

What is frontotemporal dementia?



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Information in this introductory booklet is for anyone who wants to know more about frontotemporal dementia (FTD). This includes people living with FTD, their carers, families and friends. The booklet aims to give an introduction to FTD. It provides an overview of the causes, symptoms and treatments.

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This information does not replace any advice that doctors, pharmacists or nurses may give you but provides some background information that we hope you will find helpful.

The booklet was updated in January 2020 and is due to be reviewed in January 2022. Please contact us if you would like a version with references or in a different format.

What is frontotemporal dementia?

Dementia is not a disease in itself, it is a word used to describe a group of symptoms. These may include changes in personality, behaviour or mood, memory loss, confusion and difficulty with day-to-day tasks.

Dementia is caused by different brain diseases. The symptoms someone has will depend on which disease is affecting their brain.

Frontotemporal dementia (FTD) is a rarer form of dementia. It is thought to account for fewer than one in 20 of all dementia cases. It commonly affects people between the ages of 45 and 64. However, FTD can affect people younger and older than this.

Originally called Pick's disease, after the scientist who first observed the symptoms, FTD is now known to be made up of several different diseases. Your doctor may refer to these by their specific names or may describe them all as 'frontotemporal dementia', as we will in this booklet.

Frontotemporal dementia includes the following diseases:

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

FTD associated with motor neurone disease

You can find out more about semantic dementia and progressive non-fluent aphasia in our booklet '**What is primary progressive aphasia?**'.

FTD is the second most common cause of dementia in people under

65

FTD commonly affects people between the ages of

45-64

FTD is caused by damage to cells in areas of the brain called the frontal and temporal lobes. These areas control our personality, emotions and behaviour, as well as our speech and understanding of language.

In FTD, there is a build-up of proteins in the frontal and temporal lobes. Three proteins involved in FTD are called tau, TDP-43 and FUS.

These proteins clump together and damage the brain cells, eventually causing them to die. The reason for this build-up is not yet fully understood and research is ongoing.

Symptoms

The early symptoms vary from person to person and depend on which area of the brain is affected.

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

Symptoms get worse over time, gradually leading to more widespread problems with day-to-day function. Some people may develop movement problems similar to those seen in Parkinson's disease. Over time, people with FTD can find it harder to swallow, eat, communicate and move, and may have difficulties with bladder or bowel control. They will require more support to look after themselves.

The speed of change can vary widely. The average survival time after symptoms start is about eight years, but some people live with the condition for much longer than this.



Symptoms may include:

**Changes in emotions**

This may include a change in how people express their feelings towards others or a lack of understanding of other people's feelings.

**Lack of interest**

People may become withdrawn or lose interest in looking after themselves, such as failing to maintain a normal level of personal hygiene.

**Inappropriate behaviour**

This might include making inappropriate jokes or showing a lack of tact. Humour or sexual behaviour may change. Some people become impulsive or easily distracted.

**Obsessions**

People might develop unusual beliefs, interests or obsessions.

**Diet**

Changes in food preference such as eating more sweet things, over-eating or over-drinking.

**Awareness**

People may not realise there are changes in their personality or behaviour.

**Decision making**

Difficulty making simple plans and decisions.

**Language**

Decline in language abilities. This might include difficulty speaking or understanding the meaning of words. People may repeat words and phrases or forget what words mean.

**Memory**

Day-to-day memory may be relatively unaffected in the early stages, but problems with attention and concentration could give the impression of memory problems.

**Recognition**


Difficulty recognising people or knowing what objects are for.


**Movement problems**


Around one in every eight people with behavioural variant FTD also develops movement problems of motor neurone disease. This can include stiff or twitching muscles, muscle weakness and difficulty swallowing.

Diagnosis

It is important to get the right diagnosis so that the right help can be given. If you are worried about your health or someone else's, you should talk to your doctor.

 If your doctor suspects dementia, you may be referred 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 do some thinking and memory tests.

 You may also be sent for other tests including brain scans and blood tests.

Together these tests will help to identify the likely cause of your symptoms.

Brain scans such as MRI (magnetic resonance imaging) may be used to help give a diagnosis of frontotemporal dementia. They allow the doctor to look for changes in the frontal and temporal lobes of the brain, commonly affected in this type of dementia.

