Frontotemporal dementia

This help sheet describes frontotemporal dementia, as well as its causes, progression and treatment.

- Dementia describes a collection of symptoms caused by disorders affecting the brain.
- Frontotemporal dementia causes progressive damage to either or both the frontal or temporal lobes of the brain.
- Frontotemporal dementia can affect one or more of the following: behaviour, personality, language and movement.
- Memory often remains unaffected, especially in the early stages of the condition.
- Frontotemporal dementia is more commonly diagnosed in people under the age of 65.

Signs and symptoms of frontotemporal dementia

There are several different types of frontotemporal dementia, with symptoms depending on which areas of the brain are affected first.

Frontotemporal dementia is progressive and affects everyone differently. This means that symptoms may be mild at first but will worsen over time.

Each type of frontotemporal dementia has its own signs and symptoms.

Behavioural-variant frontotemporal dementia

When the frontal lobes are affected first, the main changes are in personality and behaviour: this is known as behavioural-variant frontotemporal dementia. In this type of frontotemporal dementia, areas of the brain that control conduct, judgement, empathy and foresight are damaged.

Symptoms vary from person to person, depending on which areas of the frontal lobes are damaged. Some people become apathetic, while others become disinhibited; some may alternate between apathy and disinhibition.

Common symptoms include:

- fixed mood and behaviour, appearing selfish and unable to adapt to new situations
- loss of empathy, emotional warmth and emotional responses towards others
- apathy or lack of motivation, abandoning hobbies or avoiding social contact
- loss of normal inhibitions, talking to strangers or exhibiting embarrassing behaviour
- difficulty in reasoning, judgement and planning
- being easily distracted or impulsive
- changes in eating patterns, such as craving sweet foods, overeating, or unusual food preferences
- a decline in self-care and personal hygiene
- lack of insight
- repetitive motor (physical) behaviours such as collecting, counting and tapping.

Primary progressive aphasia

When the temporal lobes are affected first, there is a loss of language skills: this is known as primary progressive aphasia. In this type of frontotemporal dementia, other aspects of thinking, perception and behaviour are not affected as much in the early stages.

There are two more common types of frontotemporal dementia where language is impaired:

Semantic dementia

Semantic dementia is a temporal variant, where the ability to assign meaning to words, to find the correct word, or to name people and objects is gradually lost. Reading, spelling, comprehension and expression are usually unaffected.

Symptoms of semantic dementia include:

- gradually losing a range of vocabulary, using more general words instead
- losing the ability to understand single words, especially uncommon ones
- difficulty finding the right word, or someone's name
- forgetting what familiar objects are used for, or being unable to name them.

However, grammar and the ability to speak fluently remain, so someone with the condition may sound fluent, but their speech may lack meaning.

Many people with semantic dementia retain other functional abilities (such as decision-making or motor skills) and can undertake activities of daily living until very late in the disease. Changes in behaviour may also be present, such as becoming obsessed about daily routines and emotional responses.

Progressive non-fluent aphasia

In this type of frontotemporal dementia, a person will have problems with speaking and, over time, will lose their ability to speak fluently.

Symptoms vary, but include:

- speaking differently, such as producing words slowly, stuttering or having slurred speech
- remaining articulate, but saying the wrong word, using incorrect grammar or using shorter or incomplete phrases
- difficulty following conversations, communicating with groups of people, or using the telephone
- a declining ability to read and write.

Overlap with motor disorders

A small number of people affected by frontotemporal dementia also develop conditions that affect their movement. Motor symptoms can occur either before or after the symptoms of dementia first appear. These conditions are relatively rare, but include motor neurone disease and other movement disorders such as corticobasal syndrome and progressive supranuclear palsy.

What causes frontotemporal dementia

Frontotemporal dementia is caused by brain disease, but why some people get it is unknown (except in familial frontotemporal dementia, which is caused by a gene mutation). People with frontotemporal dementia can have one of a number of different underlying changes in brain cells in either the frontal or temporal lobes, or both.

Who gets frontotemporal dementia

Frontotemporal dementia can affect anyone.

Symptoms of frontotemporal dementia typically occur between the ages of 40 and 65, though it can affect people younger or older than this. Almost a third of people with frontotemporal dementia have a family history of dementia. However, only about 10 to 15 per cent of people with the condition have familial frontotemporal dementia caused by a gene mutation.

The genetic basis of the condition is not fully understood and is being researched.

Diagnosing dementia

It is important that someone with suspected frontotemporal dementia is assessed by a neurologist, geriatrician or psychiatrist specialising in dementia.

A typical assessment includes:

- a detailed medical history from the person
- a conversation, if possible, with a close family or carer who has observed symptoms, when they began and how often they occur
- a physical examination

- blood and urine tests
- a psychiatric assessment
- a neurological assessment (tests of cognitive abilities such as comprehension and problem-solving)
- brain imaging (magnetic resonance imaging, known as an MRI).

Treatment options

Currently there are no treatments available to cure or slow disease progression, but several clinical trials are currently underway in Australia and around the world.

Various therapies can help with some of the symptoms, such as changes in behaviour and language.

- Talking to a counsellor or psychologist is important to help manage changes in behaviour and mood.
- Occupational therapy can help improve everyday functioning at home.
- Speech therapy can help people with semantic dementia and progressive non-fluent aphasia to develop alternative communication methods.

Secondary symptoms such as depression or sleep disturbances may be helped by medication.

Learning more about frontotemporal dementia and its impacts on the brain can help others to understand why someone is behaving in a particular way.

With support, family members and carers can develop strategies to support someone impacted by behavioural and psychological symptoms.

How frontotemporal dementia progresses

Frontotemporal dementia is a terminal illness. As the disease progresses, additional areas of the brain may be affected. It causes progressive and irreversible decline in a person's abilities over a number of years.

Additional reading and resources

- **Dementia Australia library service**
  Visit: **dementia.org.au/library**
- **Dementia Australia support**
  Visit: **dementia.org.au/support**
- **Dementia Australia education programs**
  Visit: **dementia.org.au/education**
- **Frontotemporal Dementia Research Group (FRONTIER)**
  Visit: **frontierftd.org**
- **The Australian Frontotemporal Dementia Association (AFTDA)**
  Visit: **theaftd.org.au**
- **The FTD Toolkit**
  Visit: **ecdc.org.au/ftd-toolkit**

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au