



DementiaUK

Helping families face dementia

Understanding frontotemporal dementia (FTD)



Understanding frontotemporal dementia

Frontotemporal dementia (FTD) is an umbrella term for a group of dementias that mainly affect the frontal and temporal lobes of the brain, which are responsible for personality, behaviour, language and speech.

This group of dementias consists of:

- behavioural variant frontotemporal dementia (bvFTD), also known as Pick's disease or frontal dementia – this mostly affects the frontal lobe in the area regulating social behaviour. This is the most common form of FTD
- primary progressive aphasia (PPA). Variants include:
 - semantic variant or semantic dementia (SD) – this affects the temporal lobe in the area that supports understanding of language
 - nonfluent variant or progressive nonfluent aphasia (PNFA) – this affects the person's ability to use speech,

for example not knowing what words mean

- logopenic variant or logopenic aphasia (LPA) – this causes difficulty finding words when speaking, and muddling words, eg saying 'aminal' rather than 'animal'

FTD is a rare form of dementia. It is thought that only around one in 20 people with a dementia diagnosis have FTD. However, it is the most common type of dementia in people aged 60 and under.

What causes frontotemporal dementia?

In FTD, there is an abnormal build-up of proteins within the brain, which clump together and cause damage to the cells. At present, it is not known why this occurs. However, it is thought to have a genetic link in about one third of people with the diagnosis. For bvFTD, it is likely that around 40% of people with the diagnosis have a form of 'familial' FTD due to a genetic problem.

In common with other dementias, the onset of FTD tends to occur



gradually and get worse over time. FTD tends to be diagnosed more commonly in 40- to 60-year-olds, but some people may be younger or older than this. It affects both men and women equally.

What are the symptoms of frontotemporal dementia?

The symptoms of FTD usually develop gradually, and differ from the early memory and concentration symptoms that are common in other forms of dementia. In FTD, the changes are mainly in personality, behaviour and problem-solving. People with

PPA usually have difficulty with language and communication.

Symptoms of behavioural variant FTD (bvFTD)

- reduced motivation or lack of interest in things the person used to enjoy, or in other people, including family members
- inappropriate behaviour, eg making insensitive or suggestive comments, staring at strangers and being over-familiar with them
- reduced empathy and ability to understand what others may be feeling

- difficulty focusing on tasks and being easily distractible
- obsessive or repetitive behaviour, eg repeating phrases or gestures, hoarding, or excessive focus on collecting things
- changes in behaviour regarding food or drink, eg craving sweet foods, poor table manners, overeating or drinking too much alcohol
- difficulty with planning, organising and decision-making, such as problems managing finances and in the workplace
- loss of insight (lack of awareness of the changes in themselves)

Primary progressive aphasias (PPA) differ from bvFTD in the early stages as the issues experienced tend to involve language rather than behaviour.

Symptoms of semantic variant or semantic dementia (SD)

- The early signs include changes in the ability to remember, find or understand words
- There is a gradual loss of vocabulary over time, starting

with less common words and then more common words as SD progresses

- A person with SD is also likely to have a tendency to forget what common objects are and what they do, eg kettle, toaster, keys

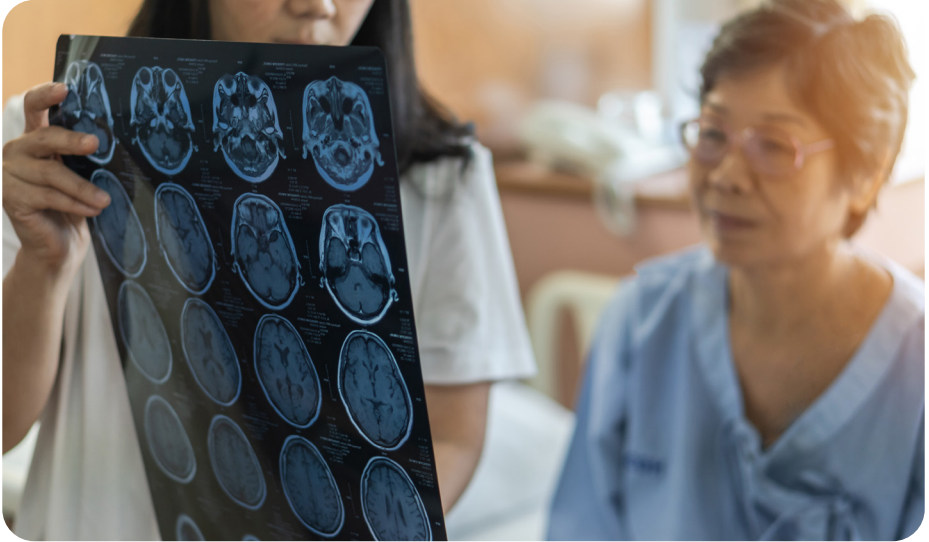
As SD develops over time, the changes are likely to become similar to those experienced in bvFTD.

