

Frontotemporal dementia

This infosheet provides information about frontotemporal dementia, including its symptoms, how it gets identified and resources to help people living with dementia, and more.

What is frontotemporal dementia?

Frontotemporal dementia (FTD) is a progressive disease of the brain, researchers estimate that approximately 10% of all dementia cases are frontotemporal dementia. However, it likely accounts for 20% or more of dementia in individuals under the age of 65.

Unlike Alzheimer's disease, which generally affects most areas of the brain, frontotemporal dementia is an umbrella term for a group of disorders that primarily affect the frontal and temporal lobes of the brain - the areas generally associated with personality, behaviour, emotions, language, speech, abstract thinking and movement. In most cases of FTD, brain cells in these areas shrink or die. In other cases, the brain cells in these areas get larger, containing round, silver "Pick's bodies". The diagnosis is then Pick's disease or behavioural variant frontotemporal dementia (bvFTD), the most common frontotemporal disorder.

Other names often used for frontotemporal dementia, in addition to Pick's disease, include: frontal lobe dementia, frontotemporal lobar degeneration and Pick's complex, Tau disease, Semantic dementia, non-fluent primary progressive aphasia, corticobasal degeneration and progressive supranuclear palsy. In general, they all eventually lead to similar physical signs or symptoms associated with FTD. FTD involves changes in personality, behaviour and judgment. People with this dementia can act inappropriately around other people, resulting in embarrassing social situations. In the early stage of FTD, behaviour changes and/or problems

How is frontotemporal dementia assessed?

- No single test can diagnose frontotemporal dementia. Doctors diagnose the disease through a process of identifying characteristic features of the disease and ruling out other possible causes.
- The diagnosis of frontotemporal dementia generally involves:
 - Medical history, brain imaging such as MRI (magnetic resonance imaging), PET (positron emission tomography), and SPECT (single photon emission computed tomography), and detailed neurological examination.
 - Physical and neuropsychological examination to assess language, behaviour, memory, executive and visual-spatial functions.

with speech (language) can appear separately. As the disease progresses, these two areas will overlap, language problems will progress and affect the ability of the person to communicate.

Over time, language or movement problems may occur, and the person may need more care and supervision.¹ Unlike Alzheimer's disease, a person with frontotemporal dementia often remains oriented with respect to time and has preserved memory in the early stages. In the later stages of the disease, general symptoms of dementia arise, i.e. confusion and forgetfulness, as in other dementias.

How does frontotemporal dementia affect the person?

Since the frontal and temporal areas of the brain can be affected, symptoms often affect personality, behaviour, emotions, language, speech, abstract thinking and movement.

- **Changes in behaviour** may include becoming either withdrawn or disinhibited (e.g., losing the ability to restrain one's behaviour and actions). The person may show reduced initiative and lose interest in personal hygiene, become easily distracted or repeat the same action over and over again. Overeating or compulsively putting objects in the mouth may occur. Sometimes incontinence is an early symptom of the disease. People with FTD may become indifferent toward other people or may experience abrupt and frequent mood changes or excessive emotions.
- **Problems with language** can range from trouble finding the right word or reduction of speech to total loss, i.e. becoming mute. Echoing what has been said by others and stuttering are common symptoms. The person may have difficulty sustaining a train of thought or maintaining a conversation for any length of time. Writing and reading are also affected.
- **Problems with movement.** People with FTD may experience decreased facial expression, slowness of movements, rigidity and postural instability. Shaking, difficulty walking, frequent falls and poor coordination can be common. Motor skills are lost and swallowing difficulties may occur.

What are the risk factors for frontotemporal dementia?

Frontotemporal dementia tends to occur at a younger age than Alzheimer's disease and can affect both men and women. The average length of the disease is 2-10 years. Little is known about the cause of frontotemporal dementia and risk factors have yet to be identified. Recent research has shown genetic mutations underlying some cases of FTD. However, more than half the people who develop frontotemporal dementia have no family history of dementia.

¹ *Frontotemporal disorders: Information for patients, families and caregivers*, National Institute on Aging. September 2010.

Is there treatment?

At present, there is no known cure and no effective way to slow its progression. Cholinesterase inhibitors used as treatment for Alzheimer's disease do not work for the treatment of FTD as different areas of the brain are affected. Treatment currently focuses on managing symptoms.

New behavioural therapeutic strategies are also helping people living with the disease. Therapeutic techniques like physical activity and music are being used as viable and useful treatments. Research shows that the quality of life of people with dementia, and also their caregivers, is significantly improved by activities that emphasize their strengths and abilities. By understanding the person's personality, life experiences, support systems and ways of coping, a person-centred approach to care can be created that preserves and improves quality of life.

For more information:

Visit the Alzheimer Society's website at alzheimer.ca or contact your local Alzheimer Society.

More information can be obtained from the following:

- The Association for Frontotemporal Degeneration: theaftd.org
- Frontotemporal dementia and other frontotemporal disorders, National Institute on Aging. nia.nih.gov/health/frontotemporal-disorders
- Rare Dementia Support. Frontotemporal dementia. raredementiasupport.org/frontotemporal-dementia

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The information provided in this resource by the Alzheimer Society is for general purposes only. It is not meant to replace any diagnosis, treatment or medical advice and does not replace your relationship with your health-care providers. The Alzheimer Society encourages you to talk to a qualified health-care provider before making any health-related decisions.

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