

## FACTSHEET 1

# WHAT IS FRONTOTEMPORAL DEMENTIA?

**Frontotemporal dementia or FTD is a progressive disorder of the brain. It can affect behaviour, language skills and movement.**

The brain is made up of four lobes – the frontal lobe, parietal lobe, temporal lobe and occipital lobe. In FTD, there is progressive loss of cells in the frontal and temporal lobes of the brain.

The main subtypes of FTD are called:

- Behavioural variant FTD or bvFTD
- Primary progressive aphasia or PPA

PPA can be further split into three main subtypes known as:

- semantic variant, also known as semantic dementia or SD
- nonfluent variant, also known as progressive nonfluent aphasia or PNFA
- logopenic variant, also known as logopenic aphasia or LPA

## What causes FTD?

For most people, the cause of FTD is not known

FTD can affect both men and women. It usually affects people in their 50s or 60s, although it can affect people both younger and older than this.

In around a third of people however it can be triggered by a genetic problem – we call this *familial FTD*.

The main genes involved are called:

- Tau or MAPT
- Progranulin or GRN
- C9orf72

See [FACTSHEET 2](#) for more details on familial FTD.

## What are the symptoms of FTD?

Damage to the frontal and temporal lobes causes problems with behaviour and language skills.

### Behavioural variant FTD

In bvFTD the initial symptoms are usually a change in personality or behaviour. These may include:

- Behaving inappropriately
- Becoming less interested in things or in people
- Becoming more obsessive or repetitive
- Changes in the types of food eaten
- Problems with planning or problem solving
- Difficulty concentrating

For more details about bvFTD see [FACTSHEET 3](#).

### Primary progressive aphasia

In PPA the initial symptoms are problems with language skills. For more details about PPA see [FACTSHEET 4](#).

#### *Semantic variant*

In the early stages there may be subtle changes in the ability to find or understand words. For more details see [FACTSHEET 5](#).

#### *Nonfluent variant*

The main problem is usually producing speech. Speech may become slow and hesitant, and words may be missed out or pronounced incorrectly. For more details see [FACTSHEET 6](#).

### *Logopenic variant*

People may pause in the middle of sentences and have difficulties finding words.

## **Do people with FTD have physical problems?**

It is uncommon to have physical problems in the early stages but some people may also develop problems with movement:

- Motor neurone disease – see [FACTSHEET 7](#)
- Parkinsonism where there are symptoms similar to Parkinson's disease – see [FACTSHEET 8](#). The two main types of parkinsonism seen are called corticobasal syndrome or CBS, and progressive supranuclear palsy or PSP. See [FACTSHEETS 9 and 10](#) for more details.

## **How is FTD diagnosed?**

Usually a diagnosis is made by a specialist rather than a GP. There is no single test that will make a diagnosis except in people who have a genetic cause. A series of tests are usually performed including a scan of the brain. Diagnosis is discussed in more details in [FACTSHEET 11](#).

## **Is there a treatment for FTD?**

There is currently no cure for FTD but there are some important things which can help when caring for someone. These include:

- Strategies for dealing with behavioural symptoms
- Speech and language therapy for people with PPA
- Genetic advice and counselling for people with familial FTD
- These are discussed in more detail in [FACTSHEET 12](#).

## **What is the prognosis of FTD?**

The rate of progression is very variable and can range from two to twenty years. As the disease progresses, people will need help with most aspects of daily life. People may need nursing care.

## **What support is available?**

Useful organizations that can provide information include:

- Rare Dementia Support (UK)  
[www.raredementiasupport.org](http://www.raredementiasupport.org)
- Alzheimer's Society (UK)  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)
- Association for Frontotemporal Degeneration (US)  
[www.theaftd.org](http://www.theaftd.org)
- The Australian FTD Association (Australia)  
[www.theaftd.org.au](http://www.theaftd.org.au)
- For links to other support groups around the world – [www.worldftdunited.net](http://www.worldftdunited.net)