provider to recall and record the incidence and severity of listed behavioural symptoms. The user may occasionally be asked to try and link the observed behaviour to a probable cause.

Traditionally in Residential Aged Care, such tools focused on the BPSD that would gain funding, specifically wandering and physical or verbal aggression. In the community the focus has been on carer burden with such tools as the Cohen Mansfield Agitation Index (CMIA) which catalogues the incidence of the more common behaviours of concern.

The frontal behavioural inventory (FBI) and Cambridge behavioural inventory (CBI) are particularly focused on frontal/temporal lobe function and assessing the incidence of FTD symptoms such as aphasia, verbal apraxia, utilization behaviour and excessive jocularity. An important but possibly underutilised application for such tools is the initial benchmarking of behavioural symptoms and then ongoing evaluation to demonstrate the effectiveness of care and strategies aimed at reducing the impact of behavioural symptoms.

There are some general principles of which it is useful to be aware when using an assessment tool.

The outcome of an assessment can be affected by the:

- knowledge, empathy and skills of the assessor;
- impact of the environment e.g. noise, light, distractions;
- premorbid levels of education and language skills of the client; and
- general health, mood, degree of tiredness, sensory deficits, comfort and confidence of the client.

Tools are designed to standardise the data being collected and guide the assessor but they may also limit the type and amount of information collected.

**Whilst highlighting validated FTD assessment tools is useful for health professionals and carer workers, these assessment tools only complement and never replace observation and interview and will only partially inform how we should provide care for the person with FTD. Assessment is a complex and ongoing process.**
Person Centred Care: A Model for Assessment and Care Planning

The management of FTD disabilities and causes of the behavioural and psychological symptoms of FTD is greatly facilitated by a person-centred approach [2, 3]. To be person-centred is to focus primarily on the unique story, circumstances and context of care of the affected individual that are contributing to the manifest symptoms, rather than merely focusing on the symptoms, disabilities and behaviours themselves.

Different people may also respond to the same management technique in very different ways, depending on factors such as personality style, life experience, environmental circumstances and remaining strengths.

Figure 1. Illustration of person-centred care (courtesy Dr. Sam Davis, 2009)

Figure 1 illustrates that behaviour is a product of all that we are – our biology, our past, and our emotions. To respond to the BPSD, we must respond to the person in his or her entirety.

A problem-solving approach is also a key element of effective management of FTD symptoms. Problem-solving involves collecting information not only about the cognitive impairment and BPSD but also about the person, their lifestyle and their environment in order to identify the cause of problems, set goals and plan, implement, and evaluate tailored care that manages the cause of the problem rather than reactive decisions made in response to presenting behaviours.

The CAUSED model developed by Alzheimer's Australia Vic in 2006, but yet to be published, is used by DBMAS Vic staff and has been found to be particularly useful when problem-solving in dementia. This model encourages consideration of all potentially contributing factors and unmet needs.
This simple acronym helps us think about all the confounding factors that may have CAUSED a person’s symptoms and behaviour.

Communication: e.g., does the person understand what is expected of him or her?

Activity: e.g., is the person over-stimulated or bored; does the assistance we provide or the task itself, enable or disable?

Unwell: e.g., is the person depressed, in pain or simply uncomfortable?

Story: Who is this person? What were his or her interests, habits, former occupation(s), personal preferences, significant life events, culture and attitudes? How are these likely to influence the person’s behaviour?

Environment: e.g., are there physical obstacles, noise, unfamiliarity or other aspects of the environment that are either enabling or disabling?

Dementia: e.g., what are person’s cognitive disabilities; retained abilities and how is this affecting them?

One method of facilitating a critical analysis of the assessment data we collect, and of documenting a person-centred problem-solving approach is concept mapping. [4, 5] Concept mapping is a visual representation of, and guide to, thinking and problem-solving. This process is employed by DBMAS Vic staff to problem solve for clients with behavioural and psychological symptoms of dementia and to mentor and teach others how to do this.

