



Alzheimer's  
Research  
UK

# What is frontotemporal dementia?



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## Introduction

Information in this booklet is for anyone who wants to know more about frontotemporal dementia, also known as 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, diagnosis, and treatments.

This information does not replace any advice that doctors, nurses, or pharmacists may give you. If you are worried about your health, including memory and thinking problems, speak with your doctor as soon as possible.

The booklet was updated in January 2022 and is due to be reviewed in January 2024. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers. Please contact us if you would like a version with references or in a different format.

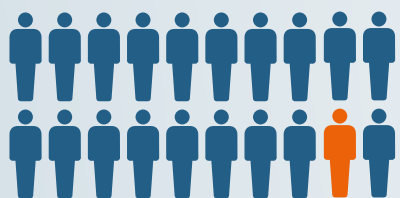
If you have questions about dementia or dementia research you can contact the **Dementia Research Infoline** call **0300 111 5111** email [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)  
Or write to us using the address on the back page.

## What is frontotemporal dementia?

Dementia is a term used to describe a group of symptoms that may include changes in personality, behaviour or mood, memory loss, confusion, and difficulty with day-to-day tasks.

Dementia is caused by different diseases that affect the brain, the most common being Alzheimer's. Frontotemporal dementia, also known as FTD, is a rarer type of dementia.

It is thought to account for less than one in 20 of all dementia cases. It typically affects people between the ages of 45 and 64. However, FTD can affect people younger or older than this.



Frontotemporal dementia is rare, accounting for **less than 1 in 20** of all dementia cases



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

FTD is caused by the build-up of three proteins. The proteins are called tau, TDP-43 and FUS. These proteins clump together and damage the brain cells, eventually causing them to die. As the damage spreads through different parts of the brain, the symptoms of dementia get worse. So over time a person with FTD will need more help with everyday life.



Originally called Pick's disease, FTD can be caused by several different underlying diseases. A doctor may call the underlying diseases their specific names, or may describe them all as 'frontotemporal dementia', which we do in this booklet.

**Frontotemporal dementia includes the following:**

**Behavioural variant** FTD (bvFTD).

**Semantic dementia** - the word semantic means the meaning of language.

**Progressive non-fluent aphasia** - aphasia is where people have problems speaking and writing.

**Frontotemporal dementia** - 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?**'. You can find details to order our information on the back of this booklet.

## Risk factors

Some people with frontotemporal dementia have a family history of the condition. Directly inherited dementia is rare, but in around 30% of FTD cases a family history of the condition is known. In these cases the cause is likely to be genetic and this is known as familial frontotemporal dementia.

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 frontotemporal dementia. It is important to note that most cases of FTD do not have a genetic basis.

Research has 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 history, you may be offered genetic counselling and testing to see if you carry the gene too.

Their family members can also be referred for genetic counselling and testing. For more information ask us for our leaflet '**Genes and dementia**', contact details can be found on the back of this booklet.



In cases of FTD where there is no family history, the risk factors for the disease are not yet fully understood. Because FTD is a rarer type of dementia it is harder for researchers to study its causes.

To reduce our risk of other types of dementia we can take steps to look after our brain health, and this may well be important for the risk of non-genetic FTD too.

# Symptoms

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

## Symptoms may include:



### Decision making

Difficulty making plans, following instructions, and deciding what to do.



### Lack of interest

Becoming withdrawn or losing interest in everyday life. People can stop looking after themselves, such as not washing or dressing properly.



### Movement problems

Around one in eight people with behavioural variant FTD also develops movement problems. This can include stiff or twitching muscles and muscle weakness.



### Obsessions

People might develop new beliefs, interests, or obsessions. For example shopping too often or gambling.



### Memory

Day-to-day memory may be less affected in FTD, but problems with attention and concentration can be common.



### Recognition

Difficulty recognising people or knowing what objects are used for. For example, understanding that the kettle is used to boil water.



### Inappropriate behaviour

Making inappropriate jokes or behaving strangely. Sense of humour, or sexual behaviour may change. Some people become impulsive or easily distracted. People may not realise that their behaviour or personality is changing.



### Changes in emotions

A change in how people express their feelings, or understand other people's feelings. For example, not recognising when someone is upset.



