

FRONTOTEMPORAL DEMENTIA

What is Dementia?

Dementia is the umbrella term for a number of diseases and causes of problems with thinking and memory that are severe enough to make managing day to day life more difficult to achieve. Signs and Symptoms can vary considerably but may include memory loss, poor concentration, difficulties with planning and organising, and disorientation problems.

What is Frontotemporal Dementia?

- Frontotemporal Dementia, (FTD), is caused by damage to the neurons in the frontal and temporal lobes of the brain. It is, therefore, associated with problems with movement, behaviour, personality, and language.
- Frontotemporal Dementia is a rarer form of dementia, but it is still common enough to be quite well known. It is more common for people who are younger in age than other forms of dementia. Approximately 60% of people with Frontotemporal Dementia are under the age of 65.
- It is a progressive disease with symptoms getting worse and increasing over time as other parts of the brain become affected.

The Relationship Between Brain Injury and Frontotemporal Dementia.

- It is possible that people with Chronic Traumatic Encephalopathy, (CTE), can, overtime, begin to exhibit signs of dementia, including Frontotemporal Dementia as there is frequently degeneration in the frontal lobe in Chronic Traumatic Encephalopathy.
- More research needs to be carried out to understand why some people with repeated head injuries develop Chronic Traumatic Encephalopathy and others don't. Research is currently being undertaken to ascertain whether certain genes, age, or lifestyle factors are also common influences. Nevertheless, it is important to ensure preventative measures are carried out to minimise head knocks and proper medical attention is also sought if you or someone you care about sustains a head injury.

What You Might See in Frontotemporal Dementia

- 'Frontotemporal' means that the neurons in the frontal and temporal lobes of the brain have been affected. These areas of the brain relate to personality, behaviour, language, and, in some instances, movement.
- Symptoms connected with personality and behaviour include:
 1. Inappropriate social behaviour e.g. inappropriate laughing or crying.
 2. Inability to empathise - due to emotional detachment.
 3. Poor Judgement.
 4. Disinhibition.
 5. Apathy and a decrease in interpersonal skills e.g. being disinterested or lacking sensitivity.
 6. Decreased interest in personal hygiene.
 7. Increasing dependence.
 8. Increase in compulsive behaviours, especially around food, e.g. preferring sweets and high carbohydrate foods, and or overeating.
 9. Increased agitation
- Symptoms associated with language include:
 1. Difficulty using and understanding both written and spoken language.
 2. Difficulty with word finding and understanding word meanings.

3. Naming things may become more difficult causing the person to replace specific words with more general ones. E.g. calling a book 'it'
 4. No longer knowing the meaning of more common words.
 5. Hesitant speech, using short sentences. Difficulty building sentences.
 6. Less frequent speech.
- Rare types of Frontotemporal Dementia may have symptoms similar to Parkinson's Disease. Symptoms associated with movement include:
 1. Rigidity.
 2. Tremor.
 3. Muscle spasms.
 4. Poor Co - ordination.
 5. Swallowing difficulties.
 6. Muscle weakness.
 7. Increased falls or difficulty walking.
 - Psychological symptoms are rare but can include:
 1. Hallucinations
 2. Delusions.

Things you can do that may help:

- **Make sure the GP is involved in the care.** Monitor for any changes or new symptoms and discuss these with the doctor. It may be necessary to ask for referrals to other health professionals to assist with tools and strategies for care.
- **Contact your local Dementia New Zealand affiliate for support.** The team at Dementia New Zealand are always happy to help with a listening ear and support.
- **To help with behaviour related signs and symptoms:**
 1. It is important to recognise that the behaviour exhibited in Frontotemporal Dementia is due to the illness and the changes that are occurring in their brain, NOT the person with dementia. They are not being 'difficult' or 'mean'. They are no longer able to process information the way they used to due to the physiological changes in their brain. It is important that you don't take these things personally.
 2. Arguing or reasoning with the person with dementia will not help, in fact it will impede the situation. A person with Frontotemporal Dementia will not be able to use logic or reasoning and their social filter may no longer be functioning as it did. They may no longer be able to control themselves or even understand that their words or behaviour are unusual or distressing to those around them.
 3. Have realistic goals. Having unrealistic goals can cause frustration and fatigue for all concerned. Aim for the person with dementia having their optimal sense of wellbeing.
 4. Think about what might triggering behaviour. All behaviour occurs for a reason. Often it conveys a message that the person with Frontotemporal Dementia is no longer able to express in words. It is important to look for any unmet needs the person might have.
 5. Try to respond to the emotions behind the behaviour rather than the behaviour itself.
- **To help with language related symptoms:**
 1. Speak slowly and clearly.
 2. Use simple sentences and one step commands.
 3. Be prepared to take your time and repeat things if necessary.
 4. Ask for clarification if you don't understand.
 5. Avoid arguing and correcting.

6. Use visual cues, such as an album with labelled photos of people and familiar objects to aid communication if word finding is difficult. If required, ask for a referral to a Speech Language Therapist, who will help you to work out the best tools and strategies for your person with Frontotemporal Dementia.
 7. Your local Dementia New Zealand affiliate may have a specialised communication course that could also be helpful with tools and strategies for communication.
- **Some types of Frontotemporal Dementia cause problems with movement, balance, walking, and swallowing.** Ask your doctor for a referral to other health professionals who could assist with these difficulties if necessary.

Acknowledgements

- [National Institute on Aging - What Are Frontotemporal Disorders? Causes, Symptoms, and Treatment](#)
- [John Hopkins Medicine - Frontotemporal Dementia](#)
- [Mayo Clinic - Frontotemporal Dementia](#)
- [Cleveland Clinic - Frontotemporal Dementia](#)
- [Dementia Australia - Mood and behaviour changes](#)
- [Dementia New Zealand - Dementia and Behaviours](#)
- [Dementia New Zealand - Genetics and Dementia](#)
- [Dementia New Zealand - Positive Communication](#)

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