We will use a spider concept map format which places the person and their wellbeing central to our thinking as the key concept and depicts other factors that impact on the person’s well-being as sub concepts. Making links between all the concepts, we create a visual representation of all possible contributing factors, the relationship between them and their impact on the well-being of the person. Mapping is useful not only for problem-solving but also for learning from the process [6].
An outline of an example spider concept map using the CAUSED framework is shown here in figure 2:

![Spider Concept Map](image)

**Figure 2. CAUSED model**

Concept mapping can be completed as a team, or by an individual, to clarify thinking and organize facts[7]. Ideally, in a residential or community setting, a team approach would be used as different members of the care team come to the process with different information. Some of that information inevitably may not have been formally documented, and may be somewhat subjective in the form of a ‘feeling’ or ‘belief’, but it is important that it is discussed.

A community care team may consist of a case manager, care worker, family, RDNS, GP and other health professional or client representatives concerned in the case. In residential care the team may likewise be made up of the manager, RN other staff, family, lifestyle staff, GP and other health care providers.

Figure 3 shows that each of the factors in the CAUSED model of assessment may be found to impact on the person. However more importantly, the impact of each factor may be intensified[5] when combined with the others. Similarly strengths may be amplified.
Figure 3: Person Centred Approach

For example, difficulty in concentrating, or being given a too complex task, or poor communication skills of staff or family, may individually hinder a person’s ability to cope with their world, but in combination the impact can be catastrophic.

A natural curiosity, combined with good health and mobility, good eyesight and a desire for occupation, are all strengths which when combined and encouraged can create a positive experience for the person through exploring and interacting with their environment.

A concept map is a documentation of a full global review of care, and an evaluation of the strengths and issues for the person and of existing approaches to care or care plans. It will reveal and link the probable causes of behavioural symptoms, unmet needs and potential risks. Importantly, it also highlights the person’s strengths and preferences, and links these to strategies which may be encouraged to counter the causes of problems.

Concept mapping does not replace the normal assessment processes or tools we use, but it brings information from these to a team discussion and facilitates an accurate analysis of that data as well as the prioritisation of findings and actions to be taken.

The outcome for the person with FTD, staff and the organization is improved care. Importantly, staff also learn from the process of concept mapping, from each other, and
from the facilitator who can pass on recent research findings and evidence-based practice concepts in a straightforward and usable fashion.

Further information about concept mapping and links to education on this approach can be obtained via DBMAS Victoria ph 1800 699 799 from within Victoria or (03) 9816 0619 from other states.

**Using an FTD Case Study to demonstrate the Concept Mapping Process**

**Overview of Process**

Figure 4 (next page) illustrates how assessment data can be categorised into a concept map using the CAUSED headings.
Impact of dementia on:
- Short and long term memory.
- Insight.
- Judgement.
- Planning/organisation
- New learning or concentration.
- Behaviours
- Emotional regulation
- Physical abilities
- Visuospatial skills
- Recognising things for what they are
- Initiation and follow through
- Reading, writing and speaking.

• Who is acceptable to the person and who is not. Why?
• Long term communication skills of person.
• Time needed and allowed to respond.
• Communication skills of family carers/staff.
• Culture and attitudes of family carers/staff e.g. fearful, custodial, use of humour etc.
• Does the person feel ‘at home’ and safe here.
• What wants/needs are being communicated? (have we asked?)

• Person’s degree of interest in task.
• Complexity of task.
• Necessity of task
• Habits.
• Are the person’s skills matched to activities?
• Are their motivations matched to activities?
• Time allowed and timing of tasks.
• What works in assisting the person with tasks/activities?
• Use of aids and their impact on person.

Figure 4: SPIDER CONCEPT MAP
These lists of headings are suggestions for mapping and are not exhaustive.
Once all available information and assessment data are on the board, look for links and patterns that indicate cause and effect.
**Case Study: Angela**

Angela and Jim live in their own home in an inner suburb of Melbourne. Angela is 59 years old and still works part time in a large retail business. Theirs is a second marriage of 7 years for both parties.

Angela is a Type 2 insulin dependent diabetic who has recently been diagnosed with a Behavioural/Frontal Variant of FTD. Her presenting symptoms 3 years ago were; reduced concentration, increased irritability and mood swings and reduced ability to plan and initiate activities of daily living such as gardening, housework and community activities.

Angela was prescribed the antidepressant Sertraline 100mg daily by her GP three years ago and has recently been commenced on the antipsychotic Quetiapine 25mg twice daily, primarily at her husband’s request because of her aggressive outbursts and his difficulty in coping with these. However there has been no improvement noted by Jim in these symptoms.

