

What is frontotemporal dementia?



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**



Contents

Introduction	03	Treatments	09
What is frontotemporal dementia?	04	Support	11
Symptoms	06	Causes	11
Diagnosis	08	Risk factors	12
		Research	15

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.

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 written in January 2014 and is due to be updated in January 2016. 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 include memory loss, confusion, mood changes and difficulty with day-to-day tasks.

What is frontotemporal dementia?

Frontotemporal dementia or FTD (sometimes called Pick's disease) is a relatively rare form of dementia. Although it is thought to account for less than 5% of all dementia cases, it is the second most common cause of dementia in people under the age of 65. It usually affects people aged between 30 and 60.

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.

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There are several different conditions which affect the frontal and temporal lobes of the brain – together called frontotemporal lobar degeneration. 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

Dementia 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 depend on which area of the brain is affected. In behavioural variant frontotemporal dementia, the parts of the frontal lobe which regulate social behaviour may be most affected. In semantic dementia, the parts of the temporal lobe which support understanding of language and factual knowledge are most affected. In progressive non-fluent aphasia, parts of the frontal and temporal lobes which 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

People may change their humour or sexual behaviour, become violent or develop unusual beliefs, interests or obsessions. Some people become impulsive or easily distracted.

Therefore symptoms can vary from person to person. There may also be overlap of some symptoms between the different forms of FTD. As the disease progresses, people may have problems with movement similar to those seen in Parkinson's or motor neurone disease. In FTD, symptoms get worse over time. The speed of change can vary widely, but some people live with the condition for more than 15 years.



Decision making

Difficulty with simple plans and decisions.



Awareness

Lack of awareness of any personality or behaviour changes.



Language

Decline in language abilities. This might include difficulty getting words out or understanding words. 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 remain intact in the early stages, but problems with attention and concentration could give the impression of memory problems.

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, they may refer you 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 a memory test.



They may also send you 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 specific brain areas commonly affected in this type of dementia.



Treatments

While there are currently no treatments specifically for FTD, there are treatments which 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) to treat symptoms of depression or help manage challenging behaviour. CBT provides an opportunity for people to talk about their worries and concerns with a specialist practitioner. Antidepressants may not always be suitable for someone with frontotemporal dementia and your doctor will carefully consider what may be appropriate.

Treatments *(continued)*

To help relieve symptoms of severe agitation and aggression a doctor may consider an assessment of someone's health and environment. This could help identify any causes or triggers of agitation or aggression. Non-drug approaches such as aromatherapy or music therapy may also be considered. This might depend on your preference 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.

You can discuss your treatment options with your doctor.

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

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** 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** 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.

Causes

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 could have a family history. This figure is thought to be much lower for other forms of FTD. Scientists have found a number of faulty genes which can cause inherited forms of FTD. These include the tau gene, the progranulin gene and C9ORF72. If your doctor suspects a strong family link, they may offer you a genetic test and/or genetic counselling to close relatives. 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.

Scientists have found a number of faulty genes which can cause inherited forms of FTD





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 ☐

Treatments for dementia ☐

Genes and dementia ☐

Caring for someone with dementia: organisations that can help ☐

The latest dementia research ☐

Title

Name

Address

We would like to keep you informed about our research and our progress in defeating dementia. However, if you do not wish to receive any further communications from us, please tick here: ☐



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2



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Research

Over the last decade Alzheimer's Research UK has funded more than £10 million of pioneering research across the UK into FTD. This work is increasing our understanding of the condition.



This research is looking at the proteins that build up in the brain in FTD and the factors that increase the risk of developing it. This work is helping 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**

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 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

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Registered charity number 1077089 and SC042474

