Module 5:
Managing the impact of FTD disabilities and symptoms

Non-pharmacological (non medication) approaches to the management of FTD behavioural symptoms and disabilities

Non-pharmacological approaches are widely considered to be the first line response to symptoms of dementia because they can address a wide range of problems, such as cognitive impairments, sleep difficulties, communication problems, inactivity, and loneliness, some of which may not be amenable to pharmacological treatment. Non pharmacological approaches also attempt to identify underlying causes for behaviours and problems rather than treating symptoms only.

Furthermore, a non-pharmacological approach in conjunction with family carer education, can help people with dementia and carers to work around dementia-related disabilities and behavioural symptoms and improve the quality of life and relationships between carers and care recipients.

When skilfully applied, non-pharmacological approaches can also offer a lower cost and more tolerable alternative to treating with medication, particularly when side effects and potential adverse outcomes of medications are considered.

Given the limited evidence base specific to the non-pharmacological management of symptoms in FTD, many principles used in FTD management to date have been borrowed from those used to manage behavioural and psychological symptoms of acquired brain injury and dementia more generally.

The following tables intend to provide some practical strategies which may be useful in managing some of the more common disabilities and symptoms in FTD.
The strategies provided here are organised according to the categories of the CAUSED assessment and problem solving model.

Where evidence gaps exist in the literature, the interdisciplinary panel of FTD expert consultants who contributed to this toolkit have provided ideas based on their experience supporting people with FTD and their caregivers.

It is important to highlight that many behavioural and psychological symptoms of FTD are actually triggered by the caregiver's approach and attitudes toward the person with FTD in a given scenario [21, 22]. This is more likely when caregivers have unrealistic expectations of the person or when care delivery and strategies are not tailored to the person's preferences, abilities and strengths.

These suggestions are not exhaustive. The symptoms experienced by individuals with FTD are highly variable, regardless of diagnostic subtype. Similar symptoms in different individuals may require very different management techniques to enable the individual.

Not every strategy will work for every affected individual, and not every strategy will work every time it is applied. Each case and situation will need an individually tailored response.

As highlighted in module 4, do your assessment first. Make sure the person with FTD has the skills to adopt or respond to the strategies selected.

For health professionals, ensure that care-givers supporting the person with FTD also have the knowledge, skill and desire to adopt your recommended strategies. All care and behaviour management plans should start with educating those who are expected to adopt the strategies or follow through on the care plan.

What do family carers of people with FTD suggest?

- *Don't try to reason with your loved one if he or she is unable to do so*
- *Choose your battles*
- *Modify your own expectations rather than expecting the person to be the way the way or she was before...acceptance is slow but is the key to setting you free*
- *If the person has impulse control difficulties, don't set them up to fail by presenting them with environmental cues that will elicit problems*
- *If the person is frustrated by communication difficulties, avoid placing them in situations in which communication is heavily relied upon, such as phone calls, group day-care or large social gatherings*

Communication

Communication breakdown commonly underpins behavioural symptoms of concern, so addressing communication impairments is fundamental. This list of communication strategies for people with FTD is not exhaustive but is intended to give the reader ideas of what is possible.

Language and communication changes are earlier and more predominant features in primary progressive aphasia, (the language onset variants of FTD,) such as semantic dementia (SD) and progressive non fluent aphasia (PNFA). In progressive non fluent aphasia for instance, people can often progress to complete mutism.

However the presence of communication difficulties is very common in most forms of FTD as the disease progresses in to the temporal lobes.

A loss of communication skills can be devastating to family members and friends. It can also be intensely frustrating to the person with FTD if they have retained insight in to their difficulties (e.g., early PNFA), or if they lack insight and cannot understand why others are not responding appropriately to their expressions or needs.

Many different strategies can be used to help improve communication between carers and the person who has difficulty with their speech and/or language. Which strategies are effective will be highly dependent on the type, severity, and stage of language and speech difficulties. In addition, the cognitive, emotional, and behavioural aspects of FTD can impact on the person's desire and ability to communicate.

Early referral to a speech pathologist can be of great assistance in tailoring communication strategies for the individual and their care givers. The focus of therapy will vary according to the individual's speech profile. It is important to note that therapy will not eliminate communication difficulties, and that even if there is improvement in communication it does not signify reversal of the progressive disease process [5].

In general, therapy will involve either working on language skills, or the provision of non-verbal strategies and assistance with alternative communication systems. Early speech pathology intervention and regular monitoring can assist in the provision of strategies that are appropriate at the different stages of FTD.

A guiding principle in dealing with communication difficulties is that others should focus on modifying their own communication styles to suit the affected person's needs.

Some common communication difficulties and specific strategies are outlined in Table 1.

Table 1: Communication strategies that may be useful in the management of common FTD symptoms.

Communication Difficulty	Possible Communication Strategies
Greatest difficulty is in expressing self. Comprehension of language is relatively intact	• Encourage and use other modes of communication in addition to speech. Use gestures, eye contact, facial expression, drawing, writing and pointing. • Do not presume the person who has difficulty expressing themselves also has trouble understanding language. Often, the person comprehends more than their verbal output would suggest. Listen for occasional words that give an indication that they are on the same topic. • Try to make all communication attempts positive and successful. It is helpful if the person feels they have communicated their message, even if it is laboured and difficult. • Allow plenty of time for the person to speak and to respond. • Avoid talking for the person unless they are happy for this to occur or looking to you for assistance. • Use yes/no questions if an open ended response seems too difficult. • Try to continue normal activities and include the person in group conversations and family decision making if the person is willing and able. • If communication is becoming distressing or frustrating for the person with FTD, take a break and shift the focus towards activities that are not heavily language dependent (e.g., go for a walk). It may be important for the person to communicate their message, so consider re-introducing the topic after a break. • If the person appears withdrawn or reluctant to participate in conversation, do not push participation. • If the person tries to talk or to use non-verbal communication, try to understand their message and interact positively to reinforce the communication.

Communication Difficulty	Possible Communication Strategies
Difficulty with the grammatical aspects of language	• Adjust expectations regarding how the person expresses themselves. It is not critical if their sentences are not grammatically correct so try not to over-correct or interrupt. What is important, is their ability to understand instructions and communicate their needs • Correcting the person's grammar will not improve the problem. • Use short, simple phrases when communicating with the person.
Apraxia of speech (difficulties producing speech) but intact comprehension of language and intact reading/writing abilities	• Try electronic communication alternatives [5], such as laptop computers with digitally stored words, phrases or pictures. • Keeping in touch by email and letters may be easier than by phone • Cue cards displaying specific messages or word books that can be pointed to may be helpful. • Learn and practice alternative strategies well before the individual needs to use them (i.e., in early stage disease) so they are readily available and more easily used when need emerges [5].
Word-finding or naming difficulties	• Provide verbal or visual cues (e.g. photos or picture cue cards) • Avoid correctional responses unless it is critical to clarify the meaning [6] • Ask for a gesture or demonstration instead of the sought after word [6] • Narrow the options with closed check-back questions to establish the sought after word/name e.g. "oh...so you saw Paul today?" or "did you mean…?" [6].
Difficulty understanding language (receptive language difficulties)	• Simplify communication: shorten sentences, reduce rate of speech, emphasise key words • Give the person plenty of time to process verbal input • Repeat questions, statements if the person does not appear to have understood or responded • Face-to-face and one-on-one interactions will be more enabling and less overwhelming than group scenarios, reduce background noise/distractions

Case Vignette

Gillian is 64 and lives in regional Victoria with her husband James. She is an ex-school teacher who has always been very socially active in her community, running various committees, charitable events and functions. She was recently diagnosed with progressive non-fluent aphasia. Friends and family noticed a considerable decline in her ability to run various meetings due to more effortful and halting speech over the last 2 years.

Unfortunately, she was not diagnosed until her language impairments were quite obvious, due to a lack of access to specialist services in her region. By the time she accessed a specialist; she had become used to deferring to her family to speak for her and had become quite socially withdrawn.

She was teary during her interview with the clinic speech pathologist, particularly when her previous committee work was raised. She was able to impart in broken speech and writing, that she missed this work but was embarrassed about making so many errors. During depression screening, Gillian admitted to feeling that her life no longer had purpose.

Responding to Gillian's Case:

The speech pathologist determined that Gillian still retained insight in to her difficulties. She was able to comprehend and performed better with expression during one on one conversation. Whilst verbal expression was impaired she could still read and write.

