



DementiaUK
Helping families face dementia

Understanding frontotemporal dementia



2 Dementia UK

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 frontotemporal dementia.

Primary progressive aphasia (PPA): this type affects mainly language and has three variants:

- **Semantic variant or semantic dementia (SD):** this affects the area of the brain that supports understanding of language
- **Non-fluent 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’

While all three variants are forms of PPA, the semantic and non-fluent variants are mainly linked with frontotemporal dementia. The logopenic variant is usually associated with Alzheimer’s disease, even though it can affect the temporal lobes.

Frontotemporal dementia is considered a rare form of dementia. It is most common in people aged 45 to 65 – around 12% of younger people with dementia have a frontotemporal type, compared to around 2% of older people. However, people can develop it at any age. It affects men and women equally.



What causes frontotemporal dementia?

In frontotemporal dementia, 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’ frontotemporal dementia due to a genetic problem. Please see Sources of support on p14 for more information on genetic forms of dementia.

Signs and symptoms of frontotemporal dementia

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

4 Dementia UK

Symptoms of bvFTD

- reduced motivation or interest in things the person usually enjoys, or in other people, including family members
- inappropriate behaviour and/or loss of inhibition, for example making insensitive or suggestive comments, 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; being easily distracted
- obsessive or repetitive behaviour, for example repeating phrases or gestures, hoarding or excessive focus on collecting things
- changes in behaviour regarding food or drink, for example craving sweet foods, poor table manners, overeating or drinking too much alcohol
- problems with executive functions, such as planning, organising and decision-making – for example, difficulties with managing finances or coping with work
- lack of insight and awareness of the changes in themselves

Symptoms of PPAs

PPAs differ from bvFTD in the early stages as the changes tend to involve language rather than behaviour.

Symptoms of semantic variant or semantic dementia

- changes in remembering, finding or understanding words
- a gradual loss of vocabulary, starting with less common words and then more common words as semantic dementia progresses



- tendency to forget what common objects are and what they do, eg kettle, toaster, keys

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

Symptoms of non-fluent variant or progressive nonfluent aphasia

- 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

- 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

6 Dementia UK

- stopping speaking mid-sentence as they try to find the right word to say

Unlike in SD, people with early logopenic aphasia 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 frontotemporal dementia for a combination of reasons:

- a lack of awareness of the early signs, which often do not involve memory
- mistaking these signs for other conditions such as depression, anxiety, stress, relationship problems, work-related issues or other life pressures
- the common misconception that dementia only occurs in older people, meaning it is overlooked in a younger person

It is important to get an accurate diagnosis of frontotemporal dementia 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. Here are some suggestions for addressing this:

- Speak to the person gently and explain that their symptoms may be due to treatable conditions such as stress, mood problems, physical illness or side effects of medications. Seeing a GP will help to identify these issues so they can offer the most appropriate treatment
- Ask someone else who the person usually listens to and trusts to encourage 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 breach their patient's confidentiality, they should consider the information and decide whether to call the person in for a general health review

For more information 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

Seeing the GP

If possible, a family member should attend any medical appointments and assessments with the person so they can share information on the changes they have noticed.

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 frontotemporal dementia. 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. The specialist may also arrange a scan such as an MRI (magnetic resonance imaging) to look for any changes in the brain.

If familial frontotemporal dementia 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 frontotemporal dementia. For example, there is a higher risk of the person's children developing the condition, and knowing this could be upsetting.

Medications for frontotemporal dementia

Currently, there is no known prevention or cure for frontotemporal dementia. However, in some cases, medication may help to reduce some of the symptoms. For example, a form of antidepressant

called selective serotonin reuptake inhibitors (SSRIs) 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 frontotemporal dementia and may make any behavioural issues worse.

It is also important to note that all medications may cause side effects, so any decisions will involve carefully weighing up the risks and benefits with the person's prescriber.

Practical tips for managing frontotemporal dementia

Frontotemporal dementia is a complex form of dementia because of 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 person's dementia and are not intentional. Because the person 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 frontotemporal dementia:

- It is a good idea for the person to carry a card with details of their diagnosis and what help they may need. This can be useful in public situations 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 to 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 frontotemporal dementia and their families to share experiences and advice. These may take place locally, 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 with frontotemporal dementia and can lead to 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 people with frontotemporal dementia. To prevent weight gain 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 more information on employment and dementia
- Focus on what the person can still do rather than what they cannot. Encourage them to keep up with activities they enjoy, for



example sport, art, going to the theatre, socialising, 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 frontotemporal dementia and their family receive specialist advice and support. This could be from a medical professional, 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 frontotemporal dementia. 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 them understand the situation and reduce confusion. Please see Sources of support on p14 for more information on supporting children and adolescents when a parent has young onset dementia.



Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Denial and lack of insight in dementia

[▶ dementiauk.org/understanding-denial-and-lack-of-insight](https://dementiauk.org/understanding-denial-and-lack-of-insight)

Different symptoms of young onset dementia

[▶ dementiauk.org/young-onset-dementia-different-symptoms](https://dementiauk.org/young-onset-dementia-different-symptoms)

Eating and drinking with dementia

[▶ dementiauk.org/eating-and-drinking](https://dementiauk.org/eating-and-drinking)

Employment and young onset dementia

[▶ dementiauk.org/employment](https://dementiauk.org/employment)

Getting a diagnosis of dementia

[▶ dementiauk.org/how-to-get-a-diagnosis](https://dementiauk.org/how-to-get-a-diagnosis)

Getting a diagnosis of young onset dementia

[▶ dementiauk.org/young-onset-dementia-getting-a-diagnosis](https://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/personal-checklist

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

➤ dementiauk.org/supporting-children

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, advice and direct support around 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

The online community for everyone living with, working with or interested in young onset dementia, 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](mailto:helpline@dementiauk.org)

Book a virtual appointment:

[▶ dementiauk.org/book](https://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](https://dementiauk.org/donate)
- Scan the QR code



Thank you.



DementiaUK

Helping families face dementia



dementiauk.org • info@dementiauk.org

Publication date: March 2026 Review date: March 2029. © Dementia UK 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).