What is frontotemporal dementia (FTD)?

Alzheimer's Society

Together we are help & hope
for everyone living with dementia

This factsheet is for anyone who wants to know more about Frontotemporal dementia (FTD). It explains what FTD is, its symptoms, and who gets it. It also describes how FTD is diagnosed and the treatment and support that is available.

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1 What is frontotemporal dementia (FTD)?

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Frontotemporal dementia (FTD) is one of the less common types of dementia. It covers a range of different conditions that can affect personality, behaviour and language. FTD is mostly diagnosed in people under 65. It is sometimes called Pick's disease or frontal lobe dementia.

The word 'frontotemporal' refers to the two sets of lobes (frontal and temporal) in the brain that are damaged in this type of dementia. FTD occurs when disease damages nerve cells in these lobes. This causes the connections between them and other parts of the brain to break down.

The levels of chemical messengers in the brain also get lower over time. These messengers allow nerve cells to send signals to each other and the rest of the body. As more and more nerve cells are damaged and die, the brain tissue in the frontal and temporal lobes starts to get smaller.

There are two broad types of FTD:

- **Behavioural variant FTD** – where damage to the frontal lobes of the brain mainly causes problems with behaviour and personality. These lobes are found behind the forehead and process information that affects how we behave and the control of our emotions. They also help us to plan, solve problems and focus for long enough to finish a task.
- **Primary progressive aphasia (PPA)** occurs when damage to the temporal lobes – on either side of the head nearest the ears – causes language problems. This part of the brain has many roles. A key function of the left temporal lobe is to store the meanings of words and the names of objects. The right temporal lobe helps most people recognise familiar faces and objects. For more information on this see factsheet 456, **Dementia and the brain**.

The first noticeable symptoms for a person with FTD will be changes to their personality and behaviour and/or difficulties with language. These are very different from the early symptoms of more common types of dementia. For example, in Alzheimer's disease, early changes are often problems with day-to-day memory. In the early stages of FTD, many people can still remember recent events.

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2 Symptoms

Frontotemporal dementia affects everyone differently. Its symptoms vary a lot and depend on which areas of the frontal and temporal lobes are damaged – and so the type of FTD the person has.

As with most forms of dementia, FTD is progressive. This means its symptoms may be mild at first, but they will get worse over time. For more on this see factsheet 458, **The progression and stages of dementia**.

Behavioural variant FTD

This is the most common type of FTD. In the early stages it mainly causes changes in someone's personality and behaviour.

A person with behavioural variant FTD may:

- lose motivation to do things that they used to enjoy
- struggle to focus on tasks and become distracted easily
- find it difficult to plan, organise and make decisions – these problems may first appear at work or with managing money
- lose their inhibitions – behaving in socially inappropriate ways and acting impulsively or without thinking. For example, making insensitive or rude comments about someone's appearance, making sexual gestures in public, staring at strangers, or being verbally or physically aggressive
- lose the ability to understand what others might be thinking or feeling – they may be less considerate of the needs of others, lose interest in social activities or be less friendly. They may also have less of a sense of humour or laugh at other people's problems. This can make the person appear cold and selfish
- show repetitive or obsessive behaviours – for example, repeating phrases or gestures, hoarding or being obsessed with timekeeping. They may also take up new interests – for example, music or spirituality. These might give the person a positive focus but can become obsessive in nature
- crave sweet, fatty foods or carbohydrates and forget their table manners. They may also no longer know when to stop eating, drinking alcohol or smoking.

FTD can also affect how sensitive a person is to physical or environmental stimulation such as temperature, sounds and even pain.

A family member has been diagnosed with FTD and is starting to display mild aggression and other behavioural issues.

Family member of a person with FTD

Most people with behavioural variant FTD are not fully aware of their symptoms. Instead, these changes are often first noticed by the people who are close to them. As a result, people with this type of FTD rarely think they need to seek medical help for their condition. They may also refuse to do so if others suggest it. This can cause long delays in getting an accurate diagnosis. The person may also have problems taking medication or going to therapy sessions if they are not aware of their condition. Safe driving will also be difficult. For more information see factsheet 439, **Driving and dementia**.

This can all be very stressful for the family and carers of a person with behavioural variant FTD. It can also affect the person's relationships. It may be helpful to call Alzheimer's Society support line on **0333 150 3456** or visit our online community, Dementia Support Forum at **forum.alzheimers.org.uk**

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Primary progressive aphasia (language variants of FTD)

The other main type of FTD is primary progressive aphasia (PPA) where the early symptoms are mostly problems with language. Other aspects of thinking, perception and behaviour are not affected as much during the early stages. However, as the disease progresses, there may start to be changes in these areas.