She was offered speech therapy and counselling sessions and linked in with the Australian Aphasia association. The speech pathologist assessed that Gillian was still computer literate and so it was suggested that Gillian may still be able to engage in her committee work, if this was re-directed to more administrative and promotional duties where she did not have the pressure of so much face to face discussion.

Her family passed on communication guidelines from the speech pathologist to the committee organisers. This helped them understand how to interact with Gillian so they could all continue to benefit from her inclusion.

The family were also instructed to monitor Gillian's depressive symptoms, which fortunately did improve when she regained some of her previous committee activities.

Key Messages in relation to communication:

1. ***Remember the importance of comprehensive person centred assessment in tailoring your communication strategy:***

- ***Activity*** *- if the person can follow non verbal cues, mimic or shadow you, this may be a more effective way of motivating the person in to action than relying on language alone.*

- ***Unwell****- If the person is unwell or doesn't have access to their sensory aids such as glasses/hearing aid, this will exacerbate communication problems.*

- ***Story****- for people who have lost verbal fluency but still comprehend, use their motivations and familiar topics to stimulate communication. Life story books, photos can be used to provide cues/clues for interaction in this context.*

- ***Environment****- Deficits will be confounded by busy distracting environments. Communicate important facts in quiet one on one environments where possible.*

- ***Dementia****- The type of FTD will impact strategies chosen,*
  For example:

  People with semantic dementia whom have lost the meaning of concepts, may not be able to recognise and respond to picture cue cards as a strategy. This needs to be evaluated and tested.

  People with bvFTD may be exceedingly verbose, loud or use inappropriate language. This is due to the loss of capacity to adapt their communication style to match the social context. In this context the person with bvFTD will be unaware of their social error. Gently interrupting, using touch or gesture may help re-direct them. Using FTD companion cards may help explain this behaviour to others and diffuse any anger/embarrassment.

2. ***Seek <u>early</u> speech pathology input to inform appropriate communication technologies or techniques. Practice the techniques well before the individual needs to use them (i.e. in early stage disease) so they are readily available and more easily used when the need emerges.***

3. ***Take care not to over-correct, talk over or patronise the person with FTD who is experiencing communication difficulties. This will exacerbate their likelihood of social withdrawal or defensive/angry responses.***

4. ***For the person with FTD who retains insight in to their difficulties, don't invalidate or dismiss the level of frustration that can accompany these communication difficulties. Empathise with the person's frustration and show patience and tolerance. Reassure the person that if the words won't come now, that you will work together to find the words or solution. Alternatively, if the person is getting angry, apologise for not being able to understand and reassure them that you want to help or that you'll try again when everyone is calmer.***

Other freely available resources regarding the management of communication difficulties, many of which have been consulted in the development of this module, include:

- *Language and Communication in Frontotemporal Dementia and Semantic Dementia*: summary of a talk given by Jackie Kindell, Specialist Speech and Language Therapist, available on the Manchester Cerebral Function Unit's Carers' Support Group website
  www.cerebralfunctionunit.co.uk/kindell_talk.html

- *Managing Primary Progressive Aphasia:* information provided on the website of The National Aphasia Association
  www.aphasia.org/Aphasia%20Facts/understanding_primary_progressive_aphasia.html

- *Primary progressive aphasia – Treatments and drugs:* information provided on the website of The Mayo Clinic
  www.mayoclinic.com/health/primaryprogressiveaphasia/DS00750/DSECTION=treatments-and-drugs

- *Treatment Strategies for Primary Progressive Aphasia:* tips provided on SpeechPathology.com
  www.speechpathology.com/ask-the-experts/treatment-strategies-for-primary-progressive-801

- *Communication cue cards:* developed by Eastern Health Tran cultural Services (Melbourne) to assist health professionals and clients/carers who have communication difficulty.
  www.easternhealth.org.au/services/cuecards/default.aspx

  DBMAS Victoria has adapted these cue cards into laminated books in many languages. These can be posted free of charge.
  Email: dbmas@svhm.org.au or free call 1800 699 799

- *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

- *Effective Communication in Dementia*
  Guidelines developed by DBMAS WA, phone 1800 699 799 for a copy

- *Managing language problems*
  www.latrobe.edu.au/aipca/projects/mci/
  Tip sheet developed by clinicians and researchers in Melbourne, available for download by health professionals, targeted at patients and families of those in the early stages of dementia

- *Language and Communication:* tip sheet available from Alzheimer's Australia
  www.alzheimers.org.au/services/tip-sheets.aspx

- *Communication: Caring for someone with dementia*: tip sheet available from Alzheimer's Australia
  www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx

- *Managing Changes in Communication*: general communication tips provided by Alzheimer's Australia, along with personal tips written by a person with dementia
  www.alzheimers.org.au/services/managing-changes-in-communication.aspx

- *FTD Companion Cards:* developed by Alzheimer's Vic in collaboration with DBMAS Vic and the Eastern Cognitive Disorders Clinic call DBMAS 1800 699 799 or Alzheimer's National Dementia Line

Non Pharmacological Management Strategies for Behavioural and Psychological Symptoms of FTD

Apathy: is best described as the absence of internal drive to accomplish tasks
People with apathy may present with:

- A lack of interest in daily activities and personal care
- Reduced social interaction
- A loss of interest in pastimes and routines they previously enjoyed
- Diminished spontaneous speech
- Indifference/emotional blunting
- Loss of motivation/initiation of tasks

Apathy is commonly misdiagnosed as depression. However unlike depression, it is not usually associated with insomnia, impaired attention or feelings of hopelessness, anxiety or sadness.

Tony is a 51 year old motor mechanic who is married with 2 children in their late teens still living at home. Tony's wife Barbara presented to her GP concerned that Tony was depressed as he had lost all interest in his work-shop was getting complaints from customers about his workmanship and time taken to complete repairs. On weekends he seemed withdrawn from his family and spent most of his day watching TV. He was later diagnosed with bvFTD (hypoactive type).

Using 'CAUSED' to identify possible strategies:	
Communication	• Accept that you may need to initiate and carry conversation • The use of verbal requests, lists, picture cue cards or timetables to prompt activity and task completion will be dependent on the person's ability to understand language and concepts. Match communication strategy to the person's abilities/disabilities • Use positive motivation and feedback don't nag or harass
Activity	• Rewards may help motivate activity but will need to be re-introduced each time. Rewards for reinforcing positive behaviour and activity are dependent on an appreciation of actions and consequences which is often diminished in people with FTD • The person with apathy will need set up and prompts. Cuing activity through gentle touch, physical guidance, demonstration, or helping them initiate the task may assist • The person may need to be redirected and supervised to keep them on task

Activity Continued	• People with apathy may be unable to reliably attend to Self care tasks. Look for signs of self neglect and intervene accordingly • Match tasks to abilities to reduce risk of frustration • Capitalise on remaining strengths and abilities to promote activity. E.g., retained literacy/numeracy could allow the person to engage in Sudoku or puzzles
Unwell	• The use of a validated depression scale may assist clinicians to differentiate between apathy and depression • A sudden or acute deterioration in motivation or level of alertness may signal acute illness, seek medical review and delirium screening • Apathy may reduce the person's response to issues of risk and safety. Risks and the person's ability to respond to risk need to be assessed and addressed. • In severe apathy, the person will require hands on assistance to complete essential personal care tasks and meet their needs: toileting, washing, skin care, meaningful activity etc. This may require assessment for community or residential services. • There is some limited evidence suggesting that SSRI's (anti-depressants) may help in people with severe apathy which is impacting the person with FTD's health and safety, seek medical/specialist opinion
Story	• Use shared experiences to promote opportunities for meaningful conversation • Focus on known topics of interest/strength to promote likelihood of conversation • Use the person's known preferences, hobbies, well engrained life roles to identify meaningful activity opportunities. Use something the person likes or wants to motivate them to complete activity, e.g. If the person with FTD loves seeing their grand-children, use a visit with them to motivate and give reason for them to get in to the shower.
Environment	• Establish a timetable and direct the person to this timetable or list of tasks to prompt activities throughout the day, routine will help (note that written timetables may not work if there are semantic language difficulties) • Provide opportunities and cues for activity, e.g., spontaneous activity hubs around the home/ care facility

Environment Continued…	• The person could be cued to engage in activity if others around them are engaging in the wanted activity, e.g. They may be more likely to eat if they are in an environment where others are eating, so that they can copy the sequence of the task
Dementia	• Remember, apathy is a disability caused by the disease, it is not laziness • The apathetic presentation tends to be associated with extensive frontal lobe involvement extending into the dorsolateral prefrontal cortex and cingulate cortex. • Apathy is due to the loss of the 'starter motor' functions of the brain in the frontal lobes which drive our impulses to initiate activity • External cueing is required for the person to initiate. Essentially carers need to take over these 'starter motor' functions

Responding to Tony's case:

Education about the cause of apathy, greatly assisted Tony's family to overcome their frustrations with his behaviour and accept this as part of his disease. It also helped them to start to adjust their expectations.