### Communication

Problems with speaking and understanding words. People may struggle to say the right word or forget what words mean.

**In behavioural variant frontotemporal dementia**, the parts of the frontal lobe that control social behaviour may be most affected. This means changes to behaviour, emotion and awareness are common symptoms.

**In semantic dementia**, the parts of the temporal lobe that support understanding of language and factual knowledge are most affected. This means people forget the words for things and can struggle with concepts, like money and paying for items.

**In progressive non-fluent aphasia**, the parts of the frontal lobe that control speech are most affected. This means struggling to find the right word or difficulty holding conversations can be common symptoms.

Frontotemporal dementia is a progressive disease. Over time symptoms get worse and someone will require more support to look after themselves and with day-to-day activities.

The speed of change in symptoms can vary widely from person to person. People with FTD can find it harder to swallow, eat, communicate, and may have difficulties with bladder or bowel control as symptoms become more severe.

Some people may develop movement problems similar to those seen in Parkinson's disease.



# Diagnosis

If you are worried about dementia symptoms in yourself or someone else, you should talk to your doctor as soon as possible. Diagnosing dementia, and where possible the type that someone has, is important.

It means that the right treatments, support and help can be given, and people can plan for the future.



## During the appointment the doctor will:

- Ask about your symptoms and how they are affecting you.
- Ask a relative or close friend if they have noticed any changes.
- Check your medical history.
- Give you a physical check-up, checking your blood pressure and balance.
- Run a blood test, to rule out other possible causes of the symptoms like vitamin deficiencies and thyroid disorders. They may also ask you for a urine sample.
- Ask you to do some memory and thinking tests.

If your doctor suspects dementia, you may be referred to a memory clinic or another specialist doctor. Here you may have another physical check-up and complete some more memory and thinking tests.







### A memory clinic or specialist can perform:

- Brain scans such as MRI (magnetic resonance imaging) may be used to help make 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.



### Genetic counselling and testing

- In situations where there is a strong family history of FTD, you may be offered genetic counselling and testing as part of your diagnosis.
- This is to identify whether you have a faulty gene inherited by a parent who also had FTD.
- You will be supported by specialist doctors if you decide to undergo genetic testing.
- You can find contact details for Rare Dementia Support on page 17 who can provide more information about this.

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



For more information on getting a dementia diagnosis you can ask us for our information '**Problems with your memory?**'. Get in touch or order this information using the details on the back page.

## Treatments

Currently there are no medications available to treat frontotemporal dementia, so the focus is on helping people with the disease manage their 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, speech therapists or cognitive behavioural therapists can also help you to maintain your independence for as long as possible.

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, spelling boards and simpler approaches like picture cards.

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

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.

## Support

Living with frontotemporal dementia can be very difficult. Some people affected by the disease may have jobs, 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 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**.

Contact details can be found online at [www.raredementiasupport.org](http://www.raredementiasupport.org) or by ringing **0203 325 0828**. Online information about FTD can also be found at the FTD talk website at [www.ftdtalk.org](http://www.ftdtalk.org)

You can also speak to your doctor or nurse for advice **Admiral Nurses**, who are dementia specialist nurses can be contacted on **0800 888 6678** or [helpline@dementiauk.org](mailto:helpline@dementiauk.org)



There are other support organisations that offer help and advice about dementia. For more information, contact **Alzheimer's Research UK's Dementia Research Infoline** on **0300 111 5111** or [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)

Ask us for our booklet '**Support for people affected by dementia: organisations that can help**'.

## How to get involved

People with and without dementia, and dementia carers are needed for research studies. You may be asked to take part in online surveys, memory and thinking tests or to try new methods of diagnosis or treatment.

You can register to the **Join Dementia Research** service, which is run by the NHS. This will match you to research studies you are suitable for, so you can see what type of research you could take part in. You can find out more and register here [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk). You can also register over the telephone on **0300 111 5111**.



## Research

Alzheimer's Research UK has funded more than **£13.3 million** of pioneering research to help advance our understanding of frontotemporal dementia.

We've funded over **140 research projects** into FTD, including studies investigating 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, and investing in research to make breakthroughs possible.

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

We provide free dementia health information, like this booklet and others. If you would like to view, download or order any of our other booklets please details below.

**Contact us**

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