Dementia UK
Helping families face dementia

Understanding frontotemporal dementia

Frontotemporal dementia (FTD) is an umbrella term for a group of dementias that mainly affect the frontal (front) and temporal (side) 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 area of the brain regulating social behaviour. It is the most common form of FTD.

Primary progressive aphasia (PPA). Variants include:

- semantic variant or semantic dementia (SD) – this affects the area of the brain 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, affecting only around one in 20 people with a dementia diagnosis.

What causes frontotemporal dementia?

In FTD, there is an abnormal build-up of proteins within the brain, which clump together and damage 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. Please see Sources of support on p13 for details of our leaflet on genetic forms of dementia.

FTD is most commonly diagnosed in people aged 45 to 65, but some people may be younger or older than this. It affects both men and women equally.

Signs and symptoms of frontotemporal dementia

The symptoms of FTD develop gradually and get worse over time. Unlike many other forms of dementia, where memory and concentration are often affected first, the early signs of FTD are changes in personality, behaviour and problem-solving.

Symptoms of behavioural variant FTD (bvFTD) include:

- reduced motivation or lack of interest in things the person used to enjoy, or in other people, including family members
- inappropriate behaviour and/or loss of inhibition, eg making insensitive or suggestive comments, making sexual comments in public, acting impulsively, 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 distracted
- 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 coping with work
- lack of insight and awareness of the changes in themselves

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

Signs and symptoms of semantic variant or semantic dementia (SD) include:

- changes in the ability to remember, find or understand words
- a gradual loss of vocabulary, starting with losing less common words and then more common words as SD progresses
- tendency to forget what common objects are and what they do, eg kettle, toaster, keys

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

Symptoms of nonfluent variant or progressive nonfluent aphasia (PNFA) include:

- changes in the person's use of speech, including forming sentences and using grammar correctly
- difficulty conducting a conversation – for example using shortened sentences, speaking more hesitantly or using the wrong words

Signs of logopenic variant or logopenic aphasia (LPA) include:

- changes in the person's word-finding ability – this is usually more problematic when they are communicating about something specific, or are searching for an unfamiliar word
- stopping speaking mid-sentence as they try to find the right word to say

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:

- a lack of awareness of the early signs
- mistaking these signs for other conditions such as depression, stress, relationship problems and work-related issues
- the common misconception that dementia only occurs in older people and usually involves memory problems, meaning it is discounted in a younger person

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 difficult 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 and explain there are other potentially treatable conditions that could be causing 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
- Contact the GP by letter, email or phone about your concerns – while they will not be able to discuss their patient for reasons of confidentiality, they should consider the information and decide whether to call the person in for a general health review

For details of our leaflet on denial and lack of insight, please see Sources of support on p13.

It is useful to write a brief list of your concerns to show the person's GP, including:

- what the issues are
- when they started
- what happens
- how they affect the person's life and the people around them
- if there is any family history of dementia

In an initial appointment, the GP should ask the person about their symptoms and perform some physical checks to rule out other conditions, including requesting a blood test. They 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; and any family history of dementia.

A comprehensive assessment focusing on attention, memory, fluency, language, visuospatial abilities and behaviour changes should be conducted, including an MRI scan of the brain.

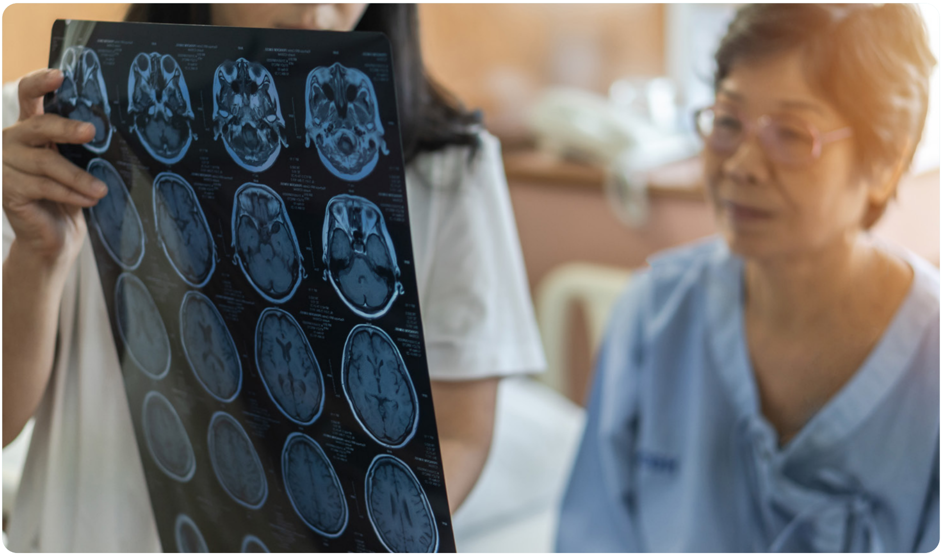
If possible, a family member should attend these appointments so they can share information on the changes they have noticed.

If 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 first to discuss the implications of identifying inherited FTD – for example, there is a higher risk of the person's children developing the condition, which could be upsetting.