It was identified that Tony was having difficulty initiating the sequence of tasks due to his loss of planning skills and was tiring more at work because of this. After consideration, Tony went in to early retirement, which gave him more energy to engage with his family. However he still tended to spend long periods watching TV.

Tony's specialist provided a medical report which facilitated early access to their superannuation.

Tony's son, who was also mechanically minded, helped his Dad maintain a meaningful work role in the earlier stages of his disease, by working alongside his Dad to help him initiate and follow through on some mechanical repairs for family and friends.

Over the coming years as the disease progressed, Tony lost capacity to do full scale repairs but with prompting and set up, was occupied with smaller scale mechanical pieces to tinker with. His family took him to watch car races or watched the racing with him on TV. Tony's wife began to struggle with the additional responsibilities she had taken on and was later supported to access some home services and respite by linking Tony in to a community men's shed program.

Disinhibition and Impulsivity

Some people with FTD can have difficulties controlling their responses or impulses, even when this behaviour may not be within social conventions, lawful boundaries or hurtful to themselves/others.

Disinhibition and impulsivity can present as follows:

- Outburst of aggression and irritability
- Intrusiveness
- Wandering
- Loss of social graces or social rule breaking
- Excessive jocularity or 'immature' behaviour
- Shoplifting/ Impulse buying
- Impulsive eating and drinking
- Sexual Disinhibition (will be discussed under changed sexual behaviour)
- Risk taking behaviour / poor judgement
- Dangerous driving, e.g., speeding, road rule breaking and road rage (see module 5 driving assessment)

After Gina was diagnosed with bvFTD aged 49, her daughter Maria started providing regular supportive visits and found that Gina was purchasing excessive amounts of cosmetics and confectionary and leaving her with insufficient funds to cover her bills. As her disease progressed Gina also started pocketing items she took a fancy to in shops. This resulted in a charge of shoplifting. She was also presenting with increasingly pressured and repetitive speech.

Communication	Possible considerations and strategies
Swearing, shouting, laughing loudly at inappropriate times, belching, making crude comments	• Use firm but kind limit setting to re-direct from this behaviour • Humour may help soften the limit setting and reduce the risk of eliciting a defensive response. For example if the person with FTD makes a crude comment, instead of saying; Bill...that's disgusting" or "this won't be tolerated", try "Now, now Bill, you'll get us in trouble with the swear police, you best watch your language" or try a swear jar to collect fines for swearing to reinforce the limit setting. • Companion cards for people with FTD can be accessed from Alzheimer's Vic and DBMAS Vic. These can be used by carers to diffuse embarrassing public displays by discretely handing over the card to those witnessing or affected by the behaviour. (see figure 1 under communication resources)
Aggressive responses to communication, requests or limit setting	• Avoid trying to rationalise with the person • Try to remain calm, don't respond with anger or frustration • Don't persevere if a communication or request is triggering aggression. Try changing tactics to empathise with their frustration and ask how you can help

Aggressive responses to communication, requests or limit setting continued..	• If the person continues to escalate and it's safe to do so, walk away and try again later • Avoid known triggers/topics of contention • Take time to ventilate your frustrations with a counsellor, friend or colleague. This will help reduce the risk of ventilating with the person with FTD you are supporting and inadvertently triggering their defensiveness.
Activity	**Possible considerations and strategies**
Over-spending and shoplifting	• Can shopping become an activity to be enjoyed together with the family carer or respite worker rather than performed independently? This increases supervision and external control of impulses • Where there is high risk of shoplifting, consider whether smaller retail outlets may be more manageable and easier to supervise • Impulsive stealing can sometimes become a significant issue of risk and burden to carers/care workers. In this instance, consider alternative environments for social activity and outings which won't cue this behaviour
Aggressive outbursts and behaviour	• Is the person frustrated by their inability to respond to our activity request? If so how we can we adjust our communication approach or the task itself to increase the chance of success? • Match tasks and activities to the person's strengths and abilities to avoid frustrating the person and triggering aggression. • Is the activity necessary? If so how can we modify it to make it easier or less intrusive in order to reduce the triggers for aggression? • Maintain a safe distance/body position during interventions and activities and have an exit strategy or escape plan worked out • Withdraw if the person is escalating and try again later
Agitation	• Is the person bored/under-stimulated. Can they be given some meaningful activity or task? • Could physical exercise assist in diffusing agitation?

Unwell (Health/Wellbeing)	Possible considerations and strategies
Impulsiveness and disinhibition may increase the person's risk taking behaviour and impact their safety	• Capacity to safely perform activities of daily living requires assessment and any risks addressed. For example: road safety and driving ability • An Aged Care Assessment Service (ACAS) or Occupational Therapist (OT) may be able to conduct an assessment of the person's safety to independently go out in the community and can also assess their safety performing activities in their home/residential care environment • A neuropsychologist or medical specialist can assess the person's capacity to make reasonable financial and life style and medical care decisions
The safety of others may also be impacted by these disabilities, especially where this leads to physical aggression	• When supporting someone with a history of aggressive behaviour, establish communication and activity strategies which aim to reduce triggers and risks • Contact your specialist, DBMAS 1800 699 799 or your local aged person's mental health service for advice regarding managing aggression risk and incidents. • If you are in immediate risk of assault/injury due to an aggressive outburst find an exit strategy. If you are in the community: call 000 for assistance. They will provide an immediate response and involve the appropriate mental health services if necessary. • If you are in a care facility/hospital use your duress policies and procedures.
Impact of acute illness on stress threshold	• Remember an acute increase in agitation/aggressive outbursts, excessive teariness or increased wandering could signal acute illness and delirium. Always rule out and seek treatment for reversible causes and try to anticipate unmet needs that may be driving this behaviour such as pain and boredom
Story	**Possible considerations and strategies**
Using long term habits, skills and behaviours which are not acceptable or safe in current circumstances e.g. dismantling furniture	• Interrupt the activity calmly and offer something equally interesting to the person in its stead. For example, if the person liked tinkering, re-direct the person from dismantling furniture to a similar task that is less destructive, i.e., a small craft or construction project, or consider whether a men's shed planned activity group may offer these activity opportunities in a safe/supervised environment

History of Alcohol use continued...	• Does the person have a history of alcohol dependence/abuse? If so, this habit may be exacerbated by impulse control problems and disinhibition. In this case, complete abstinence may not be a realistic goal. See environmental modification tips for reducing risk • Is it part of the person's cultural background to enjoy wine with a meal? If so, this should be enabled but with some modification to how much wine is on offer
Does life story indicate a history of aggression as a stress reaction or defence mechanism	• A person with a life history of anger management difficulties, jealousy or propensity for violence is more likely to react with anger when frustrated as their FTD progresses, especially as they become more disinhibited and less able to control impulses. A comprehensive assessment should ask: How was this managed before? What did the person or others do to reduce the triggers and escalations? The answers should help inform potential strategies and interventions
Environment	**Possible considerations and strategies**
Impulsive wandering or other unsafe behaviours	• Arrange an Occupational Therapy Assessment to determine the person's level of risk when wandering. Some people with FTD will still have well preserved orientation and capacity to access their communities independently • Register people at risk of wandering with police (in Victoria, see www.safereturnhome.com.au). • Try technological options for monitoring and maintaining safety in the home, such as door alarms, sensor mats, or GPS tracking devices • Provide clear visual cues to re-direct wandering (e.g., a sign stating "Turn around" rather than "Stop") [9]. • Contact Alzheimer's Australia or DBMAS for strategies or details on where to access technologies or see www.dementiatechnology.org.au.
Overspending or gambling	• Reduce access to unwanted marketing by signing up for "do not call" register www.donotcall.gov.au and adding "No junk mail" sign to letter box, or diverting mail to post office box [8]. • In extreme risk cases, some carers have put pass codes on telephone dialling and have modified web access to reduce use of these mediums by the person with FTD for purchasing • Reduce access to large sums of money.

