

FACTSHEET 3

WHAT IS BEHAVIOURAL VARIANT FTD?

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

Behavioural variant FTD is one of the subtypes of FTD. It is also known as bvFTD. The first symptoms are usually changes in behaviour or a change in personality. In the early stages these changes may be very subtle and not be noticed as abnormal at first.

Symptoms can include:

Behaving inappropriately – disinhibition

- Losing normal inhibitions
- Losing manners
- Being more extrovert than previously
- Making inappropriate comments to people
- Acting more impulsively such as spending excessive amounts of money
- More or inappropriate interest in sex

Becoming less interested in things – apathy

- Less motivation to do things
- Being more passive than before
- Needing prompting to do routine activities
- Paying less attention to personal hygiene and dress
- Loss of interest in sex

Becoming less interested in people – loss of empathy

- Being less sympathetic to others than before
- Interacting less with people
- Withdrawing from social activities

Becoming more obsessive or repetitive in their behaviour

- Being fixed in the way they do things
- Having to stick to routines
- Saying things repetitively
- Collecting or hoarding things

Changes in the types of food eaten, such as sweet foods

- Increased craving for certain foods, often sweet things
- Food fads – eating one specific type of food
- Binge eating
- Increased consumption of alcohol or cigarettes
- Eating very quickly

Usually the person will be unaware of the true extent of their problems and lack insight into what is happening to them.

As well as changes in behaviour, there may be problems with thinking as well:

- In the early stages of the disease this may be problems in planning, organisation, making decisions or solving problems.
- People may have difficulty concentrating on one thing and seem very distractible

As the disease progresses problems with behaviour will tend to become worse. However some behaviours such as disinhibition may become less of a problem.

Other parts of thinking may also become affected over time such as:

- Finding the right word
- Understanding speech
- Remembering things

Does bvFTD run in families?

In about a third of cases bvFTD can be a genetic disorder and run in families. Mutations in the tau, progranulin or C9orf72 genes are the most common. See [FACTSHEET 2](#) for more details about familial FTD.

How is bvFTD 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 some people who have a genetic cause. A series of tests are usually performed including a scan of the brain – see [FACTSHEET 11](#) for more details.

Is there a treatment for bvFTD?

There is currently no cure for bvFTD but there are some important things which can help when caring for someone – see [FACTSHEET 12](#) for more details.

What is the prognosis of bvFTD?

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. Continence may become a problem and people commonly develop problems with swallowing. Eventually nursing care may become necessary.

What support is available?

Useful organizations that can provide information include:

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