Symptoms of nonfluent variant or progressive nonfluent aphasia (PNFA)

- This type of dementia affects the person's ability to use speech, including forming sentences and using grammar correctly
- The person with PNFA may be less able to conduct a conversation due to these changes – for example, they may use shortened sentences, be more hesitant in their speech or use the wrong words to convey their intentions

Symptoms of logopenic variant or logopenic aphasia (LPA)

- This type of dementia affects the person's ability to find the right words



- The person with LPA may stop speaking mid-sentence as they try to find the right word to say. This is usually more problematic when communication is about something specific, or if they are searching for an unfamiliar word
- Unlike in SD, people with early LPA are unlikely to forget the meaning of words or what common objects do

Getting a diagnosis of frontotemporal dementia

There are often significant delays in getting a diagnosis of FTD for a combination of reasons, including a lack of awareness of the early

signs and mistaking these for other conditions such as depression, stress, relationship problems and work-related issues. There is also a common misconception that dementia only occurs in older people and usually involves memory problems.

It is important to get an accurate diagnosis of FTD so that advice, support and services can be arranged to help the person and their family. However, this can be problematic if the person lacks awareness of the changes in their personality and behaviour and therefore refuses to visit the GP.

These are some suggestions for addressing this reluctance to seek advice.

- Speak to the person who has symptoms of FTD and explain there are other potentially treatable conditions that could explain their difficulties, as listed above. Seeing a GP will help to identify these issues so they can offer the most appropriate treatment
- Ask someone who the person usually listens to and trusts to persuade them to visit the GP for a check-up. This could be a friend, family member or colleague
- Arrange for the person to be called into the surgery for a health check or screening tests – see below

Prior to booking an appointment, it is useful to provide the GP with brief details of your concerns, explaining what the issues are, when they started, what happens, how they affect the person's life and those around them, how long this has been happening for, and if there is any family history

of dementia. You can do this by phone, letter or email.

While the GP will not be able to discuss their patient for reasons of confidentiality, they should consider the information provided and decide whether to call the person in for a review or visit them at home.

The GP should conduct a range of blood tests and physical examinations to rule out any potentially treatable conditions like physical or mental health issues. The GP may also conduct a brief cognitive assessment, but as these are usually focused on testing memory and orientation, the person may score highly, which could further delay a referral for a specialist assessment.

If the person needs further tests, they should be referred for an assessment with a specialist in FTD. A full history of their symptoms should be gathered, including details of changes in personality, behaviour, mood and everyday living abilities.

A comprehensive assessment focusing on attention, memory,



fluency, language, visuospatial abilities and behaviour changes should be conducted, including an MRI scan of the brain. It is important that the family is also involved in the assessment so they can share their experience of the changes in their family member.

Where familial FTD is suspected, the specialist may refer the person for a blood test to identify any genetic abnormality. It is important that counselling is given before the blood test due to the implications of identifying inherited FTD – for example, there is a higher risk of the person’s children developing the condition.

Treating frontotemporal dementia

Currently, there is no known prevention or cure for FTD, although there is ongoing research into its causes, potential treatments and cures. However, there are things that can help the person and their family to live as well as possible after a diagnosis – see p8 for advice on preventing or managing some of the common issues experienced in FTD.

In some cases, medication may help to reduce some of the symptoms of FTD. Medication should only be used after all other

approaches have been tried due to the possibility of adverse side effects. Medications usually used for Alzheimer's disease (donepezil, rivastigmine and galantamine) are not suitable in FTD and may actually increase any behavioural issues.

