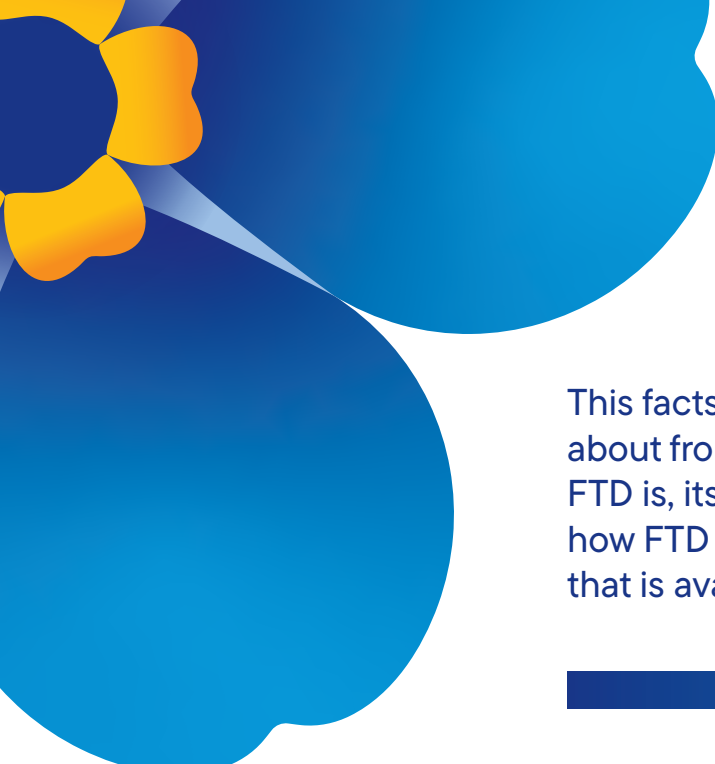


# What is frontotemporal dementia (FTD)?



**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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## Contents

|          |   |           |
|----------|---|-----------|
| <b>1</b> | <b>What is frontotemporal dementia (FTD)?</b> | <b>1</b>  |
| <b>2</b> | <b>Symptoms</b>                               | <b>2</b>  |
| <b>3</b> | <b>Who gets FTD?</b>                          | <b>9</b>  |
| <b>4</b> | <b>Getting a diagnosis</b>                    | <b>10</b> |
| <b>5</b> | <b>Treatment and support</b>                  | <b>12</b> |
|          | <b>Other useful organisations</b>             | <b>16</b> |

# 1 What is frontotemporal dementia (FTD)?

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Frontotemporal dementia (FTD) is a less common type 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 frontal lobe dementia and it used to be called Pick's disease.

The word 'frontotemporal' refers to two parts of the brain – the frontal lobes and the temporal lobes. FTD occurs when disease damages nerve cells in these lobes. This causes the connections between the lobes and other parts of the brain to break down.

As more and more nerve cells are damaged and die, the brain tissue in the frontal and temporal lobes gets smaller.

## Types of FTD

There are two types of FTD:

- **Behavioural variant FTD**

Damage to the frontal lobes of the brain mainly causes problems with behaviour and personality. These lobes are found behind the forehead. They process information and influence how we think, behave and manage our emotions.

- **Primary progressive aphasia (PPA)**

Damage to the temporal lobes initially causes difficulties with language. Some people have trouble remembering words and names of objects. Others may struggle to speak at their usual speed or to use words in the right order. This is known as 'language-led' dementia. The temporal lobes are on either side of the head, nearest the ears.

The first noticeable symptoms for a person with FTD will be changes to their personality and behaviour, or difficulties with language. Sometimes it can involve both. This is very different from the early symptoms of more common types of dementia. For example, in Alzheimer's disease, early changes are often problems with short-term memory. Many people with FTD don't have a significant problem with their memory during the early stage of their condition.

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# 2 Symptoms

Frontotemporal dementia (FTD) affects everyone differently. Its symptoms depend on which areas of the frontal and temporal lobes are damaged.

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 stage, behavioural variant FTD mainly causes changes in someone's personality and behaviour. It can also affect their mood and their ability to think things through properly.