Prior to onset of symptoms 3 years ago, Angela was a shy and retiring person in a loving, supportive relationship with Jim. Together, she and her husband had bought, and were renovating, their existing home. Her hobbies and interests include gardening, card games, reading and music; she was also a bit of a wizard with word processing.

Four years ago she decided on a career change and went from a role as a PA for a senior accountant and took on her current retail job. However, her manager has been receiving complaints about her moodiness from both customers and other staff. This has resulted in a written warning and a move away from customer service to a storeroom and shelf stocking role. She has also started to turn up late to work or call in sick as Jim states she is tired all the time and sometimes not wanting to get up in the morning.

Angela’s driving licence was suspended nine months ago, because of her unstable diabetes, making getting to and from work more difficult. She currently uses public transport, a 30 minute trip on a bus, as her husband no longer feels confident to drive outside their neighbourhood and refuses to drive her there.

Angela has become obsessive about her insulin administration, fearing the long term effects of high blood sugar. Whilst she can recite her dosages she does not seem to know how to relate these to her needs for the correct dose to manage her blood sugar levels and does not follow the recommended dosages or procedures.

A further complication, especially on days she works, is her tendency to forget to eat. The result has been repeated hypoglycaemic attacks and lost consciousness as well as one fall resulting in a severe laceration to her arm.
Jim states he is fed up and at his wits end about how to overcome this issue. He expresses frustration that she is choosing to do this when the doctors and diabetes educators have told her again and again what to do. Whilst Jim is concerned regarding Angela’s inability to manage her diabetes he will no longer try to help her with this, as his intervening tends to trigger her aggression. Jim has complained that he gets angry, yells a lot and feels like hitting her back when she becomes aggressive with him.

On the home front, Angela is becoming increasingly withdrawn. She and her husband were in relationship counselling “off and on” for three years before her FTD diagnosis. Both see the other as being at fault. Jim complains of her lack of interest in the home, her unnecessary spending on un-needed items and lack of participation in the renovation. The renovation has stalled and her house work and cooking have deteriorated. Jim states he “resents having to do all the work around the home”. Angela states that her husband is a “bully” and hard to live with. Their previously close physical relationship ended some time ago and they now sleep in separate rooms. Angela will withdraw to her room most afternoons, complaining of tiredness.

Angela has also been verbally aggressive towards Jim on a regular basis, hitting out at him on occasions, especially when he tries to correct her insulin administration or get her to do things around the house. Angela has not been physically aggressive towards anyone else and on a superficial level, presents well to health professionals with fluent communication abilities. She is responsive, engages well and even jokes with staff. There are no clear indications of depression. Neuropsychological testing reveals poor insight into her medical conditions, with an inability to follow through on her diabetes management even though she can verbalise her insulin regime using long term memory.

We will concept map and analyse the following case study. This is initially shown as lists of data in Figure 5 under the sub headings of spider concept map.

The data in the map is analysed in Figure 6 to demonstrate the links between concepts and the impact on the central concept of the well-being of the person with FTD. Question marks are used to denote points that need further assessment.
Short and long term memory intact. Registration or concentration impaired. Poor insight and judgement. Orientated to time place and person. Impaired capacity for decision making. Visuospatial skills intact. Recognises things for what they are. Calculation skills. Reading, writing and speaking intact.


Living in old house 7 years half-way through renovation. Now not well maintained as a home, untidy and cluttered with unnecessary buying. Angela and Jim using separate bedrooms.

Current health status
Recent change:
- Unstable diabetes and failure to manage
- Introduced Quetiapine
- Antidepressant? for depression or apathy in FTD
Complaints of tiredness
Forgetting to eat
Effects, side effects and drug interactions.
Very mobile but recent falls with hypo

Lack of participation in activities of daily living related to home life. Loss of skills. Loss of driving and independence. Necessity for assistance but lack of capacity to understand need. Loss of ability to initiate and follow through on leisure activities such as computer, gardening.

Australian born 1948, raised in Melbourne. Married 7 years
2nd marriages for both
Estranged son from first marriage
An accountant to sales person 4 y ago, now working in a store room
Early strong relationship with husband now breaking down, 3 years of counselling but bilateral lack of desire and affection.
Husband not coping with wife’s FTD or her failure to manage her diabetes.
She is very worried about the long term effects of diabetes.
Retiring woman, now more so, and no friends or extended family.
Likes to read

Figure 5: Categorised data in a Spider Concept Map format for Case Study: Angela
Presented as apathy of 5 yrs

Diagnosed FTD 1 yr ago

Registration or concentration impaired
Poor insight, reasoning planning organising and judgement.
Impaired capacity for decision making

Decreased short term memory due to reduced concentration/attention
But long term memory intact.