Overspending or gambling continued	• Reduce independent access to environments which cue this behaviour or shop in centres which are not as large/busy to aid supervision • Arrange a decision making capacity assessment to inform whether the person requires an Enduring (Financial) Power of Attorney (if possible) or Administrator (see Module 5).
Impulsive drinking/eating that may put the person at risk of choking or burning themselves	• Provide supervision as the person may not be able to monitor their safety • Reduce access or visual cue for non supervised eating/drinking (locked cupboards and remove from view) • One drink /food item at a time
Dementia	**Understanding the Brain-Behaviour Link**
	• These behaviours are not within the person's full control as the functions of the frontal lobes which help us manage our impulses and monitor our conduct and safety, have been disrupted in FTD • For people with these disabilities, carers need to help the person maintain dignity by providing explanation for socially unusual conduct and help regulate the person with FTD's conduct and safety by externally cuing the person and becoming the 'substitute brakes' for behaviour.

Responding to Gina's Case:

Given Gina's presenting risks of financial losses and poor financial judgement, her specialist arranged for a neuropsychological evaluation of Gina's decision making capacity. On the basis of deficits noted in this assessment, Gina's daughter was advised to evoke her enduring power of attorney for her mother and speak to Gina's solicitors and bank regarding reducing Gina's access to large amounts of funds.

This capacity assessment and a letter from her specialist were also presented to her legal counsel as proof of her reduced capacity under the law, which helped to dismiss shoplifting charges against her.

After this incident, Gina's daughter arranged for a council respite worker to take Gina on supervised shopping trips and eventually other outings to reduce the cue for impulse stealing. Given Gina's love for makeup, one of her weekly activities became a visit to the beauty salon for make-up and a manicure, before going out with her daughter or friends.

As a previously keen piano player, Gina was also linked in with regular music therapy sessions and a dementia choir, as it was noted that her vocalisations temporarily reduced when she was distracted or engaged by music. This also helped provide her daughter with some respite.

Perseveration, stereotopies, obsessive, compulsive, inflexible and ritualistic behaviours

Perseveration is like the needle getting stuck on a record, where the same sounds, words, behaviours or tasks get repeated over and over. For example:

- Repetitive vocalising and calling out
- Constant use of the same repeated rope phrases

Stereotopies are repetitive/purposeless movements. Examples may include:

- clapping, tapping or foot shuffling

Utilisation Behaviour is when the person with FTD can't resist the urge to manipulate objects within their visual field, even if it is not contextually or socially appropriate to do so.

Andy is 59 and has been diagnosed with semantic dementia. He has developed multiple rituals including eating fruit loops at the exclusion of other meals. His wife states he has also become obsessed with Sudoku and has developed a compulsion of constantly counting items out loud. Andy has also started showering up to 6 times per day and needs significant encouragement to get out of the shower, sometimes becoming angry when his wife suggests he get out because he is wasting water.

Obsession is a constant worry/concern about something, where as compulsion is the feeling of need to perform a task over and over. True Obsessive Compulsive Disorder (OCD) is driven by fear and anxiety that 'something bad' will happen if the task or ritual is not performed. People with FTD tend to have minimal insight in to their **compulsive and repetitive traits,** which appear to be involuntary rather than driven by obsession, anxiety or fear. So whilst these symptoms mimic OCD, this is an important distinction.

These symptoms of FTD can present as:

- **Rigidity/inflexibility -** Difficulties changing direction in thought or deviating from set routines
- Gambling
- Excessive substance use, e.g., alcohol
- Over-eating/ eating only fixed food types
- Sexual Compulsion (will be discussed under changed sexual behaviour)
- Repetition of tasks or routines, e.g., hand-washing, chain smoking
- Hoarding

Communication	Possible considerations and strategies
Repetitive Vocalisations	• These are notoriously difficult behaviours to treat/change. External auditory cues or alternative sensory inputs/distractions can assist to interrupt the circuit for this behaviour; e.g., music, chimes, touch, robotics pets/dolls that elicit sound, talking books etc • Music and singing may interrupt the repetition temporarily and may become a more acceptable outlet • Those around the person with this behaviour will require regular respite and breaks.

Repetitive Vocalisations Continued	• In a facility, moving the person to different areas throughout the day will help give co-residents a break • Asking simple closed ended questions may help the person keep conversation flowing and interrupt repetition
Activity	**Possible considerations and strategies**
Compulsions E.g. Gambling	• Can the person's gambling be re-directed to computerised simulated gambling games or games of black jack/roulette in the home or residential care environment with limited funds? This may help the person satiate their impulse or desire to gamble but reduce their financial losses
Stereotopism and utilisation behaviour	• Can the behaviour be re-directed in to something that has purpose, e.g., can repetitive tapping be re-directed in to stamping envelopes or polishing silver. Can clapping be re-directed in to something that is more contextually appropriate, such as clapping along to music? • Offer something else in the visual field to cue a less disruptive or destructive utilisation behaviour, e.g., for someone who exhibits hyperorality and is constantly chewing on their sleeves, offer lollypops or chewing gum if swallowing is still safe/intact. For someone who is constantly picking up items belonging to others, offer objects of interest, photo albums, fiddle mats, sensory/stress balls etc as alternative objects to manipulate that won't upset others • Offer sensory alternatives to divert from more destructive utilisation behaviour, such as massage or art
Ritualistic behaviour	• Don't expect the person with FTD to be able to adapt to our expectations or new/novel environments and routines • Trying to disrupt rituals or routine can sometimes cause a de-compensation in the person's mental state and behaviour. Try to honour the person's rituals and keep to their preferred routines if these are harmless. Choose your battles.
Unwell (Health/Wellbeing)	**Possible considerations and strategies**
	• Acute illness may exacerbate or intensify these symptoms, rule out reversible causes, e.g., constant picking or scratching of the skin may be perseverative or compulsive but equally, could be due to medication reactions or skin conditions/irritations.

Unwell continued…	• Hyperorality (constant chewing/sucking) could be caused by dental problems or oral thrush • Assess the risk of the stereotopy or repetitive behaviour to the person with FTD and other's around them, intervene only if risk necessitates this • Assess and rule out other causes for overeating/drinking, e.g., diabetes, thyroid problems, medication etc • Try to prevent excessive weight gain from eating compulsions by managing food portions and types that are accessible to the person with FTD • Vocalising can sometimes be caused by pain/discomfort, boredom or loneliness, rule out any reversible causes or unmet needs • Compulsions can sometime be responsive to medications used to treat OCD such as SSRI medications used for depression/anxiety, seek medical opinion if non pharmacological strategies are not effective or if the behaviour is causing major risk/concern. However note that these medications may exacerbate other symptoms of FTD such as weight gain from over-eating
Story	**Possible considerations and strategies**
Using long term habits, skills and behaviours which are not acceptable or safe in current circumstances e.g. dismantling furniture Hoarding	• Consider whether previous life roles may provide clues for re-directing perseveration, compulsion and utilisation in to meaningful activities and roles. For example: a previous homemaker or industrial cleaner may still perform repetitive household tasks well such as sweeping, polishing, folding, and drying the dishes. A secretary may enjoy filing, paper sorting tasks, whilst a gardener may enjoy raking. • Does the hoarding compulsion have a context, is the person compensating for failing cognitive function by keeping all items on display/within reach? Would labels and signage help direct the person to their items to overcome this tendency? • Does the person fear their items will be stolen, if so, how can we reassure them/make them feel secure
Environment	**Possible considerations and strategies**
Impulsive wandering or other unsafe behaviours	• Arrange an Occupational Therapy Assessment to determine the person's level of risk when wandering. Some people with FTD will still have well preserved orientation and capacity to access their communities independently