A person with behavioural variant FTD may:

- struggle to focus and become distracted easily
- find it difficult to plan, organise and make decisions – these problems may first appear at work or with managing money
- behave in socially inappropriate ways and act without thinking – for example, making insensitive or rude comments about someone's appearance, making sexual gestures in public, 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
- lose motivation to do things they used to enjoy
- have less of a sense of humour, or laugh at other people's problems – this personality change can appear cold and selfish, though it is just a symptom of disease
- show repetitive or obsessive behaviours – for example, repeating phrases or gestures, hoarding or being obsessed with timekeeping
- take up new interests – for example, music or spirituality – these might give the person a positive focus, but can sometimes become obsessive in nature
- crave sweet, fatty foods or carbohydrates and forget their table manners
- no longer know when to stop eating, drinking alcohol or smoking, or may feel a strong urge to do these activities.

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

## Symptom awareness

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 closest to them. As a result, people with this type of FTD rarely think they need to seek medical help for their condition. They may 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. Driving can be a difficult issue if they do not see a need to stop doing it. For more information see factsheet 439, **Driving and dementia**.

This can all be very stressful for family members and carers – particularly when someone goes for several years without an accurate diagnosis. It can strain personal relationships. It may be helpful to call our Dementia Support Line on **0333 150 3456** or visit our Dementia Support Forum at **forum.alzheimers.org.uk**

## Primary progressive aphasia (language variants of FTD)

The other main type of FTD is called primary progressive aphasia (PPA). This is when the early symptoms of dementia are dominated by problems using language. Problems with other aspects of thinking, mood and behaviour tend to be less noticeable at first. However, as the disease progresses, they may become more severe.

The two main types of language-led FTD are:

- semantic variant PPA
- non-fluent variant PPA.

There is also another type of PPA called logopenic aphasia. However, this is generally a type of Alzheimer's disease, not FTD. For more information see factsheet 401, **What is Alzheimer's disease?**

Some people with PPA don't fit neatly into any of these diagnoses. If so, they may have a diagnosis of mixed or 'atypical' PPA.

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**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**

”

### Semantic variant PPA

This condition causes a person to forget the meaning of words. It’s sometimes known as semantic dementia.

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 ‘adhesive’). 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. This tends to happen later on.

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.

Although the main symptoms of semantic variant PPA involve language, the condition usually also causes changes in behaviour. It’s common to become obsessed about daily routines or have eating problems – as happens with behavioural variant FTD.

## Non-fluent variant PPA

This condition causes a person to have difficulty speaking. As a result, they talk slowly with lots of gaps and errors. Even this can take a lot of effort.

Over time, a person with non-fluent variant PPA will find it more and more difficult to speak out loud. They may:

- **speak differently** – much more slowly, often using the wrong forms of words or putting them in the wrong order. For example, 'I...walking...shop' rather than 'I'm going to walk to the shop'. For this reason, non-fluent PPA is also sometimes called agrammatic/non-fluent PPA, meaning 'without grammar'.
- **use shorter, simpler sentences** – leaving out shorter words and sounding more like a text message – for example, 'Tired. Going bed now.'
- **say the opposite of what they mean** – for example, saying 'yes' when they mean 'no'.
- **have difficulty physically speaking** – forming words correctly requires a lot more effort and the sounds might not come out right. This is known as 'apraxia of speech'.
- **have difficulty swallowing or moving** – some people may have symptoms similar to Parkinson's disease, where they are only able to move slowly or stiffly. They may also lose their balance more easily.

People with non-fluent variant PPA are often still able to understand individual words. However, they increasingly struggle to understand how words are being used.

For example, a person may know what a spoon is, but they may not understand the meaning of 'Can you pass me the spoon that's over there on the table, please?'. This is because language relies on being able to understand the meaning behind the order of words, or the different forms they take.

These difficulties make it increasingly challenging to have a conversation, which can be frustrating and isolating. At some point, most people with non-fluent variant PPA stop speaking completely.

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### Later stages of FTD

As FTD progresses, the differences between the various types become less obvious. Many people with the behavioural variant develop language problems and may eventually lose all speech. Similarly, many people with language-led dementia develop clear changes in their behaviour and personality.