FTD is an uncommon form of dementia, not often seen by doctors. It may take longer than usual to get the right diagnosis.



Treatments

Currently there are no drugs to treat FTD, so the focus is on helping people with the disease and their carers to manage symptoms in everyday life.

This support can come from a range of places, including the NHS and social services as well as specialist support groups and local groups or organisations in your community.

Support to manage symptoms, as well as sharing experiences with others in a similar situation, can be a real help. Occupational therapists can also help you to maintain your independence for as long as possible.

Physical symptoms of FTD, such as problems swallowing or moving, may need careful management. You may be offered speech therapy or physiotherapy to help with these symptoms.

Speech therapists can also give advice about communication techniques for people with language problems. Some people find it helps to use alternative communication methods, including specialist smartphone and tablet apps or simpler approaches like picture books.



While drug treatments are limited, a group of antidepressant medications called SSRIs can sometimes help to manage behavioural symptoms in people with FTD.

If someone with FTD is experiencing severe agitation or aggression, a doctor may first assess their general health and environment. This could help identify any causes or triggers of these symptoms. Non-drug treatments such as aromatherapy or music therapy might also be suggested. Such approaches take into account a person's own interests and may help to relieve aggression and agitation.

In rare cases, 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. They can have serious side-effects and their use should be carefully monitored.

For more detailed information ask for our **'Treatments for dementia'** booklet or talk to your doctor to discuss treatment options.

Risk factors

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, one in every two or three people with the disease could have a family history. This figure is thought to be much lower for other forms of FTD. Overall, around one in ten cases of FTD are thought to be caused by a faulty gene passed down in families. This is also known as familial frontotemporal dementia.

Scientists have found a number of faulty genes that can cause inherited forms of FTD, including tau, progranulin and C9ORF72. If your doctor suspects a strong family link, you may be offered a genetic test and close relatives may be offered genetic counselling. For more information contact us for our leaflet **'Genes and dementia'**.

In cases of FTD where there is no family history, the risk factors are not yet fully understood and research is underway to find out more.

Support

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

As well as supporting the person with FTD, it's important that family and carers also access practical and emotional support for themselves.

Rare Dementia Support runs three national groups providing support and information for people with FTD, their families and carers. These are the **Frontotemporal Dementia Support Group**, the **Primary Progressive Aphasia Support Group** and the **Familial Frontotemporal Dementia Support Group**.

Regional contact details can be found online at www.raredementiasupport.org or by ringing **07341 776 317** (FTD), **07388 220 355** (PPA) or **07592 540 555** (familial FTD).

Online information about FTD can also be found at the FTD talk website at www.ftdtalk.org

There are other support organisations that offer help and advice about dementia. For more information, visit our website at www.alzheimersresearchuk.org or ask us for our booklet '**Support for people affected by dementia: organisations that can help**'. You can also speak to your doctor or nurse for advice.



Send me more information

For free information, simply complete this slip and drop it straight in a post box. Alternatively, phone us on **0300 111 5555**.

I would like to know more about

Dementia: symptoms, diagnosis, causes and risk reduction (SCIHIAAD)

Treatments for dementia (SCIHITMT)

Genes and dementia (SCIHIGENE)

Support for people affected by dementia: organisations that can help (SCIHICARE)

What is primary progressive aphasia? (SCIHIPPA)

Name

Address

Email

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Let us know how we can contact you (tick below):

Post Email Telephone Text message

You can change how we talk to you at any time, by calling **0300 111 5555** or emailing enquiries@alzheimersresearchuk.org

Our Privacy Notice can be found at www.alzheimersresearchuk.org/privacy-policy and explains how we will use and store your information.



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Research

Alzheimer's Research UK
has funded more than
£27.3 million
of pioneering research to
help advance our understanding
of FTD.



Our research is looking at the proteins that build up in the brain in FTD and the risk factors for developing the disease. This work will help scientists to understand FTD, diagnose it more accurately and develop new treatments.

Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make breakthroughs.



Find out more

If you have questions about dementia research or want to find out more about how to get involved in research, contact our **Dementia Research Infoline** on **0300 111 5 111** or email **infoline@alzheimersresearchuk.org**

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages.

We are the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



Contact us

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