Frontotemporal Dementia (FTD)

FTD is caused by damage to cells in areas of the brain called the frontal and temporal lobes. The frontal lobes regulate our personality, emotions and behaviour, as well as reasoning, planning and decision-making. The temporal lobes are involved in the understanding and production of language.

There are several different conditions which affect the frontal and temporal lobes of the brain – together called frontotemporal lobar degeneration. These include:

- Behavioural variant FTD (bvFTD)
- Semantic dementia (the word semantic means the meaning of language)
- Progressive non-fluent aphasia (aphasia is a language disorder where people have problems speaking and writing)
- Dementia associated with motor neurone disease

Your doctor may refer to these conditions by their specific names or may describe them all as 'frontotemporal dementia'.

The early symptoms of FTD depend on which area of the brain is affected.

In behavioural variant frontotemporal dementia, the parts of the frontal lobe which regulate social behaviour may be most affected. In semantic dementia, the parts of the temporal lobe which support understanding of language and factual knowledge are most affected. In progressive non-fluent aphasia, parts of the frontal and temporal lobes which control speech are most affected.

Therefore symptoms can vary from person to person. There may also be overlap of some symptoms between the different forms of FTD. Some of these symptoms may include:

- Personality changes. This may include a change in how people express their feelings towards others or a lack of understanding of other people's feelings. They may also show a lack of interest or concern, become disinhibited or behave inappropriately.
- Lack of personal awareness. People may fail to maintain their normal level of personal hygiene and grooming.
- Lack of social awareness. This might include making inappropriate jokes, or showing a lack of tact.
- Changes in food preference, over-eating or over-drinking.
- Behaviour changes. People may change their humour or sexual behaviour, become violent, develop unusual beliefs, interests or obsessions. Some people become impulsive or easily distracted.
- Difficulty with simple plans and decisions.
- Lack of awareness of any personality or behaviour changes.
- Decline in language abilities. This might include difficulty getting words out or understanding words. People may repeat commonly used words and phrases, or forget the meaning of words.
- Difficulty recognising people or knowing what objects are for.
- Day-to-day memory may remain intact in the early stages, but problems with attention and concentration could give the impression of memory problems.

FTD is a progressive condition which means symptoms get worse over time. The speed of progression of FTD can vary widely, but often unfolds over years – with some people living with the condition for more than 15 years. As the disease progresses, people may start to show some problems with movement similar to those seen in Parkinson's or motor neurone disease.

It is important to get the right diagnosis so that the right treatments and help can be given.

If you are worried about your health or someone else's, you should talk to your GP.

If your GP suspects dementia, they may refer you to a memory clinic or another specialist clinic. You will be asked about your symptoms and medical history. You may have a physical check-up and a memory test. They may also send you for other tests including brain scans and blood tests. Together these tests will help to identify the problems in thinking and function, and the likely cause.

Brain scans such as MRI (magnetic resonance imaging) or CT (computerised tomography) may be used to help give a diagnosis of frontotemporal dementia. They allow the doctor to look for changes in the specific brain areas commonly affected in this type of dementia

While there are currently no treatments specifically for FTD, there are treatments which could help with some of the symptoms.

People with all forms of dementia may be offered antidepressants or non-drug alternatives, like cognitive behaviour therapy (CBT) to treat symptoms of depression or help manage challenging behaviour. CBT provides an opportunity for people to talk about their worries and concerns with a specialist practitioner. Antidepressants may not always be suitable for someone with frontotemporal dementia and your doctor will carefully consider what may be appropriate.

To help relieve symptoms of severe agitation and aggression a doctor may consider an assessment of someone's health and environment. This could help identify any causes or triggers of agitation or aggression. Non-drug approaches such as aromatherapy or music therapy may also be considered. This might depend on your preference as well as the availability of treatments. In rare circumstances antipsychotic drugs may be used to relieve severe symptoms. These drugs are not suitable for everyone so your doctor will carefully consider what is appropriate. These drugs can have serious side effects and their use should be carefully monitored.

It's possible that cognitive stimulation activities may be helpful for people with frontotemporal dementia. These activities are designed to stimulate thinking skills and engage people. They are often group-based and include games, with an emphasis on enjoyment.

Physical symptoms such as problems swallowing or moving may need careful management in their own right. You may be offered speech therapy or physiotherapy to help with these symptoms.

You can discuss your treatment options with your doctor.

Living with frontotemporal dementia can be difficult. Younger people affected by the disease may be working, and have family and financial responsibilities.

The Frontotemporal Dementia Support Group (formerly Pick's Disease Support Group) provides support and information for people with FTD, their families and carers. There are other support organisations that offer help and advice about dementia.

In frontotemporal dementia (FTD) the brain shrinks in the frontal and temporal lobes. There is also a build-up of specific proteins in these areas of the brain.

These proteins can clump together and become toxic to brain cells, causing them to die. Three major proteins identified in FTD are called tau, TDP-43 and FUS. The reason for their build-up is not yet fully understood and research is ongoing.

Some people with FTD have a family history of dementia and the condition may be inherited in some of these families.

For behavioural variant FTD, a third to half of people could have a family history. This figure is thought to be much lower for other forms of FTD. Scientists have found a number of faulty genes which can cause inherited forms of FTD. These include the tau gene, the progranulin gene and C9ORF72. If your doctor suspects a strong family link, they may offer you a genetic test and/or genetic counselling to close relatives.