

FACTSHEET 11 HOW IS FTD DIAGNOSED?

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

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 or semantic dementia
- nonfluent variant or progressive nonfluent aphasia
- logopenic variant or logopenic aphasia

Some people may also develop problems with movement:

- · Motor neurone disease or MND
- Parkinsonism, of which two main types are seen called corticobasal syndrome or CBS, and progressive supranuclear palsy or PSP.

Diagnosis is usually made by a specialist and involves a clinical assessment and a series of tests.

Clinical assessment

The initial part of the diagnostic process is an assessment by a specialist. They will go through the symptoms that have been happening and ask about problems that run in the family. The specialist will also perform some tests of thinking, memory and language as well as a physical examination to look for signs of MND or parkinsonism.

It is important to have a partner, family member or close friend with you at this appointment.

Blood tests may be performed at this appointment to exclude some rare causes of dementia.

Genetic testing

In around a third of people FTD is due to a genetic problem with the main genes involved being called:

- Tau or MAPT
- · Progranulin or GRN
- C9orf72

It is possible to test for problems in these genes at specialist centres by taking a blood test. This is done if there is a strong family history of dementia or if there are symptoms and signs suggestive of a genetic cause. It may take a number of months before a result is available.

Neuropsychology

Sometimes more detailed thinking, language and memory tests are performed by a neuropsychologist. This testing may take a couple of hours and provides the specialist with a more complete picture of the problems that are happening.

Brain imaging

Brain imaging should be performed to help make a diagnosis of FTD. This may be a CT scan but more commonly is a magnetic resonance imaging or MRI scan. This involves lying down in the scanner for around twenty minutes to half an hour. The images that are produced are then

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looked at by a neuroradiologist, a doctor trained in looking at brain imaging, to see if there are signs of FTD.

Lumbar puncture

Also called a spinal tap, this is a medical procedure where cerebrospinal fluid or CSF is taken by inserting a needle into the lower part of the spine. The whole procedure takes about twenty minutes in total.

This is sometimes performed when trying to diagnose FTD and can be helpful to exclude other diagnoses.

EMG

If there is a suspicion that someone may have MND then a needle test of the electrical activity of the muscles is performed. This is called electromyography or EMG.

Apart from a genetic test there is no single test that diagnoses FTD. A specialist will gather all of the information from the different tests together to help them make a diagnosis. They will go through the results of the tests with you at a second appointment and tell you what they think the diagnosis is.

Sometimes the diagnosis is not completely clear at the first couple of appointments and it is only over time that the diagnosis becomes clear.