

# 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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The information here 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 2018 and is due to be reviewed in January 2020. Please contact us if you would like a version with references or in a different format.

## What is frontotemporal dementia?

The word dementia is 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.

Frontotemporal dementia (FTD) is a relatively rare 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 conditions. Your doctor may refer to these conditions by their specific names or may describe them all as 'frontotemporal dementia', as we will in this booklet.

Frontotemporal dementia includes the following conditions:

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**Behavioural variant FTD** (bvFTD)

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**Semantic dementia** (the word semantic means the meaning of language)

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**Progressive non-fluent aphasia** - aphasia is a language disorder where people have problems speaking and writing

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**FTD associated with motor neurone disease**

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Semantic dementia and progressive non-fluent aphasia are types of primary progressive aphasia. You can find out more about these conditions in our booklet '**What is primary progressive aphasia?**'.

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

65

FTD usually 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 regulate our personality, emotions and behaviour, as well our speech and understanding of language.

In FTD, there is 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.



### Symptoms

The early symptoms of FTD 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 regulate 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. 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 their 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**

Lack of awareness of any changes in their personality or behaviour.

**Decision making**

Difficulty with simple plans and decisions.

**Language**

Decline in language abilities. This might include difficulty getting words out or understanding them. People may repeat commonly used words and phrases, or forget the meaning of words.

**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 GP.



If your GP 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 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 problems in thinking and function, and the likely cause.

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 as it can be difficult to recognise the symptoms.

## Treatments

There are no treatments at the moment specifically for FTD, so the current 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 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.

Speech therapists can also give advice about communication strategies for people with language problems. Some people find it helps to use alternative communication strategies, including specific tablet apps or more simple approaches like picture books.

While drug treatments for FTD are limited, a group of antidepressant medications called SSRIs can sometimes help to manage aspects of behaviour 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 approaches such as aromatherapy or music therapy might also be considered, and take into account the person's own interests as well as the availability of treatments.

In rare cases antipsychotic drugs may be used to relieve severe symptoms. They 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.

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, a third to half of people 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 – 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/or 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 be working and have family and financial responsibilities.

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

Rare Dementia Support runs three national support groups providing support and information for people with FTD, their families and carers: 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](http://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](http://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](http://www.alzheimersresearchuk.org) or ask us for our booklet '**Caring for someone with 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 (SCIHCARE) ☐

What is primary progressive aphasia? (SCIHIPPA) ☐

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

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## Research

Alzheimer's Research UK  
has funded more than

**£21.9 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 factors that can increase the risk of developing it. 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.



### 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](mailto: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.



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