

# What is frontotemporal dementia?



**Alzheimer's  
Research  
UK**

**The Power  
to Defeat  
Dementia**



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 which we hope you will find helpful.

The booklet was updated in January 2016 and is due to be reviewed in January 2018. Please contact us if you would like a version with references or in a different format.

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.

### What is frontotemporal dementia?

Frontotemporal dementia, or FTD, is a relatively rare form of dementia. It is thought to account for less than 5% of all dementia cases. It usually affects people between the ages of 45 and 64, but three out of every 10 people with FTD develop the condition at an older age.

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.



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

65

FTD usually affects people between the ages of

45-64

## What is frontotemporal dementia?

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. 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

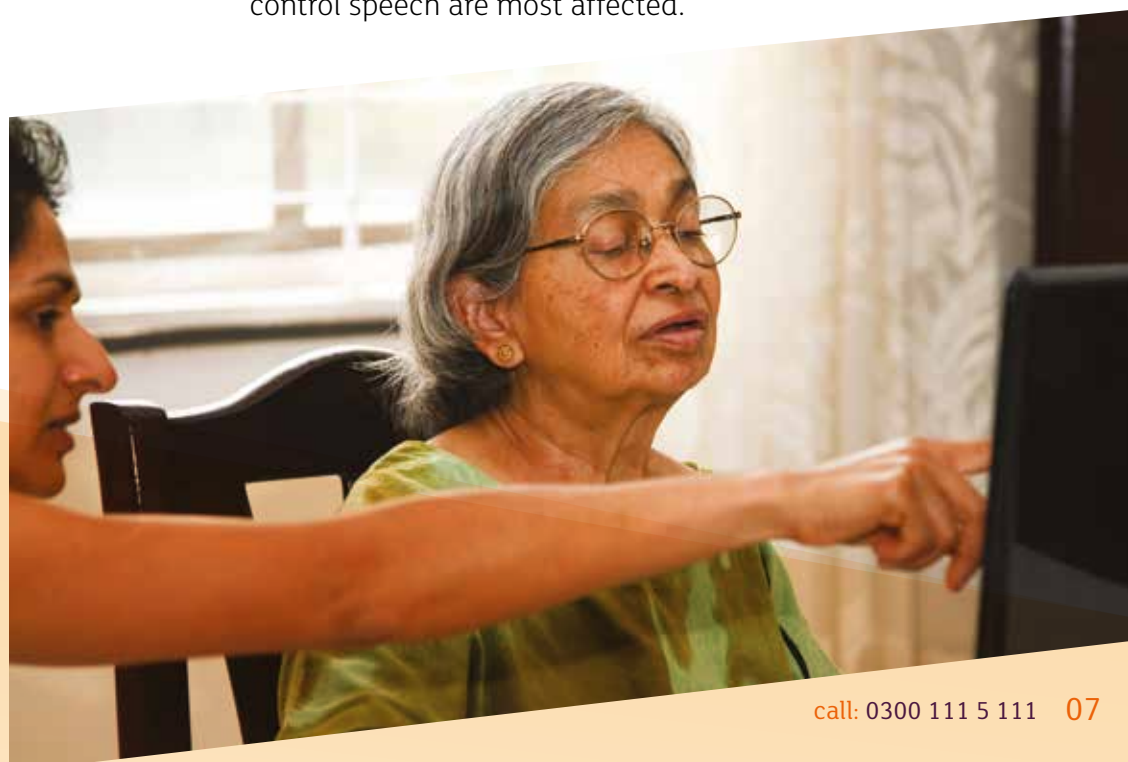
**FTD associated with motor neurone disease**

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.

## 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 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, parts of the frontal and temporal lobes that control speech are most affected.



## 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.



### Diet

Changes in food preference, over-eating or over-drinking.



### Behaviour changes

Humour or sexual behaviour may change. People may become more aggressive, develop unusual beliefs, interests or obsessions. Some people become impulsive or easily distracted.



### Decision making

Difficulty with simple plans and decisions.



### Awareness

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



### 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.



### Recognition

Difficulty recognising people or knowing what objects are for.



### 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.



### 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.

Symptoms get worse over time, gradually leading to more widespread problems with day-to-day function. Some people may develop motor problems similar to those seen in Parkinson's. Over time people with FTD can find it harder to swallow, eat, communicate and move. They will require more support to look after themselves. The speed of change can vary widely, but some people live with the condition for more than 15 years.

## Diagnosis

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, 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) 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 frontal and temporal lobes of the brain, commonly affected in this type of dementia.

## Treatments

While there are currently no treatments specifically for FTD, there are treatments that 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). These can help to treat symptoms of depression or help manage behavioural symptoms. CBT provides an opportunity for people to talk about their worries and concerns with a specialist practitioner. CBT and antidepressants are not always 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 assess someone's 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 your own interests 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.

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

## More about the disease

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.

## 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 have a family history. This figure is thought to be much lower for other forms of FTD.

Overall, around one in ten of 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.

The Frontotemporal Dementia Support Group (formerly Pick's Disease Support Group) provides support and information for people with FTD, their families and carers. Regional contact details can be found online at [www.ftdsg.org](http://www.ftdsg.org) or by ringing **07592 540 555**.

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.

## Research

Alzheimer's Research UK has funded more than £12.5 million of pioneering research across the UK into FTD. This work is increasing our understanding of the condition.



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.

We believe that dementia can only be defeated through research. Thanks to the generosity of our supporters, we hope to fund many more pioneering studies into frontotemporal dementia.



### 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.



## Send me more information

For free information, simply complete this slip. You can drop it straight in a post box or put it in an envelope labelled with the freepost address overleaf. Alternatively, phone us on **0300 111 5555**.

### I would like to know more about

Dementia: symptoms, diagnosis, causes, prevention and care (SCIHIAAD)

Treatments for dementia (SCIHITFD)

Genes and dementia (SCIHIGENE)

Caring for someone with dementia: organisations that can help (SCIHCARE)

The latest dementia research (SMTTHINK)

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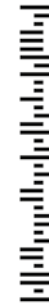
We'd really like to keep you updated with the latest research developments, how your support is making a difference, and fundraising activities that you can get involved in. Your details are always held securely, but if you'd rather not hear from us please tick the relevant box:

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Alzheimer's Research UK  
The Boulevard  
Orbital Park  
Ashford  
TN24 0GA



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Dementia



# We are the UK's leading research charity aiming to defeat dementia.

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

Alzheimer's Research UK  
3 Riverside, Granta Park, Cambridge CB21 6AD



## Supporter care

T: 0300 111 5555  
E: [enquiries@alzheimersresearchuk.org](mailto:enquiries@alzheimersresearchuk.org)



## Dementia Research Infoline

T: 0300 111 5 111  
E: [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)

[www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)



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