Impulsive wandering continued	• Determine if there is an unmet need or purpose to the wandering that could be addressed • Register people at risk of wandering with police. In Victoria, see www.safereturnhome.com.au • Try technological options for monitoring and maintaining safety in the home, such as door alarms, sensor mats, or GPS tracking devices • Provide clear visual cues to re-direct wandering (e.g., a sign stating "Turn around" rather than "Stop") [9]. • Contact Alzheimer's Australia or DBMAS for strategies or details on where to access technologies or see www.dementiatechnology.org.au
Hoarding or gambling	• Arrange a decision making capacity assessment to inform whether the person requires an Enduring (Financial) Power of Attorney (if possible) or Administrator (see Module 5). • Reduce access to unwanted marketing by signing up for "do not call" register (www.donotcall.gov.au) and adding "No junk mail" sign to letter box, or diverting mail to post office box [8]. • In extreme risk cases, some carers have put pass codes on telephone dialling and have modified web access to reduce use of these mediums by the person with FTD for purchasing • Reduce access to large sums of money. • Reduce independent access to environments which cue this behaviour such as shopping centres/pubs and clubs
Excessive alcohol intake	• Reduce access (locked cupboards and remove from view) • One glass at a time • Dilute or refill bottle with reduced/non alcoholic substitute • Try to limit cues/opportunities for independently purchasing alcohol
Compulsive eating and gluttony	• Remove visual cues (hide/secure food items) • Reduce access to large portions, unhealthy snacks • Provide one food item at a time, avoid buffet style eating • Supervise intake to avoid choking, burning as the person may not be able to monitor this themselves • Assist the person with shopping. Discreetly return unwanted food items without the person knowing if they are hoarding, rather than confronting them if there is compulsion driving the behaviour • Provide healthy alternatives to satisfy sweet craving and reduce weight gain such as sugar free lollies, fruit products

Dementia	Understanding the Brain-Behaviour Link
	• As well as being the "starter motor" of the brain, the frontal lobes are also the "brakes of the brain" and help provide feedback on how we are performing tasks, pick up on environmental/emotional cues as to how we are being perceived socially and help us regulate our impulses, behaviour and performance accordingly. • Carers will often describe more impulsive, "childish" or "selfish" behaviour or socially awkward conduct. People with FTD can also become more reactive to cues in their immediate physical and social environment. • For people with these disabilities, carers need to help the person maintain dignity by providing explanation for socially unusual conduct and help regulate the person with FTD's conduct and safety by externally cuing the person and becoming the 'substitute brakes' for behaviour.

Responding to Andy's case:

The focus of intervention was to help Andy's wife differentiate which of these symptoms were relatively harmless rituals and which required intervention.

She was also assisted to change her communication approach when she was trying to re-direct Andy from the shower. Rather than requesting that Andy get out of the shower, he was shown an egg timer that he was told was provided by Yarra Valley water to monitor household water consumption. This strategy was based on Andy's life story of always being very "careful with money and bills." He seemed to be able to absorb authority form Yarra Valley water more easily than authority form his wife, because he had always been 'the man' of the home and had a life history of not wanting to be told by women. His wife started using the timer whenever she showered to reinforce this.

With constant reinforcement, the egg timer became entrenched as one of his rituals. It became a visual and auditory cue for when to get out of the shower. A shower tick sheet was also introduced to see if it could be referred to as a reminder that he had already showered, but this only marginally reduced his multiple shower habit and didn't always work to divert him. However Andy's wife was satisfied that at least the shower length had reduced.

The wife was also helped to identify patterns in when the showering often occurred. This helped her identify when to be ready with other favourite activities to divert his attention from showering.

The Sudoku was flagged as a great opportunity for occupation and the counting was re-directed in to a purposeful task of sorting out the kid's money boxes.

The fruit loop cravings were managed by purchasing only single serve fruit loop packs and labelling them Monday through to Sunday. This limited helpings to once per day. Other healthier options were made immediately available as soon as Andy started rummaging for food and fruit was constantly accessible.

These strategies are working for now but are likely to need review as Andy's understanding of language and concepts diminishes.

Changes to relationships and social and sexual conduct

Hyper-sexualised behaviours such as **sexual compulsions and sexual disinhibition** do occur in people with FTD.
This can lead to:

- Unwanted advances or sexualised comments/contact
- Frequent and persistent demands for gratification or self gratification
- Lack of discrimination, e.g., sexualised behaviour toward inappropriate targets or in inappropriate contexts/environments

However, by far, the more commonly observed change to sexual behaviour in FTD, is a **loss of libido/initiation of sex and intimacy** in the context of apathy and emotional blunting.

Helena is a 48 year old divorced woman Her 19 year old daughter Lisa, lives in a granny flat behind her Mum's home. Lisa has expressed great embarrassment and concern over her mother's recent overt sexualised behaviour toward men, including Lisa's own boyfriend. Whilst Helena's bvFTD diagnosis is understood by her boyfriend, Helena's 28 year old male neighbour has complained that Helena is frequenting his home and making sexualised suggestions to him. She then becomes tearful and agitated when he tries to politely decline her advances. He is considering taking out an intervention order against Helena.

Changes in emotional registration and empathy also significantly impact the nature and quality of relationships:

- Misinterpretation of friendliness or care activities such as help with showering as sexual advances
- Emotional distance, coldness or immaturity towards spouse/children
- Loss of tolerance toward others
- Loss of consideration of others
- Lack of turn taking in conversation
- Lack of conformity to social graces and norms

Communication	Possible considerations and strategies
Swearing, shouting, laughing loudly at inappropriate times, belching, making crude comments, talking over others	• Use firm but kind limit setting to re-direct from this behaviour • Humour may help soften the limit setting and reduce the risk of eliciting a defensive response. • Do not give too much attention to the behaviour or get angry or judgemental but rather try to distract and re-direct • Companion cards for people with FTD can be accessed from Alzheimer's Vic and DBMAS Vic. These can be used by carers to diffuse embarrassing public displays by discretely handing over the card to those witnessing or affected by the behaviour. (see figure 1 under communication resources)

Communication	Possible considerations and strategies
Impacts on relationship with children	• Many people with FTD will have children, adolescents and teenager who will be directly impacted by the symptoms of the condition. Unlike adults, they may lack the experience and skills to adapt to these circumstances. Without significant support, education and counselling, the impact of the behavioural symptoms they observe can be devastating to their family relationships in their formative years and may have the potential to impact their emotional development if they are not helped to understand what is driving the symptoms. The impacts are further exacerbated when the younger person is faced with a potential hereditable form of FTD. Expert FTD counselling is strongly advised so that positive family relationships can be maintained
Impacts on relationship with spouse/partner	• Spouses and partners commonly grieve a loss of intimacy and support from their partner with FTD. Counselling and support are critical to explore how their own needs will be met once the person with FTD becomes unable to fulfil many of their partner and support functions due to FTD disabilities and behavioural symptoms. This will need to include discussions around maintaining other supportive relationships and time for self. See further details under carer wellbeing and support groups.
Sexualised comments	• If offence has not been taken, simple re-direction and firm but kind limit setting is best. • If offence is taken, then individuals affected by this behaviour should be carefully counselled and de-briefed about the incident. Companion cards or education about the nature of disinhibition in FTD may help diffuse the situation • Take care that incidents are communicated and documented objectively to avoid misjudgement of the situation or mislabelling of the person with FTD as being 'sexually predatory'
Changes to sexual relationship/behaviour	• Family/spouses should be encouraged to disclose these symptoms to the health professionals supporting them. The frontal behavioural inventory (FBI) informant assessment tool, specifically asks questions regarding sexualised behaviours as an opener to such discussion

Changes to sexual relationship/behaviour continued	• DBMAS Vic has developed a sexual history assessment called "asking the tricky questions." Call DBMAS Vic 1800 699 799 from Victoria or 9816 0618 from outside Victoria • Loss of libido, hyper sexuality and changes in emotional response can lead to grief, loss, fear, anxiety and unmet needs for intimacy for both people with FTD (who retain insight) and their spouse/partner. Sensitivity to these changes and counselling should be offered by health professionals and care workers • Spouses/partners can fear that their partner lacks capacity to consent to or engage in a sexual relationship once they have been diagnosed with FTD. Carers should be encouraged to discuss these fears with counsellors or health professionals who have FTD specific knowledge. • Given the young age of onset of FTD, many people with FTD will still be expressing and wanting to gratify sexual needs. Unmet needs and frustration in this area can drive unwanted or mis-directed behaviour. Careful counselling and honest discussion should help the spouse/partner determine whether they wish to continue a sexual relationship to meet these needs. If not, a suitably qualified/experience health professional such as a social worker, psychologist or counsellor may want to explore the spouse/partner's willingness to explore other methods for the person with FTD to meet these needs. (see activity)
Activity	**Possible considerations and strategies**
Misdirected sexualised behaviour	• Shower the person from their side rather directly in front/within easy grabbing distance • Offer sensory alternatives to meet the need for touch, e.g. hand massage, pets, warm baths or provide pleasure through other sensory options such as music, aromatherapy, dance, visual arts
Unmet sexual needs	• Some spouses may be willing to continue to engage in a sexual relationship to meet the needs of the person with FTD, (see environmental suggestions for how this can be supported.) Alternatively, some spouses/partners or other caregivers may be willing to consider alternative options for the person with FTD to meet sexual needs and appropriately direct sexual energy. These may include planned access to pornography, masturbation aids or a professional disability sex worker. Further advice can be obtained via DBMAS 1800 699 799