Over time, the disease spreads into other parts of the brain, which leads to new symptoms. At the same time, most of the existing symptoms become more severe. The condition can start to look like the later stages of other types of dementia, such as Alzheimer's disease.

The person may:

- become forgetful
- have delusions or hallucinations
- become increasingly withdrawn
- get restless or agitated easily, or behave aggressively
- become unlikely to attempt communication
- no longer recognise friends and family
- have trouble swallowing or moving (if not already)
- have poorer control of their bladder and bowels.

At this late stage, they are also likely to need full-time care to meet their daily needs, such as eating, drinking, washing, dressing and going to the toilet. At some point, they may need to be cared for in a residential care home. Finding a suitable care home when someone is younger and has an unusual type of dementia can be hard. You may need to look over a wider area to find somewhere that's right for them.

People vary greatly in how long they live with FTD. This is very difficult to predict for individual people, although generally people tend to live longer if they:

- are younger when they are diagnosed
- are diagnosed quickly before their symptoms become severe
- don't 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 FTD 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:

- motor neurone disease
- corticobasal syndrome (CBS)
- progressive supranuclear palsy (PSP).

### Motor neurone disease

Motor neurone disease (MND) is a condition that causes muscles to weaken and waste away. It is also sometimes known as amyotrophic lateral sclerosis (ALS). Eventually, a person with the condition becomes almost completely paralysed and struggles to breathe or swallow.

Some people with FTD start to have symptoms of MND as their condition progresses. This is more likely to happen to people with behavioural variant FTD, particularly if their condition is caused by a single gene. It's less likely for people who have a language-led dementia and very rare for those with semantic variant PPA.

FTD and MND are both progressive conditions that get worse over time. Having the two conditions can reduce a person's life expectancy more than having FTD on its own.

### Corticobasal syndrome (CBS) and progressive supranuclear palsy (PSP)

These conditions involve a combination of dementia symptoms and difficulties with movement. For many people, the first signs of these conditions are problems with thinking, language, mood or behaviour. This is similar to the early stages of FTD. For others, the problems with movement may come first.

As well as dementia, CBS also causes:

- muscle twitching or jerking
- stiffness
- slow movements
- slurred speech
- loss of balance or coordination.

Sometimes an arm or leg can move by itself without the person controlling it.

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CBS can start off as a language-led dementia, such as non-fluent variant PPA. It can then progress over time to involve more severe problems with movement.

PSP is similar to CBS, but also causes problems with control of eye movements, difficulty walking, and being more prone to falling.

Ideally, these conditions need specialised support from people and organisations who understand both the dementia and the movement disorders. In the UK, this is the PSP Association. For contact details, see 'Other useful organisations' on page 16.

For more information on rarer types of dementia, visit **[alzheimers.org.uk/rarer](https://alzheimers.org.uk/rarer)**

## 3 Who gets FTD?

We still don't fully understand why some people get frontotemporal dementia (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

FTD 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 very different 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. They may also find it more challenging to get a diagnosis. For advice about these issues see booklet 688, **Young-onset dementia: Understanding your diagnosis**.

### 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 causes FTD if it is passed down from a parent to a child. This is known as 'familial FTD' and it most often causes behavioural variant 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 inheriting the gene that causes disease.

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 (FTD) is much less common than other types of dementia and often has different early symptoms. This means FTD can be hard for doctors to identify, as they may not recognise its symptoms as dementia. It is usually diagnosed by a specialist, such as a psychiatrist or neurologist.

Most changes in behaviour or personality caused by FTD may not be obvious at first. They 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 mental health conditions, such as depression, anxiety, bipolar disorder, schizophrenia or a personality disorder. Problems with language or movement may also be misdiagnosed. As a result, it can sometimes take several years before a person is finally diagnosed with FTD.

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.

Some people are given a diagnosis of a certain type of FTD. Others will just have a general 'FTD' diagnosis. This can happen when it's not yet clear what specific type of FTD a person has.

### Assessments

Blood tests and a full physical examination can 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, language or behaviour may be needed.

## Scans and further tests

Most people who have symptoms of FTD will have a brain scan. These 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 can be carried out that measure activity in different parts of the brain. The specialist may also request a lumbar puncture. This involves collecting and examining fluid from inside the spine.

## 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. They can also 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.

