WHAT IS FRONTOTEMPORAL DEMENTIA?
INTRODUCTION

The 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.

The information here 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.

This booklet was updated in January 2024 and is due to be reviewed in January 2026. 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.

ANY QUESTIONS

If you have questions about dementia or dementia research, or any feedback on this booklet, you can contact the Dementia Research Infoline on 0300 111 5111. You can also email 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
- changes to speech or language
- 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 rare type of dementia. It is thought to account for less than one in 30 dementia cases.

Symptoms typically begin between the ages of 45 and 64. However, FTD can affect people younger or older than this.

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. They are also responsible for our speech and understanding of words.

In FTD, there is a build-up of proteins in the frontal and temporal lobes. Some of the proteins linked to FTD are called tau, TDP-43 and a group called FET proteins. These proteins clump together in and around damaged brain cells. 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.
FTD is sometimes described as an umbrella term because it 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’ refers to the meaning of words)
- progressive non-fluent aphasia (aphasia is where people have problems speaking and writing)
- frontotemporal dementia with motor neurone disease (FTD-MND).

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.
SYMPTOMS

Symptoms of FTD can be very different to other types of dementia. Early symptoms don’t usually include memory problems or forgetfulness.

FTD can make it harder for people to understand and process information, emotions and behaviours. The early symptoms of FTD can vary widely from person to person. This is because they depend on which area of the brain is affected first, and which type of FTD someone has.

Symptoms may include:

• **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.

• **Lack of interest** - becoming withdrawn or losing interest in everyday life. People can stop looking after themselves, such as not washing or dressing properly.

• **Inappropriate behaviour** - making inappropriate jokes or behaving strangely in front of others. Sense of humour, or sexual behaviour may change. Some people become impulsive or easily distracted.

• **Obsessions** - people might develop new beliefs, interests, or obsessions. For example, shopping too often or gambling.

• **Diet** - changes in food likes and dislikes such as eating lots of sweet things, over-eating or becoming more thirsty.

• **Awareness** - people may not realise that they are experiencing changes in their personality or behaviour.

• **Decision making** - difficulty making plans, following instructions, and deciding what to do.

• **Communication** - problems with speaking and understanding words. People may repeat words and phrases, struggle to say the right word or forget what words mean.

• **Recognition** - difficulty recognising people or knowing what objects are for. For example, understanding that the kettle is used to boil water or that the remote controls the TV.

• **Memory** - day-to-day memory may be less affected in the early stages of FTD compared with other forms of dementia, but problems with attention and concentration can be common.

• **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.

**FRONTOTEMPORAL DEMENTIA IS A PROGRESSIVE DISEASE. THIS MEANS THAT SYMPTOMS GET WORSE OVER TIME.**
BEHAVIOURAL VARIANT FTD
Damage to part of frontal lobe that controls social behaviour.
Symptoms include changes in behaviour, emotion and awareness.

PROGRESSIVE NON-FLUENT APHASIA
Damage to parts of frontal lobe that control speech.
Symptoms include struggling to find the right word or difficulty holding conversations.

SEMANTIC DEMENTIA
Damage to parts of temporal lobe that support understanding of language and factual knowledge.
Symptoms include forgetting the words for things and struggling with concepts like money and paying for items.

Around one in 10 people with motor neurone disease (MND) may also develop FTD. FTD and MND are linked to the build-up of the same proteins. While FTD affects the nerve cells in our brain, MND affects the nerve cells that tell our muscles what to do. Over time, these cells die, and we can no longer control our muscles. Symptoms tend to be more similar to behavioural variant FTD, although some people also have problems with language.

Frontotemporal dementia is a progressive disease. This means that symptoms get worse over time, and people with FTD will require more and 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 and communicate. They 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.

SYMPTOMS OF FTD VARY DEPENDING ON WHICH TYPE SOMEONE HAS. SPEAK TO YOUR DOCTOR IF YOU NOTICE ANY CHANGES TO COMMUNICATION, BEHAVIOUR OR MOVEMENT.
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 as soon as possible, 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.
- do 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, they may refer you to a memory clinic or another specialist doctor. Here you may have another physical check-up and complete some more memory and thinking tests. FTD is an uncommon form of dementia, not often seen by doctors. It can take longer than usual to get the right diagnosis.