Unwell (Health/Wellbeing)	Possible considerations and strategies
Risks related to change in social/sexual conduct and poor impulse control Risks related to change in social/sexual conduct and poor impulse control continued	• Although relatively rare, hyper sexuality in FTD can lead to sexual assault due to the person's diminished capacity to deny impulses. Denial of the person's impulses can also elicit anger, frustration and physical assault. • Carers should always be carefully questioned to identify risks and encouraged to disclose any incidents • Contact your specialist, DBMAS 1800 699 799 or your local aged person's mental health service for advice regarding managing aggression or physical/sexual assault risk and incidents. • If you are in immediate risk of assault/injury find an exit strategy and call 000 for assistance. They will provide an immediate response and involve the appropriate mental health services if necessary. Use your duress procedures if you are in hospital or residential care settings.
Impact of acute illness on stress threshold	• Remember an acute increase in symptoms could signal acute illness and delirium. Always rule out and seek treatment for reversible causes and try to anticipate unmet needs that may be driving this behaviour such as pain and boredom • Frequently what we observe as fondling or masturbation could signal genital or urinary irritations such as urinary tract infection, ill-fitting underwear or thrush, rule out reversible drivers for this behaviour
Sexuality as a human instinct and need	• Sexuality is a basic human instinct and need. The person with FTD's capacity to consent and rights to engage in sexual activity need to be carefully assessed. Just because the person with FTD may have lost decision making capacity, this does not mean they can no longer engage in a sexual relationship. Mutual consent is implied if there are signs of wellbeing from both parties and if there are no signs of ill-being or distress. Contact DBMAS for further advice: 1800 699 799
Story	**Possible considerations and strategies**
Unwanted sexual contact/comments during care interventions	• Where available use caregivers whom are less in keeping with the person's sexual preferences and more likely to be perceived as sexually neutral: e.g.,, male carers for showering a male whom exhibits sexual disinhibited behaviour toward females

Impacts of Story	• Disinhibition can at times reveal a person's true sexual nature that may have been previously suppressed (for example suppressed homosexuality) or can cause a complete change in sexual conduct. Take a comprehensive history • People that have a history of aggression, or sexual criminal behaviour, may become a higher risk in the context of FTD and disinhibition. This requires careful and comprehensive input from mental health and possibly correctional services. *Note: This is a relatively rare phenomenon and is not intended to unfairly label all people with FTD, whom on the whole do not present a risk in this regard.*
Environment	Possible considerations and strategies
	• Caregivers must be conscious of not inadvertently cuing sexual interest with our clothing/conduct during personal care tasks. Asexualise the showering scenario by wearing an apron, discreetly covering the person using a dignity cape/towel and discussing neutral subjects such as football, children etc • Try proactive hand occupation during showering with a wash cloth to reduce the risk of unwanted touching • For people with moderate to severe FTD symptoms in care, **fiddle aprons** can be used to re-direct and give context to disinhibited behaviour that may cause the person to fondle themselves or undress in public. Contact DBMAS 1800 699 799 for details and suppliers
Dementia	**Understanding the Brain-Behaviour Link**
	• Disinhibition and loss of impulse control are due to changes that occur in the frontal lobes of the brain in FTD. These symptoms are not within the person's control. • Sometimes masturbation or fondling a carer during showering is not sexual in intent. This may in fact be utilisation behaviour, where the person with FTD simply can't control the impulse to touch/manipulate objects in their immediate environment. Be careful not to jump to conclusions or label the behaviour without considering the brain behaviour links • For people with these disabilities, carers need to help the person maintain dignity by providing explanation for socially unusual conduct and help regulate the person with FTD's conduct and safety by externally cuing the person and becoming the 'substitute brakes' for behaviour.

Responding to Helena's Case:

Given that Helena's sexualised comments were not escalating to any real physical risks, they were assessed by the DBMAS worker as being of moderate risk. However, given the neighbour was threatening legal action this was clearly cause for education and intervention.

Her daughter Lisa believed that a lot of this behaviour was actually driven by loneliness and lack of occupation. She has been divorced from Lisa's father for 8 years and many of her friends had drifted away over recent years. Lisa worked full time.

Helena was observed to be quite perseverative about many things including sex. So it was felt that this could potentially be capitalised on, by diverting her perseveration to another hobby or interest.

An assessment of Helena's life story, interests and preferences revealed that Helena's Golden Retriever had died 12 months earlier and that this Dog had been the centre of her world for the last 8 years. Through discussion with Lisa, she felt she could support her Mum having another smaller pet Dog, which she agreed she would care for when her mother needed residential care.

The pet Maltese terrier was a huge success and soon occupied Jelena fully. Lisa regularly checked on the pet's welfare and managed all feeding and veterinary care.

Helena's daughter Lisa also arranged for the neighbour to meet with the DBMAS worker where the disabilities of FTD were fully explained to him. He was also advised around a few of the 'less private' behaviour care plans that were in place to try and reduce Helen's contacts with him. He was also given a list of emergency contacts for Helena's family should he need assistance to re-direct her. However in the end, Helena was so occupied with her pet that she stopped calling in on him altogether.

Lisa was reluctant to engage in discussions around her mother's sexuality or to consider how these needs may be met. In the end she agreed that Helena's sister should manage those decisions with the DBMAS worker.

After assessment, the DBMAS worker introduced some sexual aids to Jelena; however she seemed unable to engage with these. The sister did not wish to engage a sex worker, but agreed to trial a female massage therapist to promote touch, relaxation and well being. She was anxious that Jelena may not respond 'appropriately' to a male masseuse.

Jelena was also referred for an aged care assessment to determine her eligibility for a care package and working carers' respite.

Whilst Jelena is still disinhibited in her comments toward her daughter's boyfriend at times, this behaviour has also significantly reduced.

Pharmacological (Medication) Management

Treatment for FTD is currently symptom focussed [9]. There is not yet a cure, and no established means of slowing disease progression. There are drugs in development that are designed to slow the pathological process in the brain and may therefore slow the progression of symptoms, but as at mid 2011 these are still in the experimental stages of development [10]. Therefore, it is the effective management of the symptoms of FTD rather than cure or prevention that is the focus of current pharmacological approaches.

The observation of abnormalities in the metabolism of a brain chemical known as serotonin in some individuals with FTD has led to the use of **selective serotonin reuptake inhibitors (SSRIs)** in the management of FTD symptoms [11]. These medications are often used in the treatment of mood and anxiety disorders in the general public. The results of SSRI trials in FTD have been mixed [12-15], but improvements have been reported in disinhibited behaviours, repetitive behaviours, hyper-orality, and sexually inappropriate behaviours [16].

SSRI's and other medications such as Androcur used to suppress sexual desire and function, should be reserved only for sexualised behaviour that is placing the person with FTD or their carers at significant risk. It should be noted that these medications are a form of 'chemical castration' and are not without side-effects, so their use in this context needs to be considered only as the last line of treatment for hyper-sexual behaviour in FTD when non-pharmacological approaches have failed. There are also important ethical considerations to consider, as people with dementia retain the basic human right to express and gratify sexual needs. *(See further advice under non pharmacological management of sexualised behaviour in FTD later in module 5.)*

Atypical (or more recently developed) **antipsychotic medications** such as Risperidone and Olanzapine have been used successfully to manage symptoms such as agitation, aggression and psychotic features in patients with FTD and other forms of dementia [13.1, 17]. Such medications appear to be less effective in the treatment of the psychiatric symptoms of dementia than of primary psychiatric disorders possibly due to qualitative differences in seemingly similar symptoms [18].