The two main subtypes of PPA are:

- semantic variant PPA
- non-fluent variant PPA

Semantic variant PPA

This condition causes a person to forget the meaning of words. About 1 in 5 people with FTD will have this type. A person with semantic variant PPA is likely to:

- **lose their vocabulary over time** – at first mostly words they are less familiar with, such as technical words (for example 'accelerator') or less common words (for example 'crinoline'). They may try to use more general words instead – for example, calling a 'spanner' a 'tool' or a 'thingy'. As the condition develops, they will start to forget even basic words, such as 'wet' or 'sugar'.
- **forget what familiar objects are used for** – for example, a person may forget what a toaster does and why it's in the kitchen.

These changes can cause a great loss of independence for the person with dementia. Along with losing the ability to communicate clearly, they may also eventually lose the skills to use everyday objects such as cutlery, toothbrushes or doors. See the 'Treatment and support' section on page 12 for ideas about how to manage these symptoms.

Although the main symptoms of semantic variant PPA involve language, the condition usually also causes changes in behaviour. Getting obsessed about daily routines or having eating problems are common – like in behavioural variant FTD.

"My Aunt started using the word 'thingy' a lot to describe items. That's when we wondered if something was going on."

Family member of a person with FTD

Non-fluent variant PPA

This condition causes a person to have problems with speaking. About 1 in 4 people with FTD will have this condition. Over time, a person with non-fluent variant PPA will find it more and more difficult to get their words out. They may also:

- **start to speak differently** – this includes speaking more slowly, using the wrong grammar and putting words in the wrong order. For example,'I gone to the shop.'
- **use shorter, simpler sentences** that miss out shorter words (known as telegraphic speech) – for example, 'Tired. Going bed now.'
- **say the opposite of what they mean** – for example, saying 'yes' when they mean 'no'.

Unlike those with semantic variant PPA, many people with non-fluent variant PPA still understand individual words. However, over time they will struggle to understand full sentences that use these words. For example, a person with this condition may know what a 'spoon' is, but they may not know the meaning of 'Can you pass me the spoon, please?' This makes it difficult for the person to have a conversation, which can be both frustrating and isolating. At some point the person may stop speaking completely.

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Later stages of FTD

As FTD progresses, differences between the three types described above become much less obvious. Many people with the behavioural variant develop language problems and may eventually lose all speech. Similarly, many people with a language variant of FTD (especially semantic variant dementia) develop clear changes in their behaviour and personality.

The later stages of all types of FTD bring a greater range of symptoms as the disease spreads to other areas of the brain. Any symptoms the person already has will also get worse. As a result, symptoms become similar to the later stages of other types of dementia, such as Alzheimer's disease.

The person may:

- become forgetful
- have delusions or hallucinations
- get restless or agitated easily, or behave aggressively
- no longer recognise friends and family.

At this late stage they are also likely to need full-time care to meet their daily needs.

How quickly FTD progresses, and the life expectancy of someone with the condition varies from person to person. Many factors can affect the speed and pattern of progression. This includes a person's age when they were diagnosed and whether they have other health conditions. For more information, see factsheets 458, **The progression and stages of dementia**, and 417, **Supporting a person in the later stage of dementia**.

Related conditions that affect movement

About 1 or 2 in every 10 people with frontotemporal dementia also develop one of a number of conditions that makes it harder for them to move. This can happen either before or after dementia symptoms first appear. These are generally uncommon conditions but there are three that are more likely to affect people with FTD. These are:

- motor neurone disease
- progressive supranuclear palsy
- corticobasal syndrome.

Motor neurone disease (MND) is a progressive condition that causes muscles to weaken and waste away. Eventually a person with MND becomes almost completely paralysed and struggles to breathe or swallow. FTD and MND are both progressive and life-limiting conditions. Having the two conditions can reduce a person's life expectancy more than FTD can on its own.

Corticobasal syndrome (CBS) and progressive supranuclear palsy (PSP) are conditions with a combination of dementia symptoms and movement difficulties. These can include muscle twitching, stiffness, slow movements, slurred speech and loss of balance or co-ordination. PSP also causes problems with the control of eye movements. Both conditions can also cause FTD-like symptoms and,in the later stages, difficulties with swallowing.

For more information see factsheet 442, **Rarer causes of dementia**.

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3 Who gets FTD?

While researchers know a lot about how FTD develops in the brain, they still don't fully understand why some people get FTD and others don't. This is mainly because FTD is a less common type of dementia – so it is harder to study its causes. However, there are some things that are known to affect a person's chances of getting FTD.

Age

Frontotemporal dementia is mostly diagnosed between the ages of 45 and 65 (though it can affect people younger or older than this). This is much younger than more common types of dementia such as Alzheimer's disease, which mostly affects people over 65.