Medications for frontotemporal dementia

Currently, there is no known prevention or cure for FTD. However, in some cases, medication may help to reduce some of the symptoms – for example, a form of antidepressant called an SSRI may help some people with issues like loss of inhibitions, overeating and compulsive behaviour.

Medications usually used for Alzheimer's disease (donepezil,



rivastigmine and galantamine) are not suitable in FTD and may actually increase any behavioural issues. It is also important to note that all medications may cause adverse side effects.

Practical tips for managing frontotemporal dementia

FTD is a complex dementia due to the typical age of onset and the changes it causes in personality, behaviour, language and speech. It can have a negative impact on many areas of life, including work, finances, socialising, and relationships with family and friends.

It is important to recognise that these changes are caused by the effects of FTD on the brain and are not intentional. Responding in a calm, patient and empathetic manner can reduce distress for the person with FTD and the people around them.

As the person with FTD may not be aware of or able to control the changes in their personality or behaviour, correcting them if they say or do something unusual could lead to arguments and distress. It may be best not to challenge or confront them, but just let things go if it is possible and safe to do so.

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 help they may need. This can be useful in situations in public where there may be misunderstandings or a need for extra support. See p14 for a link to our printable ID cards
- The Hidden Disabilities Sunflower scheme provides a range of cards, lanyards and other information that may help alert members of the public, retail staff and service providers such as public transport to the person's hidden disability. See p15 for details
- Peer and social support groups can provide opportunities for people with FTD and their families to share experiences and advice. These may take place locally or nationally, face-to-face or online
- Look out for triggers such as being too hot or cold, pain, hunger, misunderstanding, changes in routine, lack of activity or overstimulation
- Noisy or crowded places can be distressing for people living with FTD and can trigger changes in behaviour, so try to avoid these situations or provide support if this is not possible
- 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
- Having a routine and regular activities can help the person to feel more secure

- If the person works or volunteers, encourage them to speak to their manager and other colleagues about their diagnosis so support and adaptations can be put in place to help them in their role. Please see Sources of support on p13 for our information on employment and dementia
- Focus on what the person can still do rather than on what they cannot. Encourage them to keep up with activities they enjoy, eg photography, art, exercise, swimming, walking or taking care of a pet
- Communication aids may be helpful, such as electronic devices and non-verbal approaches like gestures, writing or drawing
- Ask the person's GP or specialist for a referral to a speech and language therapist (SaLT) for assessment, advice and support

It is important that the person with FTD and their family receive specialist advice and support – this could be from a medical professional, a counsellor, other family members or a support group. You can also speak to our dementia specialist Admiral Nurses: please see Sources of support on p13.

Supporting children and teenagers

Young or adolescent children may be unsettled by the changes they are seeing in a parent with FTD. They may not understand what is happening and why. They may be embarrassed if their parent exhibits unusual or uninhibited behaviour, which might make them reluctant to go out with them or invite friends over.

It is important to explain what is happening in clear, age-appropriate language, as this will help reduce confusion and improve their understanding – please see Sources of support on p15 for details of our information on supporting children and adolescents when a parent has young onset dementia.

Sources of support

To speak to a dementia specialist Admiral Nurse about FTD or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email › **helpline@dementiauk.org**

If you prefer, you can book a phone or video appointment at a time to suit you at › **dementiauk.org/book**

Dementia UK resources

Denial and lack of insight in dementia

› dementiauk.org/understanding-denial-and-lack-of-insight

Different symptoms of young onset dementia

› dementiauk.org/young-onset-dementia-different-symptoms

Eating and drinking with dementia

› dementiauk.org/eating-and-drinking

Employment and young onset dementia

› dementiauk.org/employment

Getting a diagnosis of dementia

› dementiauk.org/how-to-get-a-diagnosis

Getting a diagnosis of young onset dementia

› dementiauk.org/young-onset-dementia-getting-a-diagnosis

Genetic (familial) types of dementia

› dementiauk.org/genetic-familial-forms-of-dementia

Personal checklist

A place to record possible dementia symptoms

- youngdementianetwork.org/resources/personal-checklist

Supporting children and adolescents who have a parent with young onset dementia

- dementiauk.org/supporting-children-and-adolescents

Tips for better communication

- dementiauk.org/tips-for-communication

Young onset dementia section

- dementiauk.org/young-onset-dementia

Young onset dementia groups and services database

- dementiauk.org/find-support

Young onset dementia ID cards

- youngdementianetwork.org/young-onset-id

Other resources

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 groups of people living with dementia

➔ dementiavoices.org.uk

Hidden Disabilities Sunflower scheme

➔ hiddendisabilitiesstore.com

Rare Dementia Support

Information and advice about rare dementias, including FTD

➔ raredementiasupport.org

tide: together in dementia everyday

A number of online dementia support groups, including a young onset dementia carers’ group

➔ tide.uk.net

Young Dementia Network

An online collaboration between people affected by and working in the field of young onset dementia to improve the lives of people with the diagnosis, hosted by Dementia UK

➔ youngdementianetwork.org

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:
0800 888 6678 or **helpline@dementiauk.org**

Book a virtual appointment:
dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan **the QR code**

Thank you.

Dementia UK
Helping families face dementia

dementiauk.org • **info@dementiauk.org**

Publication date: February 2024. Review date: February 2026.

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).

DUK51