To help make a diagnosis of frontotemporal dementia, you may be offered brain scans such as MRI or CT scans. These allow the doctor to look for changes in the frontal and temporal lobes of the brain, commonly affected in this type of dementia.

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 from a parent who also had FTD. You will be supported by specialist doctors if you decide to undergo genetic testing. On page 20 you can find contact details for Rare Dementia Support, who can provide more information about this.

For more information on getting a dementia diagnosis, you can ask us for our booklet ‘Getting a dementia diagnosis’. 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 and to stop it from progressing. So, the focus of healthcare professionals is to help 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 really helpful.

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. They may suggest complementary treatments such as aromatherapy or music therapy. These can be designed to draw on a person’s own interests and may help to relieve aggression and agitation.

In rare cases, doctors may prescribe antipsychotic drugs 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.

Treatments for frontotemporal dementia:

- Cognitive and complementary therapies to promote wellbeing and independence
- Medication for anxiety, agitation, and aggression such as antidepressants or antipsychotics when necessary
- Alternative communication methods like specialist smartphone and tablet apps, spelling boards and picture cards. A speech therapist can provide support with these
- Speech therapy and physiotherapy to help with speaking, swallowing and movement symptoms
RISK FACTORS

Some people with frontotemporal dementia have a family history of the condition, but it is important to note that most cases of FTD (around seven in 10) are not inherited.

Directly inherited dementia is rare, but in around three in every 10 people with FTD a strong family history of the condition is known. In these cases the cause is likely to be genetic. This is known as familial frontotemporal dementia.

For behavioural variant FTD, which mainly affects emotion and personality, around one in every two people with the disease could have a family history. It’s less likely for other forms of FTD to run in the family.

Research has found a number of faulty genes that can cause inherited forms of FTD. Faulty genes are passed directly from a person who is affected by a condition like familial FTD to their children. The child then has a 50% (one in two) chance of inheriting the gene.

If your doctor suspects a strong family history, you and other family members may be offered genetic testing to see if you carry the gene too. If you think this applies to your circumstances, you can speak to your doctor about your family history. For more information ask us for our booklet ‘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 how risk factors develop over time to cause it.

We do know that there are steps we can all take to improve our brain health. Eating healthily, exercising regularly, and controlling existing health conditions such as high blood pressure and diabetes may reduce the risk of dementia, including non-genetic FTD.

For information about ‘Reducing your risk of dementia’ contact us or order our booklet using the information on the back of this booklet.
SUPPORT

Living with frontotemporal dementia can be very difficult. Many 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 can 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. Contact details can be found online at [raredementiasupport.org](http://raredementiasupport.org)

Online information about FTD can also be found at the [FTD talk website](http://ftdtalk.org) You can also speak to your doctor or nurse for practical and medical advice.

**Admiral Nurses**, who are dementia specialist nurses can be contacted on [0800 888 6678](tel: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](tel: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**’.
TAKING PART IN RESEARCH

Through research we’ll bring about breakthroughs that will change lives, but scientists need your help.

People with dementia, their carers, and people without dementia are all needed to take part in vital dementia research studies. If you’re interested in taking part, you can register at joindementiaresearch.nihr.ac.uk or by calling 0300 111 5111.

SHARE YOUR STORIES

If you have been diagnosed with frontotemporal dementia and would like to share your story to inspire others, or to help shape our work please get in touch via stories@alzheimersresearchuk.org

RESEARCH

Alzheimer’s Research UK is the UK’s leading dementia research charity. We exist to change the way we treat, diagnose and prevent dementia. And then, we will find a way to cure it.

To do this, we’ve invested over £176 million in dementia research, working with the most forward-thinking scientists and world-class organisations.

This includes over £15 million into over 160 research projects into frontotemporal dementia. One such project at King’s College London aims to understand how proteins build up in the brain cells in FTD, and also how to develop potential new treatments to reverse their effects. With your support, we promise we will not stop until dementia can no longer destroy lives.

We are Alzheimer’s Research UK. We exist for a cure.
Alzheimer’s Research UK is the UK’s leading dementia research charity. 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 use the details below. If you’d like to help us review and improve our booklets, visit alzres.uk/reviewer

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