Practical tips for managing frontotemporal dementia

The changes in personality, behaviour and communication that typically occur in FTD can be challenging for the person with the diagnosis and their family. It is important to recognise that these changes are due to the effects of FTD on the brain and are not intentional. Responding to these behaviours in a calm, patient and empathetic manner can reduce distress for the person with FTD and the people around them.

These tips may help to prevent and manage the effects of FTD.

- It is a good idea for the person with FTD to carry a card with details of their diagnosis and what sort of help they may need. This can be useful in situations in public where there may be misunderstandings or a need for extra support. See p10 for a link to our printable ID cards
- The Hidden Disabilities Sunflower Scheme provides a range of cards, lanyards and other information that may be helpful to give a visual cue to members of the public, retail staff and service providers such as public transport that the person has a hidden disability. See p10 for details
- Peer and social support groups can provide an opportunity for people with FTD to share experiences and tips for preventing or managing potential difficulties. These may take place locally or nationally, and may be held face-to-face or online
- Noisy or crowded places can be distressing for people living with FTD and can trigger changes in behaviour, so it may help to avoid these situations or provide support if they cannot be avoided
- Having a routine and regular



activities can help the person to feel more relaxed

- Look out for triggers such as being too hot or cold, noise, pain, misunderstanding, difficulty with emotional control, changes in routine, lack of activity or too much or too little stimulation
- Focus on what the person can still do rather than on what they can't. Encourage them to keep up with activities they enjoy, eg photography, art, exercise, swimming, walking or taking care of a pet

- Overeating and craving sweet foods are common in FTD. To prevent an increase in weight and related health problems, offer food at set mealtimes, try to control portion size, and buy and offer healthier options
- As the person with FTD may not be aware of the changes in their behaviour and personality, trying to correct them could lead to arguments and distress. Remember that they are not deliberately causing upset or offence – it is the result of changes to the way their brain functions

People with PPA can find it very difficult to communicate due to the physical changes in their brain. As well as the tips above, the following may be useful:

- Ask the person's GP or specialist for a referral to a speech and language therapist for assessment, advice and support
- Communication aids may be helpful, such as electronic devices and non-verbal approaches like gestures, writing or drawing

Sources of support

FTD is a complex dementia due to the age of onset and the changes in personality, behaviour, language and speech. It can have a negative impact on many areas of life, including work, finances, socialising, and relationships with friends and family. This is often complicated by delays – sometimes of several years – in getting an accurate diagnosis.

It is important that the person with FTD and their family receive specialist advice and support. Our dementia specialist Admiral Nurses work throughout the UK and in many areas, can offer support in person. The person's GP or dementia specialist may also be able to tell you about other groups and services that can help.

Our free Dementia Helpline provides information, advice and support with any aspect of dementia. To speak to a specialist nurse, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org.

You can also book a phone or video appointment in our virtual clinics: visit dementiauk.org/get-support/closer-to-home.

You may find the following sources of support helpful:

Dementia UK leaflets

Getting a diagnosis

dementiauk.org/getting-a-diagnosis

About young onset dementia

dementiauk.org/about-dementia/young-onset-dementia

How to handle communication challenges

dementiauk.org/communication-challenges

Hidden Disabilities Sunflower Scheme

hiddendisabilitiesstore.com

Young onset dementia ID cards

youngdementianetwork.org/resources/young-onset-id

For further information about support groups visit:

Dementia UK – Find support

Young onset dementia groups and services database

dementiauk.org/about-dementia/young-onset-dementia/find-support

Dementia Carers Count

Free support courses for family and friends caring for someone with dementia, including young onset dementia

dementiacarers.org.uk

Dementia Engagement and Empowerment Project (DEEP)

A network of around 80 groups of people living with dementia

dementiavoices.org.uk/deep-groups
[find-a-deep-group-in-your-region](#)

Rare Dementia Support

Specialist support around rare dementias through group meetings, newsletters and direct support by email and telephone

raredementiasupport.org

tide: together in dementia everyday

A number of online groups including a young onset dementia carers group which meets monthly

tide.uk.net

Young Dementia Network

A collaboration between people affected by and working in the field of young onset dementia to improve the lives of people with the diagnosis

youngdementianetwork.org

Personal checklist

A place to record possible dementia symptoms

youngdementianetwork.org/resources/personal-checklist

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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