Orientated to time place and person.
Visuospatial skills intact
Recognises things for what they are.
Calculation skills OK
Reading, writing and speaking intact.

Impaired capacity for decision making

Visuospatial skills intact
Recognises things for what they are.
Calculation skills OK
Reading, writing and speaking intact.

Decreased short term memory due to reduced concentration/attention
But long term memory intact.

Orientated to time place and person.
Visuospatial skills intact
Recognises things for what they are.
Calculation skills OK
Reading, writing and speaking intact.

Increasing withdrawal.

Complaints of feeling bullied by husband

Lack of interest in ADLs and IADLs

Loss of skills

Necessity for assistance but lack of capacity to understand need.

Loss of independence and ability to continue leisure activities such as socialising, computer, gardening

Very mobile but recent falls with hypo

Use of RONS to monitor?

Complaints of moodiness from customers and workmates

Information and support for workplace

Loss of driving and independence

Loss of independence and ability to continue leisure activities such as socialising, computer, gardening

Forgetting to eat?

Complaints of tiredness?

Effects, side effects, drug's?

? Compliance

Antipsychotic Quetiapine

Diabetes: now unstable due to insulin overdosing

Gp prescribed Antidepressant?
Depression or FTD symptoms

Use of separate bedrooms.

Use separate bedrooms.

Now working in a store room
An accountant to sales person 4 y ago
Customer relations

Australian born 1948, rose in Melbourne.
Married 7 years 2nd marriages for both
Estranged son from first marriage why?

Retiring woman, now more so, no friends (why)
or extended family.
Likes to read

Early strong relationship with husband now breaking down,
3 years of counselling but bilateral lack of desire and affection.

Husband not coping with wife's FTD or her failure to manage her diabetes.
She is scared of hypo's

Jim's need for information support and respite?

Home, not well maintained, untidy and cluttered with unnecessarily bought items.

Living in old house 7 years
Half way through renovation.

Figure 6: Concept Map for Angela
Reading the Map

**Figure 6** shows how a finished map may look. It includes the use of colour: green to highlight strengths, red to signal problems and yellow to indicate questions that need further information or assessment before answers or facts can be confirmed.

Whilst looking at a completed concept map can be somewhat overwhelming, normally when you are included in developing the map the links between information make much more sense. Once information is exhausted and the map is complete, participants can be encouraged to brainstorm to create ways in which to use the person’s strengths, which are shaded in green, to counter the problems shown in red. Yellow highlights areas where more information or a follow-up action is required.

Constructing an Action Plan from the Map

**Step One**

Discuss with the team, reach agreement and summarise the issues in terms of a problem statement. Generate a hypothesis or probable cause. In this case, some of the problems for Angela are:

- A deteriorating relationship with her husband as well as the poor understanding with her workmates and customers, and an inability to manage her diabetes. Links are made between these problems and her lack of insight and concentration.

- Mood swings and forgetfulness are related to her dementia but further exacerbated by her unstable diabetes and so these concepts are linked on the map.

- Tiredness, risk of falls and loss of driving and independence also relate to her unstable diabetes.

The problem statements highlight the fact that her quality of life is being affected not just by her FTD. Uncontrolled diabetes in combination with FTD is not only disabling her but also putting her and her relationships at risk. Whilst we cannot cure the FTD we can help her overcome some of the deficits caused by it and better manage her diabetes.

**Step Two**

There are some highlighted question marks that indicate a need for further assessment. In this case an appropriate team member will be given the job of following these up with an inquiry, referral or assessment.

- There is the possibility that there are undiagnosed health problems causing tiredness or that this relates to side effects from medication. A delirium screen to
rule out treatable causes and medication review are warranted to see if there is a link between the commencement of the medication and the onset of increased fatigue.

• There is a question regarding her compliance with her medication, or lack of it, given her history of non-compliance with her insulin regime and her husband’s reluctance to supervise her. This in turn raises the issue of the effects and side effects of those medicines, in particular an antidepressant and antipsychotic which may, or may not, be necessary.