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# 5 Treatment and support

There is currently no cure for frontotemporal dementia (FTD) and its progression cannot be slowed down with medicines. The medicines commonly used to improve memory and thinking in other types of dementia are not recommended for people with FTD. They may even make symptoms worse.

That doesn't mean that nothing can be done to help. Some medicines and other therapies have been shown to help with some of the symptoms of FTD, although they won't slow down the disease itself.

Supporting a person with FTD involves a team of professionals. This can include a:

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

When someone has problems with movement, balance or coordination, support from a physiotherapist or occupational therapist can help.

Support groups offer useful advice and emotional support to people living with FTD and those who care for them. This can include support for families concerned about genetic causes of the condition. See 'Other useful organisations' on page 16 for details.

It can be hard to find support groups in some areas. This is especially true for people with young-onset dementia. To search for general dementia support groups and services in your local area, visit **[alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)**

Dementia Support Line is our personalised service for anyone affected by dementia. To speak to one of our dementia advisers, call **0333 150 3456**.

To talk with others affected by dementia, visit our online community in the Dementia Support Forum at **[forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)**

## Adapting to 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. It is common to feel awkward or embarrassed in these situations.

However, 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. To order these, go to **[alzheimers.org.uk/helpcards](http://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, keep to regular portions, and limit access to unhealthy snacks, if these are being eaten excessively. For more tips see factsheet 511, **Eating and drinking**.

Changes in mood and behaviour can sometimes be helped with medicines, such as those often prescribed for people with anxiety or depression. The most common medications used are citalopram and escitalopram.

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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

”

Antipsychotics are sometimes used for severe symptoms that put the person or others at risk of harm. These include hallucinations, delusions, or aggressive behaviour. However, they should only be used when all other solutions have been tried, and at the smallest possible dose for the shortest amount of time. This is because there is little evidence that they work for people with FTD and they may have potentially dangerous side effects. For more information see factsheet 408, **Antipsychotic drugs and other approaches in dementia care**.

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.

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 treatments with medicines.

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 our Dementia Support Line on **0333 150 3456** or visit our online community, Dementia Support Forum, at **[forum.alzheimers.org.uk](http://forum.alzheimers.org.uk)**

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

## Treatment for language problems

Speech and language therapy can make a big difference for someone with a language-led dementia. It uses a range of therapeutic strategies, coaching and lots of practice to keep a person communicating effectively for longer. For example, a therapist may focus on the most important words the person needs for everyday use and find ways to make them easier to use.

Speech and language therapy can also help a person's partner or carer to find more effective ways of listening and speaking. For example, this may be using simpler and shorter sentences. If a person has problems swallowing, the therapist can also give advice on how to eat and drink more safely.

As the disease progresses, the therapist can help the person to keep communicating effectively without needing to use speech or words. They can learn to use gestures, drawing or other communication aids that enable them to express their wishes and preferences. This can also help to maintain a vital connection with friends and family.

It's important to try to access speech and language therapy as soon as possible rather than waiting for a crisis, such as the loss of an essential communication skill. This is because the therapy is designed to help a person to hold on to skills for as long as possible, rather than regaining them once they've been lost.

Accessing speech and language therapy through the NHS is not always easy and straightforward. However, it should be possible for anyone with a language-led dementia to request a referral by their GP or neurologist to a speech and language therapist, who can help with communication skills. It may also be an option for some people to find a therapist who works privately. For more information see 'Other useful organisations' on page 16.

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# Other useful organisations

### **Association of Speech and Language Therapists in Independent Practice (ASLTIP)**

**0203 002 3704**

**office@asltip.com**

**www.asltip.com/find-a-speech-therapist/**

The ASLTIP provides information and a contact point for members of the public searching for a private speech and language therapist. Its website has a search facility to enable people to find a therapist with the right skills and experience for their condition.

### **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 3318 0243 (voicemail)**

**contact@raredementiasupport.org**

**www.raredementiasupport.org**

Rare Dementia Support is a UK-based service that runs specialist support groups for individuals affected by rarer forms of dementia. It has excellent information resources on its website and access to clinicians and researchers with expertise in FTD.



Factsheet 404

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This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)

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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](http://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](http://alzheimers.org.uk/donate)**



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