Alzheimer's Research UK
Defeating Dementia

What is frontotemporal dementia?

Information in this 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 by providing 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 2012 and is due to be updated in January 2014. Please contact us if you would like a version with references or in a different format.

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What is frontotemporal dementia?

Dementia is used to describe a group of symptoms – these include memory loss, confusion, mood changes and difficulty with day-to-day tasks.

FTD (originally 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.

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.

There are several different conditions which affect the frontal and temporal lobes of the brain – collectively called frontotemporal lobar degeneration. These can include behavioural variant FTD, semantic dementia, progressive non-fluent aphasia and 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 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. In other forms of frontotemporal dementia, the parts of the frontal lobe which regulate social behaviour may be most affected.

Therefore symptoms can vary from person to person. Some of these symptoms may include:

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

Difficulty recognising people or knowing what objects are for.

Personality changes. This may include a lack of social awareness, loss of sympathy and empathy, apathy and inappropriate behaviour.

Lack of personal awareness. People may fail to maintain their normal level of personal hygiene and grooming.

Changes in food preference or over-eating.

Behaviour changes. People may change their humour or sexual behaviour, develop unusual beliefs, interests or obsessions.

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

Difficulty with even simple plans and decisions.

FTD is a progressive condition which means symptoms get worse over time. The speed of progression of FTD can vary widely, but often unfolds over years – with some people living with the condition for more than 15 years. As the disease progresses, people may start to show some problems with movement similar to those seen in Parkinson's or Motor Neurone Disease.

Diagnosis

It is important to get the right diagnosis so that appropriate 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 and 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. Antidepressants or non-drug alternatives may be used to treat symptoms of depression or help manage challenging behaviour. In certain circumstances, antipsychotic drugs may be used to relieve symptoms of severe agitation and aggression. These drugs can have serious side effects and their use should be carefully monitored.

Physical symptoms such as problems swallowing or moving may need careful management in their own right.

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. Please see our contact details on the back of this booklet.

Support

Living with frontotemporal dementia can be difficult and younger people affected by the disease may be working, and have families 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.pdsg.org.uk** or by ringing **0845 458 3208**.

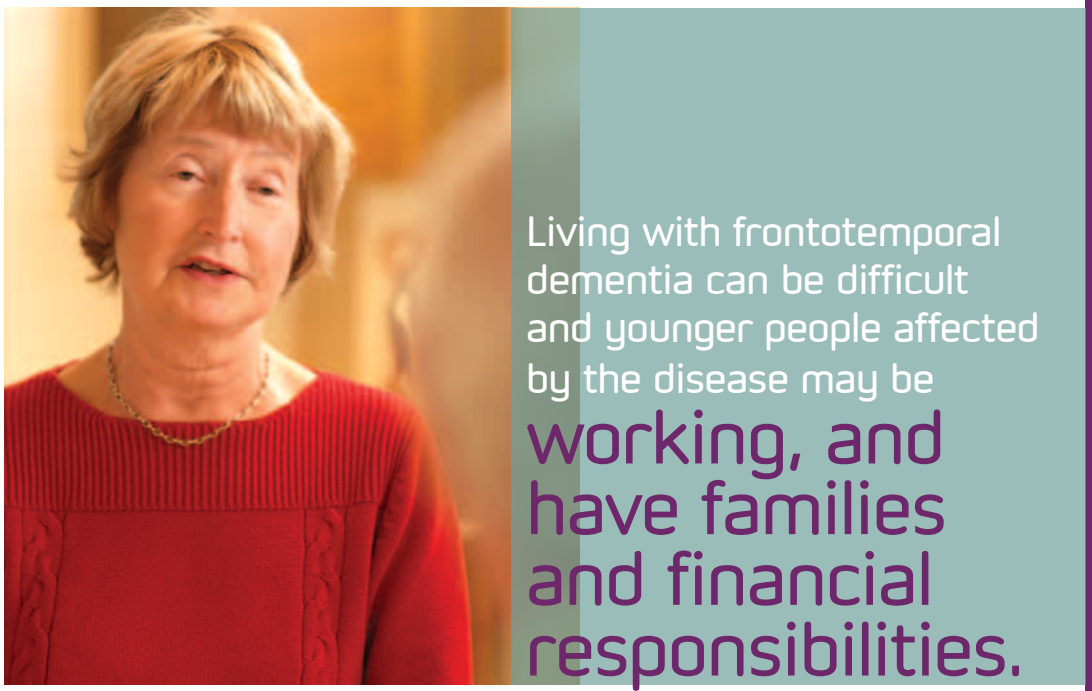
There are also a range of other support organisations who offer help and advice about dementia. For more information, ask us for our booklet 'All about dementia' or visit our website at **www.alzheimersresearchuk.org** You can also speak to your doctor or nurse for advice.

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, over a third to half of people could have a family history, but this figure is thought to be much lower for other forms of FTD. Scientists have identified a number of faulty genes which can cause inherited forms of FTD, including three genes called progranulin, tau and C9ORF72.
If your doctor suspects a strong family link, they may offer genetic counselling to close relatives. In cases of FTD where there is no family history, the risk factors are not yet fully understood.



Living with frontotemporal dementia can be difficult and younger people affected by the disease may be **working, and have families and financial responsibilities.**

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 01223 843899.

I would like to know more about

Dementia; symptoms, diagnosis, causes, prevention and care ☐

Treatments for dementia ☐

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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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No stamp required, but using one will help us put more money into research.

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Research

Over the last decade Alzheimer's Research UK has funded more than £2 million of pioneering research across the UK into FTD. This work will help to increase our understanding of the condition.

This research is looking at the proteins which build up in the brain in FTD and the factors which can increase 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.

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Have your say

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.

About us

Alzheimer's Research UK is the UK's leading dementia research charity funding world-class research to find ways to prevent, treat or cure dementia. Help us defeat dementia by donating today
www.alzheimersresearchuk.org/donate

Contact us

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