• Although it is apparent that she has always been what is generally described as a loner it does not explain the complete and current lack of support networks including that of her estranged son.

• A final query is that of possible access to practical support through the RDNS for medication management given that with an intact LTM and a fear of hypos she could recognize and accept their role as nurses. Home help may also be available to her to relieve some of the risk inherent in a disorderly environment and a stressed husband.

**Step Three**

Using her existing strengths and abilities, as well other available resources, strategies will be brainstormed, documented and implemented by the team addressing the causes of the problems and risks in her life. For example:

• Whilst reasoning and planning are impaired, long term memory is intact, and this strength may be used to help her better manage her insulin dependence. At the same time restricting her access to more insulin than she needs in a day may also help.

• her initial loving relationship with her husband may be reaffirmed if he has the information and education needed to fully understand his wife's condition and better communicate with her as well as some opportunity for respite.

• Improve communication regarding opportunity for respite.
Choosing strategies to assist the person with FTD and minimise the impact of FTD symptoms

Which strategies or care plans to implement should be informed by a comprehensive person centred assessment, including the following critical elements:

- Risk Assessment
- Establishment of Goals

Risk assessment

A risk is the chance of something happening that will have a negative impact on:
- The person with FTD
- Their family/friends
- Care staff
- Organisations
- The wider community

Risk is measured in terms of likelihood and consequences. Risk requires assessment of the degree and cause, then actions to address and minimize the cause of the risk.

Individuals with FTD and their carers may find themselves at physical or psychological risk during the course of the illness. Therefore identifying and managing risk is an important but often overlooked aspect of the overall management of FTD.

Depression/Self Harm

Some individuals with FTD are at risk of developing depression. This is mainly true for those who retain insight into their condition for longer periods of time, as often happens in slowly progressing cases of PNFA. Individuals suffering from depression may harbour thoughts of self-harm, so it is important that they receive professional support and assistance when indicated. The risk of self harm is determined by the degree to which the person has demonstrated an intent and clear plan to self harm/suicide. A person’s risk is also determined by their physical and cognitive capacity to follow through on plans of self harm.

People with less insight may have a lower risk of developing depression but may still present with symptoms of brain-based apathy or amotivation, which should be carefully distinguished from symptoms of depression.

Other risks related to FTD disabilities

Other individuals with FTD may display a lack of impulse control which may lead to risk of harming themselves or others physically, particularly if this symptom occurs in the context of increased aggression. Physical harm may also result from falls and swallowing difficulties associated with motor symptoms.
Changes in sexual behaviour may be a cause for concern in some cases, though the most typical change in sexual behaviour in FTD is a loss of libido.

Decision-making impairments, especially when combined with reduced insight, may lead some patients with FTD to engage in risky behaviours such as driving despite being impulsive and unsafe, misusing electrical appliances around the home, absconding from care, wandering or becoming lost or drinking excessively. Financial losses may be sustained if the person begins to gamble without restraint and/or lose his or her understanding of the meaning of money, placing the individual at risk of financial abuse.

*Carer burnout and risks to accommodation*

People with FTD can experience significant disability and behavioural disturbance. This not only impacts the person for FTD but the well-being of those providing care. As already identified in other modules, rates of carer burnout and distress in carers supporting someone with FTD are often higher than in carers supporting people with other forms of dementia/illness. Carer burnout is often overlooked, but should be given more priority as it significantly increases the risk of the person with FTD experiencing an accommodation and care crisis.

Carer stress and burden needs to be evaluated. Validated tools such as the Zarit Caregiver burden scale may help in identifying risk of carer burnout [8, 9]. It is critical to link carers with education, specialist support and counselling to manage these risks.

Validating and addressing carer burden and helping the carer access support services and respite will not only reduce risks to the carer's physical and psychological wellbeing, but will also go a long way to sustaining them in their care giving role. This will generally help maintain the person with FTD in their home setting for longer.

Residential care facilities and dementia care services are also currently often ill-equipped to cope with the care needs of people with FTD. Hence people with FTD can often be at risk of losing their places in community care programs and residential care.

For health professionals and care workers: team problem solving, care planning using concept mapping and regular access to specialist mentorship support and education are all critical interventions to help maintain staff capacity to cope and to secure their ongoing support and accommodation.