Some FTD patients, particularly those with FTD with Parkinsonism (FTD-17) and Parkinson's plus syndromes such as Progressive Supranuclear Palsy (PSP) may also have a hypersensitivity to antipsychotics [16]. Antipsychotics may also exacerbate the risk of falls in individuals with forms of FTD associated with movement disorders and apraxia such as PSP, Corticobasal Syndrome (CBS) or FTD in Motor Neurone Disease (FTD/MND).

Cholinesterase inhibitors, a class of drugs used widely in the treatment of AD to slow disease progression and improve level of alertness and concentration, have also been trialled in FTD. Rivastigmine has been associated with improvements in behavioural and psychological symptoms of FTD and reductions in caregiver stress [19].

However, some researchers have suggested that this class of medication may not be well tolerated by patients with FTD and may in fact worsen some symptoms such as disinhibition, agitation, and restlessness [19, 20]. This may be due to the intact status of cholinergic systems in FTD.

Hence cholinesterase inhibitors are rarely prescribed for people with FTD, unless there is a degree of uncertainty regarding the diagnosis. For instance some people with language onset dementia may start on a course of cholinesterase inhibitors if there is suspicion of logopenic aphasia (language onset Alzheimer's Disease) as the underlying pathology.

A number of other pharmacological agents including **mood stabilisers**, such as low dose Sodium Valproate (Epilim) and Carbamazepine (Tegretol) have been trialled in FTD patients, but there is only weak evidence for their efficacy [16]. These medications can however exacerbate weight gain in the person with FTD who has over-eating compulsions and sweet cravings.

It is important to recognise that many symptoms of FTD may not be amenable to any form of pharmacological therapy. Indeed, non-medicinal/pharmacological interventions are often indicated in this population.

However, in some circumstances, medications may be the most suitable course of action to treat behavioural symptoms that are creating distress or risk, such as severe agitation and aggression which is not responding to non pharmacological strategies.

Careful assessment of risk versus benefit should underpin any pharmacological intervention such as sedation that may impinge on the person with FTD's levels of alertness, quality of life, rights to freedom of movement, expression and sexuality.

Likewise, medications should be introduced one at a time to review response and regularly monitored for effectiveness. Any dose increases should occur slowly with close monitoring for side effect or excessive sedation. Medications should be weaned and ceased if they are not resulting in any benefit or if any unwanted side effects outweigh the benefits. The use of multiple medications for symptom management should be avoided where possible.

People with FTD and their care providers should be made aware of all pharmacological and non pharmacological options for symptom treatment and response, as well as possible adverse effects and limitations of any medication being considered. This will result in more informed care management decisions.

Key Messages

- *Effective management of a given symptom may vary from one person with FTD to the next*
- *Behaviours in FTD may emerge, fluctuate, and/or disappear, and may not respond to the same management techniques over time*
- *Continue problem-solving until effective techniques are identified*
- *Focus on adapting carer expectations and behaviours to the person with FTD*

Care options after diagnosis

Specialist centres and support services

In addition to the specialist diagnostic centres listed in *Module 2 – Diagnosing frontotemporal dementia*, the following services may assist in the assessment and ongoing support and management of people with FTD and their carers:

- Consultation with the GP (general practitioner)
- The Dementia Behaviour Management Advisory Service (DBMAS) is a Commonwealth funded program now established in every state and territory in Australia. **Free call 1800 699 799.** DBMAS provides advice regarding non-pharmacological management of the behaviours and psychological symptoms of dementia to family carers, health professionals and care workers. The service is operated by multidisciplinary health professionals including medical specialists, with clinical expertise in dementia care. Free education and conference presentations on management of the behavioural and psychological symptoms of dementia are also offered by DBMAS.

- Alzheimer's Australia is the peak body representing and supporting people with dementia and their carers across all states and territories. They offer a range of younger onset dementia services suitable for access by people with FTD and their carers as well as general dementia information, education, advice, support and counselling services.

In-home assessment

Follow-up with carers in the home to proactively assess for care packages or case management is recommended before the carer reaches crisis point where possible. Home assessment may also be required when disabilities or behavioural symptoms are exceeding their physical or emotional capacity or where the environment has become unsafe safe for all involved.

- Aged Persons Mental Health Team: relevant to people with diagnosed dementia and behaviours creating significant risk to self or others; the Residential Support Program or Behavioural Support Team can assist those in residential care. (www.health.vic.gov.au/agedcare/services/assess.htm).

- Aged Care Assessment Services (ACAS): multidisciplinary teams that assist older people and their carers in Victoria to identify the type of care needed. Access to government-funded care services, care packages and permanent/respite residential aged care is dependent upon ACAS assessment (www.health.vic.gov.au/agedcare/services/assess.htm).

Respite care

When an individual acts as a caregiver for someone with dementia, it is important to take regular breaks from caring. Respite care services can give carers time to themselves, allow them to de-stress and re-energise, enable them to complete important tasks such as shopping, and allow normal social interactions. Respite care can also be important for the person with dementia, whose social interactions and activities may have been limited since the onset of their condition.

Formal respite care can take a variety of forms including:

- Respite in the person's home
- scheduled outings with a one to one carer or in groups
- day programs, caring cafes or planned activity groups
- men's sheds
- day respite
- overnight and weekend respite including some special programs for working carers
- residential respite stays

There are a number of *Commonwealth Respite and Carelink Centres* and other programs to choose from. Contact the new centralised Aged Care Information Line.
National Free call:1800 200 422

Further information about respite care is available from Alzheimer's Australia under:

- *Support for Families and Carers – Taking Care of Yourself* (www.alzheimers.org.au/services/taking-care-of-yourself.aspx)

- *Respite Care for People Living with Dementia: It's more than just a short break (*www.alzheimers.org.au/research-publications/alzheimers-australia-numbered-publications.aspx*)*: Alzheimer's Australia position paper

- *Younger onset dementia – Next steps* (www.alzheimers.org.au/services/next-steps-younger-onset-dementia.aspx)

The website of the Department of Health and Ageing also includes respite care information at:

- *Taking a Break*: fact sheet (www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-factsheet-taking-break)

Residential care

In general, people with FTD will ultimately require a higher level of care than can be adequately and safely provided in the home. This care can be provided by trained staff in a residential facility. The time to move to supported care will vary greatly between individuals. Due to the nature of the behavioural problems often associated with FTD, for some sufferers this move will need to be made quite early in the disease process. For others it will be possible to remain at home for longer. For many with FTD, due to the nature of their cognitive and behavioural problems, the routine and structured environment of a supported care facility can be of assistance in managing their symptoms.

Choosing a facility can feel overwhelming. Finding the right facility may take some time and planning well ahead is advised. Many facilities will be populated by older people with dementia. Those with younger onset dementia may feel out of place, or it may be difficult for the families of people with younger onset dementia to see their loved ones surrounded by elderly people with dementia. Furthermore, facility staff may not always be prepared to deal with the unique issues of FTD. Thus, training and education for staff provided by the appropriate professionals (e.g., DBMAS or Alzheimer's Australia) can be very helpful.