Being diagnosed at a younger age can bring someone a very different set of challenges. A person under 65 may still be working, have a mortgage and other bills to pay, or have children who still rely on them. This means they may need different services and support. For more information about these issues see factsheet 440, **What is young-onset dementia?**

Risk factors

Unlike some other types of dementia, FTD seems to affect men and women about equally. However, there is not enough evidence to know if certain lifestyle factors, such as smoking, drinking alcohol, or not being physically active can increase a person's risk of getting FTD. Researchers also don't know whether other long-term health conditions, such as diabetes or high blood pressure, can make someone more likely to develop the condition.

Genetics

FTD is much more likely to run in families than more common forms of dementia. In some families, there is a single faulty gene that will definitely cause FTD if it is passed down from a parent to a child. This is known as 'familial FTD'. About 10 to 15 in every 100 people with FTD have this type. Any child of a person with familial FTD has a 1 in 2 chance of getting the same gene. It most often causes behavioural variant FTD.

Other types of genes (sometimes known as 'susceptibility' genes) can increase a person's chances of getting FTD. However, unlike familial genes, they don't always cause a person to develop FTD. Scientists know a lot less about 'susceptibility' genes than they do about 'familial' genes. This means it's not yet possible for most people to find out if they are carrying a 'susceptibility' gene.

If a person has a close family member with FTD they may want to know if they are carrying a familial FTD gene. This may be for a number of reasons – for example, if they plan to have children. A person can ask their GP to refer them to a local NHS genetics service. This service provides pre-test genetic counselling, which can help a person to consider all the possible effects of finding out if they have a familial FTD gene. This is important because test results can have a serious impact on a person's mental wellbeing and that of their family. It can also affect a person's work and personal relationships.

For more about genetic inheritance and testing see factsheet 405, **Genetics of dementia**.

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"My father passed away from FTD. I have concerns about my own memory and concentration."

Family member of a person with FTD

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4 Getting a diagnosis

Frontotemporal dementia is much less common than other types of dementia and often has different early symptoms. This means FTD can be hard for doctors to diagnose as they may not recognise its symptoms as dementia. Most changes in behaviour or personality caused by FTD may not be very obvious at first. These kinds of symptoms – for example, risk-taking, loss of social or sexual inhibitions, or obsessive behaviour – can sometimes look more like the person is going through a difficult or emotionally-challenging time. Also, if the person is under 65, doctors may not expect to see dementia in someone so young.

Even if changes in behaviour are understood as medical symptoms, they may be mistaken for depression, schizophrenia or obsessive-compulsive disorder. Problems with language or movement may also be misdiagnosed.

If a person is showing some of the symptoms mentioned in this factsheet, they may want to ask their doctor to explore FTD as a possible diagnosis – especially if they have family members with the condition.

Assessments

Blood tests and a full physical examination are important to rule out other possible causes of symptoms. A specialist – normally an old age psychiatrist or neurologist – may think a person has FTD after talking to them and to someone who knows them well. The specialist will take a detailed history of the person's symptoms and ask questions to understand the person's behaviour and abilities better.

Standard tests of mental abilities, which mostly focus on memory loss, can be less helpful in diagnosing FTD. More specialised tests of social awareness or behaviour may be needed.

Scans

CT (computerised tomography) and MRI (magnetic resonance imaging) scans are used to see what parts of the brain are most damaged. They can also rule out other possible causes of a person's symptoms, such as a stroke or tumour.

If further tests are needed, more specialised brain scans will be carried out, such as PET (positron emission tomography) and SPECT (single photon emission computerised tomography) to measure the person's brain activity. These scans are useful as they may find lower activity in the frontal and/or temporal lobes before a CT or MRI scan can find changes to the brain tissue of these lobes. Further tests may include a lumbar puncture, which involves collecting and examining liquid from inside the spine and is carried out mainly in younger people.

Genetic testing

A specialist may recommend that a person with FTD symptoms has a genetic test. This can show if the person's condition is caused by a specific faulty gene. Knowing this can help the specialist to make a more precise diagnosis and to better understand the changes that are happening in the person's brain. Having a genetic test can have a serious impact on a person and their family so genetic counselling will always be offered before a test.

Post-mortem examination

After a person dies, it is possible to make a more certain diagnosis of FTD. This is because the brain can be seen directly in post-mortem examinations. These can also help researchers to better understand how FTD affects the brain.

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5 Treatment and support

There is currently no cure for frontotemporal dementia and the progression of the disease cannot be slowed down. Drugs that are commonly used to treat other types of dementia are not recommended for people with FTD. These drugs, known as cholinesterase inhibitors (for example, donepezil, rivastigmine, galantamine) can actually make the symptoms of FTD worse. However, there are many other ways to help someone with the condition to live well.