*General Risk Assessment Principles*

In assessing an individual's degree of psychological or physical risk, it is useful to consider the CAUSED model and identify areas of potential risk in each category. Pre-existing personality traits and individual circumstances may lead to risks for patients with some of the above symptoms but not for others. It is also important to review risks regularly as they may change with the progression of the condition.
Some helpful questions to ask when establishing the degree and consequences of risk are:

- What is the nature of the actual or potential activity or incident?
- What factors, including personal, environmental, health, psychosocial, cultural, organisational and human resources are contributing to risk?
- Is the risk of serious harm high, medium or low?
- Is there a high, medium or low risk to the client if they are prevented or restrained from participating in the activity?
- What positive outcome may there be if the client engages in the activity?
- What are the positive or negative outcomes for others; are they high, medium or low?
- Can factors contributing to the risk be controlled?
- If so, by what is to be done, by whom, when, where and how?

The final step is all parties to agree upon a risk reduction action plan that documents who is to do what, by when, in order to reduce risk as much as is possible. Monitor, evaluate the outcomes and regularly review the risk management plan. Consultations with the managing team of health professionals or specialists dementia services are essential whenever risk has been identified.
**Advice and support**

For advice regarding the management of risks in FTD and linkage to specialist assessment and support call:

The Dementia Behaviour Management Advisory Service: 1800 699 799

The National Dementia Helpline: 1800 500 853

Helpful information sheets developed by Alzheimer's Australia include:

- *Depression & Dementia*  

- *Caring for Someone with Dementia: Safety Issues*  
  (www.alzheimers.org.au/understanding-dementia/update-sheets.aspx)

- *Caring for Someone with Dementia: Caring for someone who lives alone*  
  (www.alzheimers.org.au/understanding-dementia/update-sheets.aspx)

- *The environment and dementia: Health and safety for carers*  

- *Safety Issues*  
  (www.alzheimers.org.au/services/safety-issues.aspx)
What are the goals of the person with FTD/their carers?

Having assessed the person and observed what is happening, we can begin to establish a plan of action. The first step in planning intervention is to determine goals for both the person with FTD and those involved in their care. In the context of caring for someone with FTD, a goal is a statement of the best situation we could expect or achieve given any individual set of circumstances/interventions. It should be realistic.

We can never have a stated goal of curing or managing the FTD; it is an incurable and progressive condition. We can, however, enable the person to cope with the deficits caused by the FTD. For example, a goal of fluency in speech may be unrealistic but a goal of having the person able to communicate unmet needs is achievable by using communication aids or changing our approaches to communication.

A person who lacks insight and planning skills can become frustrated and angry when they fail with an activity. We cannot establish a goal that the person will achieve understanding and acceptance if that person lacks insight in the first place. However, we can set goals to decrease frustration levels when we modify the task and environment to help the person succeed. Goals, where possible, should be supported by some measurable evaluation criteria. Once a care plan or strategy has been implemented, evaluation of those plans and strategies should start with establishing how well both client and carer goals have been met [10].

Evaluating the Success of Care

Evidencing the quality and value of the care we provide is an important part of caring. Nationally and internationally it is not something health service providers are comfortable with doing, or particularly good at. This may be because it is very difficult to measure or evaluate outcomes that are subjective or abstract such as ‘quality of life’. In recent years there has been a growing concern that we find ways of measuring the quality of our psychosocial interventions and outcomes, but systematic reviews of recent research are still recommending better methodologies and measures [23-28]. However there is a growing interest in measures of professional accountability and evidence-based care [28-31]. Although we may not be directly involved with research into care, we should at least evaluate the outcomes of the care we provide for our clients’ in order to build up a data base for retrospective studies of successful interventions for FTD.
Evaluation is defined as measuring the worth and merit of care. Evaluation may be:

- **Formative** – ongoing evaluation that provides information regarding care or programs and processes as we try new things to improve our approaches to care. We can use progress or case notes and assessment tools such as behavioral or pain assessments.

- **Summative** – as in a care plan evaluation or review, conducted at the end of a set time frame or with a purpose of drawing conclusions regarding attainment of client goals and desired outcomes.
References


5. Aberdeen, S., Concept Mapping To Improve Victorian Residential Aged Care Team Learning And Problem-Solving For Clients With The Behavioural And Psychological Symptoms Of Dementia. 2010, unpublished doctoral thesis, School of Public Health, La Trobe University.