Further information about residential care is available from:

- Alzheimer's Australia, under *Support for Families and Carers – Residential Care* (www.alzheimers.org.au/services/residential-care.aspx)

- The Lovell Foundation aims to raise awareness about younger onset dementia and to ultimately provide long term accommodation services specifically for people with younger onset dementia. They have also done a lot of scoping work to inform their lobbying for younger onset residential facilities and so may also be able to provide helpful information about residential care (www.lovellfoundation.com.au/index.php?option=com_content&view=article&id=1&Itemid=3)

- Young People in Nursing Homes Alliance, which can provide advice regarding services that may support younger people who need residential care (www.ypinh.org.au; 03 9428 5677)

- Aged Care Australia (www.agedcareaustralia.gov.au/), run by the Australian Government's Department of Health and Ageing

- The Department of Health and Ageing (www.health.gov.au/internet/main/publishing.nsf/Content/ageing-rescare-index.htm), which provides fact sheets and information regarding topics such as:

    - *Eligibility for Aged Care Services*
    - *Costs of Residential Care*
    - *Support for Aged Care Residents*
    - *Your Rights*

Additional resources which may be of interest to those considering care options for a person with FTD include:

- *Caring for Someone with Dementia: Going to hospital*: help sheet available from Alzheimer's Australia (www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx)

- *Residential care and dementia* (www.alzheimers.org.au/understanding-dementia/section-4-residential-care-and-dementia.aspx): series of help sheets available from Alzheimer's Australia, including:

    - *Deciding on residential care*
    - *Which residential facility?*
    - *Caring partnerships*
    - *Good care in a residential facility*
    - *Coping with placement*
    - *Information and support*

- *Caring for Someone with Dementia: Later stages of dementia*: help sheet available from Alzheimer's Australia (www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx)

- *Palliative Care:* fact sheet available on the website of the Department of Health and Ageing (www.health.gov.au/internet/main/publishing.nsf/Content/Palliative+Care-1)

- *Caring for Someone with Dementia: Palliative care and dementia*: help sheet available from Alzheimer's Australia (www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx)

- *Palliative Care and Dementia*: Alzheimer's Australia position paper (www.alzheimers.org.au/research-publications/alzheimers-australia-numbered-publications.aspx)

Carer well-being

It is important for carers to take breaks from caring (see Care Options) and to look after themselves. The following resources may be useful for health professionals and caregivers of people with FTD:

- Looking after families and carers (www.alzheimers.org.au/understanding-dementia/section-3-looking-after-families-and-carers.aspx): series of help sheets available from Alzheimer's Australia, including:
    - Taking a break
    - Taking care of yourself
    - Feelings
    - Men and caring
    - Coping after the death of someone with dementia

- Taking care of yourself (www.alzheimers.org.au/services/taking-care-of-yourself.aspx): series of web pages developed by Alzheimer's Australia addressing issues for carers such as:
    - Feelings
    - Making the most of respite care
    - Men and caring
    - Taking a break

- Taking Care of Yourself: fact sheet available on the website of the Department of Health and Ageing (www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-factsheet-taking-care-yourself)

- Feelings: fact sheet available on the website of the Department of Health and Ageing (www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-factsheet-feelings)

- Caring for Someone with Dementia: Working with doctors: help sheet available from Alzheimer's Australia (www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx)

- Supporting someone with thinking and memory difficulties: tip sheet developed by clinicians and researchers in Melbourne available for download by health professionals, targeted at patients and families of those in the early stages of dementia (www.latrobe.edu.au/aipca/projects/mci/)

- Carers Australia

- Psychological interventions in frontotemporal dementia: chapter written by two clinical psychologists in the book "Frontotemporal Dementia Syndromes" (Ed. John R. Hodges, 2007, New York: Cambridge University Press). Relevant to clinicians and families.

- Loss and Grief: fact sheet available on the website of the Department of Health and Ageing (www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cpb-factsheet-loss-grief)

Support groups

The experience of DBMAS and ECDC has been that carers benefit greatly from attending FTD-specific informational sessions and support groups. The primary purpose of a support group is to serve as a place to discuss the unique stressors associated with caring for an individual with FTD and to receive support and insights from others in a similar situation. Groups should be moderated by trained psychologists or counsellors.

As indicated in Module 2 – Diagnosing frontotemporal dementia, FTD-specific support groups for carers and those affected by FTD are offered by the following organisations:

Eastern Cognitive Disorders Clinic
Melbourne, Victoria
Support group contact: cheree.presser@monash.edu

FRONTIER Research Group
Sydney, New South Wales
Details: www.ftdrg.org/events/

Alzheimer's Australia – Western Australia
Shenton Park, Western Australia
Groups offered: Frontal Lobe Group; Younger's Carers Group
Phone: 08 9388 2800

Other disease-support groups operate online. Alzheimer's Australia and national DBMAS services also offer a number of additional post-diagnostic support services.

Support groups specific to carers of individuals with language disorders are organised through the Australian Aphasia Association (www.aphasia.org.au/). These groups are not focused specifically on FTD and may include participants whose language has been affected by stroke or traumatic brain injury. Carers may, however, find it useful to discuss language disabilities and communication strategies with others in a similar situation regardless of the cause.

Key messages from family carers regarding their FTD carer support group

- I am often struck by the fact that despite the different forms of FTD and the different backgrounds of all present, there is a common thread of similarities in the behaviours that present.
- Often folk have been battling a system that is not always 'user friendly'. Even with close family or friends, no one but another person in a similar situation can really empathise with the challenges that living with FTD presents.
- The isolation that we as carer's face, even though our spouses are still present is another hurdle. The effort that it takes to create something positive out of this situation is enormous. I try to keep some sort of life of my own, pursuing my own interests. It is still lonely but it is well worth the effort.
- The relief to be able to share, if only for an hour or so is vast. Not only is there the empathy amongst us caring for our spouses, often at a relatively young age, there is also the professional support and information available.
- With the support of our group, now beginning its 3rd year, a calming light shines in the maze that living with FTD presents.

Individual counselling

People caring for those with FTD may find counselling helpful. Psychologists and counsellors may be useful in helping carers adjust to the diagnosis and to their new role. They can assess carers' coping styles and help them manage stress and anxiety. They can discuss relationship changes and provide counselling for young people about the changes occurring in affected parents or grandparents. Counselling can help families cope with the grieving that is commonly associated with caring for someone with dementia. [9].

If a carer's local doctor determines that they are experiencing mental health difficulties and may benefit from counselling, the doctor may prepare a mental health plan and organise a referral to a psychologist. This will enable the carer to obtain a Medicare rebate for services. See the website of the Australian Psychological Society for details (www.psychology.org.au/medicare/fact_sheet/)

Helping family carers maintain their informal support networks

Carers of people with FTD will often report a withdrawal of friends and family members and a shrinking of their social support network and opportunities. This usually occurs when people surrounding the person with FTD feel helpless or don't know how to respond, or when the family carer becomes fearful about social embarrassment or risk incidents.

This can be counteracted by helping the person's support network to understand the disabilities associated with FTD and how they can provide support.

When family carers are well informed they can in turn, find more understanding and support from those around them. They should also be encouraged to openly communicate about their situation.

Writing a letter and email to the family/friend network may promote more understanding and compassion toward the person with FTD and their direct family carers and reduce the risk of social isolation.

Letter examples and templates can be sourced via
http://www.ftdsupport.com/side-ideas-letters.htm

Self-care for the person with dementia

The current module focuses primarily on strategies and resources for those providing care to people with FTD. It is also important to acknowledge that the affected individuals themselves may seek information and support, particularly when a diagnosis is made while insight is retained.

Alzheimer's Australia provides helpful information for people with dementia under Services and Support and the heading I have dementia – What can I do? (www.alzheimers.org.au/services/i-have-dementia.aspx). Alzheimer's Australia has also developed a unique series of help sheets under the category of Understanding Dementia and Memory Loss entitled About you – Information for people with dementia (www.alzheimers.org.au/understanding-dementia/section-8-about-you---information-for-people-with-dementia.aspx).

This series of help sheet addresses issues such as:

- Looking after yourself
- Living alone
- Feelings and adjusting to change
- Keeping involved and active
- Talking about diagnosis
- Talking with your doctor
- Driving and dementia

Another series of tip sheets designed for the affected individual has been developed by Alzheimer's Australia with a specific focus on Younger Onset Dementia (www.alzheimers.org.au/services/tip-sheets.aspx). These tips sheets cover topic including:

- Concentration and Attention
- Memory
- Structure and Routine
- Strengths
- Managing the Impact of Change
- Employment
- Decision-Making Capacity – who decides?
- Legal and Financial Issues

Learning more about their condition and actively contributing to decisions about their future can be important to people affected by FTD, and may ultimately enhance quality of life. Given the nature of the cognitive and behavioural problems that can occur quite early in the disease process, however, many people with FTD are unable to benefit from this information or to contribute to decision making.

Summary

FTD presents unique management challenges to carers and health professionals. Currently, the evidence base for effective management techniques is limited. While pharmacological approaches are sometimes utilised, non-pharmacological strategies are the preferred management approach for most of the behavioural and psychological symptoms of dementia. A person-centred, problem-solving approach helps to ensure that such strategies are employed effectively for each individual.

In addition to managing symptoms in the person with dementia, carers' wellbeing must be taken into consideration. Forms of support may include respite care, support groups, and/or individual counselling.

Attending to the needs of all parties affected by FTD is critical throughout the course of the illness.

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