Patient information from BMJ

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Dementia: frontotemporal dementia

Frontotemporal dementia differs from other types of dementia in some ways. For example, it can affect people at younger ages, and the early signs don't usually include memory problems.

If you have been diagnosed with frontotemporal dementia, or if you are caring for someone who has, you can use our information to talk to your doctor about what to expect, and what treatments may help.

What is frontotemporal dementia?

Frontotemporal dementia (FTD for short) happens when nerve cells at the front and sides of the brain are damaged.

It is less common than some other types of dementia, including **Alzheimer's disease**. About 5 in every 100 people with dementia have FTD.

FTD usually affects people at a younger age than Alzheimer's does. It most commonly affects people aged 45 to 65. But it can start even earlier.

The main symptoms of FTD are changes in personality and social behaviour, and problems with speech and language. It is always fatal, usually after several years.

Almost half of people with FTD also have signs of **parkinsonism**, such as shaking and stiff muscles. And a small number of people with FTD develop **motor neuron disease (MND)**, also known as **amyotrophic lateral sclerosis (ALS)**.

It's not always possible to say what causes FTD. But we know that **genetics** (the genes you inherit from your parents) and severe **head injuries** can cause the condition in many people.

Doctors sometimes group FTD into two types, although the symptoms can overlap:

- **Behavioural FTD** mainly causes problems with personality and social conduct. This type can be hard to spot and diagnose, because the symptoms are similar to those of several other mental-health problems.
- **Primary progressive aphasia** mainly affects speech and language.

What are the symptoms?

The early symptoms of FTD often involve changes in personality and behaviour. They include:

- Changes in social behaviour. It’s often said that someone’s personality becomes more 'coarse', and that they become less polite and more direct. For example, they may seem rude or uncaring
- Struggling with self-control: someone may struggle to control their emotions, or act on impulse. For example, someone may suddenly start spending money without thinking if they can afford to
- Being less interested in looking after themselves. For example, they may not care much about how they look
- Seeming to care less than usual about other people’s needs
- Problems speaking clearly and understanding what is said to them. These language problems get worse over time
- Being easily distracted
- Developing rigid routines and habits, and
- Changes in eating habits. For example, many people with FTD often crave sweet foods.

Symptoms that affect people with other types of dementia, such as problems with memory, can also affect people with FTD. But not usually in the early stages.

If you see your doctor about your symptoms, they will ask you about them (or about the symptoms of the person you are caring for). This helps to know if your symptoms are more to do with behaviour or with speech and language.

Your doctor will also ask about whether you (they) have symptoms that suggest parkinsonism or MND, such as shaking and muscle weakness.

Making a careful record of symptoms will help your doctor to plan the care that will be needed. For example, people with FTD will gradually develop disabilities such as:

- Confusion
- Struggling to communicate
- Loss of bladder and bowel control, and
- Problems with basic tasks, such as washing and dressing.

Tests

Your doctor will probably want to do tests related to your symptoms. These could include:

- Cognitive tests. These tests are often in the form of questions. They look at things like speech, understanding, and thinking
- Blood tests, to rule out physical causes of your symptoms, such as thyroid or vitamin problems, and

- Scans of the brain.

What treatments are available?

As with other types of dementia, there is no cure for FTD. Most treatments are aimed at keeping people and their carers as **safe and supported** as possible.

But there are things that can help people with FTD to communicate and enjoy life, even when their symptoms get worse over time.

These are many of the same treatments and techniques that have been found to help people with other types of dementia, and can include therapies based around:

- Music
- Dance
- Exercise, and
- Reminiscence therapy (focusing on happy memories).

Education and support

It’s important for people with FTD, their family, and their carers to learn as much as they can about it. For example, learning about the changes in someone’s behaviour can help carers to prepare for and understand what is happening.

People with FTD need to be in an environment that’s as safe and free of risks as possible. For example, as someone’s symptoms get worse, they become more likely to fall or stumble.

So you should be helped to do a check to make **your home** as safe and suitable as possible. This may look at things such as:

- Tripping hazards
- Room temperature, and
- Noise and light levels.

You should also be given help with assessing if you are still able to drive, or to use public transport safely, and with how well you can take care of yourself.

You should also be helped to learn how to **communicate** with people with FTD. As people’s symptoms get worse, clear and simple communication becomes more important. So carers and families should be helped to learn to communicate by:

- Using short sentences
- Making eye contact
- Explaining things simply
- Listening carefully and letting the person know you are listening, and
- Staying calm when the person becomes frustrated.

People with FTD can sometimes become **aggressive** when frustrated or confused. So carers and families should be helped to understand how to deal with this.

Long-term care and decisions

It is important to prepare for someone's long-term care needs, and to make decisions about the future before someone's symptoms get worse to the point where that becomes difficult.

This may include making decisions about how much **extra help** family members and carers need, and what will happen if someone can no longer be cared for at home.

Drug treatments

Unfortunately there are very few medicines that can help with most symptoms of FTD. In particular, drug treatments don't help with cognitive problems like understanding, memory, and thinking.

Your doctor may suggest medicines to help with specific symptoms, such as agitation, aggression, or sleep problems. But they will probably be very cautious about doing this.

This is because the medicines that can help with these problems can make some other FTD symptoms worse. But if you, or someone you are caring for, are struggling with specific symptoms, talk to your doctor about what you can do.

Your doctor should also make a list of all the medicines you are taking for any **other conditions**.

This is because some medicines can cause **side effects** that can make FTD worse, such as sleepiness, confusion, and agitation. So your doctor will want to be aware of what may cause problems.

Valproate medicines and pregnancy

Younger women with FTD are sometimes prescribed **valproate medicines** to help with behavioural symptoms. This should only happen if there are no good alternatives. Valproates can cause **severe birth defects**.

If you or someone you are caring for are prescribed valproates, your doctor **must** ensure that you have taken measures to prevent pregnancy. Your doctor may call this a **pregnancy prevention programme**.

What to expect in the future

Unfortunately there are no treatments that can stop FTD from getting worse. And FTD is always fatal. Most people live between about six and 12 years after being diagnosed. But people who have FTD along with MND do not live as long as this.

Caring for someone with FTD can be very hard, no matter how much you love them. It can lead to problems such as stress, depression, and even dependence on alcohol or drugs.

So getting as much help as you can is vital to caring for someone with FTD. Your doctor may be able to help you find a **support group** near you. Or you can search online. You can talk to them about coping techniques, and about anything else you want to know about caring for someone with FTD - and for yourself.

What did you think about this patient information guide?

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