Supporting a person with FTD often involves a team of professionals that can include a:

- GP
- community nurse
- psychiatrist
- speech and language therapist
- neurologist
- social worker.

When someone has problems with movement or co-ordination, support from a physiotherapist or occupational therapist can also help.

Support groups can offer useful advice and emotional support to people living with FTD and those who care for them. There are specialist support groups for younger people with dementia or FTD and for people affected by familial FTD (see 'Other useful organisations' on page 16 for details). Spending time with other people in this way can also help if a person with FTD seems to lose motivation in things or appears bored or lonely. You can search for groups in your area at **alzheimers.org.uk/dementiadirectory**

Changes in behaviour

Many people with FTD have an active social life for some years after diagnosis. However, changes in their behaviour can make social situations more challenging, both for the person with dementia and those who care for them.

Carers may find it less stressful if they try to accept socially inappropriate behaviour as part of the condition rather than confront the person – as long as the behaviour cannot harm anyone. While these situations may be awkward or embarrassing, it is important to remember that a person with FTD has little control over these actions. They are also unlikely to understand the impact of their behaviour on others. If a person with FTD regularly behaves inappropriately in public, their carer may find it useful to:

- try to remove any potential triggers for this behaviour – such as a noisy or crowded environment
- distract the person – such as asking them a question about a completely different topic
- explain to other people that the person has dementia. Some people with dementia use helpcards that they can use to show they have difficulties and also advise how to help them when they're out in the community. You can order these at **alzheimers.org.uk/helpcards** or call **0300 303 5933**.

It may also be easier for a carer to accept other changes in the person's behaviour, if they are harmless. For example, if a person wants a fixed routine or to obsess over an activity (such as doing jigsaws or listening to music), it may be best to let them do so. However, some behaviours, such as over-eating and drinking too much alcohol, can lead to greater problems. Be aware of how much alcohol the person is drinking. If they are over-eating, it can help to only offer food at mealtimes and in suitable portions, and to swap unhealthy food for healthier options. See factsheet 511, **Eating and drinking** for more tips.

Certain changes in behaviour, such as restlessness, agitation or aggression, may be a sign that the person is in distress. The reason for this could be:

- they are too hot or too cold
- they are in pain or have another medical condition, such as constipation or an infection
- their environment is too noisy, bright or cluttered
- they misunderstood something or someone – for example, interpreting a joke as being serious
- they cannot control their emotions
- the person is frustrated because their routine has changed or they are unable to communicate effectively
- the person lacks a sense of purpose and does not have enough to keep them active.

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“My husband has frontal lobe damage and suffers from disinhibited behaviour and anger management. He has become more angry and snaps rudely at me in the presence of others.’

Partner of a person with FTD ”

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Understanding why a person's behaviour has changed may help carers support them better. Physical exercise, music or other activities that the person enjoys or finds useful are also very helpful. These activities are often the most effective way of helping a person with FTD to maintain a good quality of life. It is important to try this before considering any drug treatments, such as antipsychotics. If drugs are being considered, the person with FTD should be referred to a specialist who can advise on the risks and benefits.

Changes in behaviour can be very distressing for anyone caring for someone with FTD and it's important that carers are supported as well. Along with talking to their GP, it may be helpful to call Alzheimer's Society support line on **0333 150 3456** or visit our online community, Dementia Support Forum, at **forum.alzheimers.org.uk**

For more information see factsheets 525, Changes in behaviour, 509, **Aggressive behaviour**, and 523, **Carers – looking after yourself**.

Language problems

A speech and language therapist with the right skills and experience can support someone with FTD who is losing their language or speaking abilities. They can help the person get the most out of their existing skills and find new ways for them to communicate. For example, a person may be taught non-verbal ways of communicating, such as using gestures, drawing or electronic devices.

A therapist can also help a person's carer find new ways of listening and talking – for example, using simpler and shorter sentences. If a person has problems swallowing, a speech and language therapist can also give advice on eating and drinking. For more general information about communicating with people living with dementia see factsheet 500, **Communicating**.

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Other useful organisations

Motor Neurone Disease Association
0808 802 6262
mndconnect@mndassociation.org
www.mndassociation.org

The Motor Neurone Disease Association funds and promotes research into motor neurone disease and provides support for people affected.

PSP Association
0300 011 0122
helpline@pspassociation.org.uk
www.pspassociation.org.uk

PSP Association is a charity offering advice, support and information to people living with progressive supranuclear palsy and corticobasal degeneration.

Rare Dementia Support
020 3325 0828
contact@raredementiasupport.org
www.raredementiasupport.org

Rare Dementia Support is a UK-based service that runs specialist support group services for individuals affected by rare forms of dementia.

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information **About dementia.**

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**

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