CONDITION

Frontotemporal dementia

Frontotemporal dementia is a progressive brain condition that changes behaviour, language, judgement, or movement.

WHAT IT IS
Progressive condition affecting frontal and temporal brain regions

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Personality changes, poor judgement, language problems, movement difficulties

WHAT CAUSES IT
Abnormal brain proteins; sometimes inherited, often unknown

HOW IT IS DIAGNOSED
Specialist assessment, cognitive testing, and brain imaging

MAIN TREATMENT
Symptom treatment, therapies, safety planning, and caregiver support

CAN IT BE CURED?
No - current treatments manage symptoms only

IS IT AN EMERGENCY?
Sometimes - choking, severe injury, or immediate danger

LONG-TERM OUTLOOK
Progressive loss of independence and shortened life expectancy

Overview

Frontotemporal dementia, often shortened to FTD, is a progressive condition that damages the frontal and temporal lobes of the brain. These areas help control behaviour, judgement, emotions, language, planning, and some types of movement.

FTD may first appear as a major change in personality or social behaviour. In other people, the main early problem is speaking or understanding language. Memory can be affected, but it may be less noticeable at first than it is in Alzheimer's.

The term covers several related patterns. Behavioural variant FTD mainly affects personality, judgement, and self-control. Primary progressive aphasia mainly affects language. Some people also develop stiffness, poor balance, weakness, or other movement problems.

These changes can affect relationships, work, finances, driving, and personal safety. A person may not recognise that anything is wrong, so observations from family members or close friends are often important.

Symptoms

Symptoms usually develop gradually. The exact pattern reflects which parts of the brain are affected first.

Behavioural and personality changes may include:

These actions come from changes in the brain. They are not simply deliberate rudeness, laziness, or selfishness.

Language symptoms may include difficulty finding words, producing speech, understanding word meanings, naming familiar objects, reading, or writing. Speech may become slow and effortful. Some people continue speaking fluently but use vague words or misunderstand what others say.

Planning and thinking may also change. A person may struggle to organise tasks, switch between activities, solve problems, or understand risks. Memory may remain relatively strong early on, but it often becomes affected as the condition progresses.

Movement symptoms can include stiffness, slowness, poor balance, falls, tremor, muscle weakness, muscle twitching, or difficulty controlling eye movements. Problems chewing or swallowing may develop later. Some people have features that overlap with motor neurone conditions, progressive supranuclear palsy, or corticobasal syndrome.

- Acting without considering the effect on other people
- Losing interest, motivation, empathy, or emotional warmth
- Making unsafe, socially inappropriate, or uncharacteristic decisions
- Developing repetitive routines, movements, or fixed interests
- Eating more, craving sweet foods, or putting non-food objects in the mouth
- Neglecting washing, clothing, household tasks, or responsibilities

Causes and risk factors

FTD develops when nerve cells in the frontal and temporal regions become damaged and die. Abnormal proteins usually collect inside affected brain cells. These proteins commonly include

tau or TDP-43; less often, another protein called FUS is involved.

Why these changes begin is often unknown. FTD is not caused by someone's personality, relationships, parenting, or ordinary stress.

Genetic changes can cause FTD in some families. Important genes include C9orf72 , GRN , and MAPT . A family history of FTD, motor neurone conditions, or unexplained early dementia may increase the chance of an inherited form. However, having an affected relative does not always mean that you will develop it.

FTD often starts earlier in adult life than more common forms of dementia, although it can begin later. Age and family history are the clearest known risk factors. There is no established evidence that a particular food, job, or lifestyle choice directly causes it.

Diagnosis

There is no single routine test that confirms every case of FTD during life. Diagnosis is based on the pattern of symptoms, specialist assessment, cognitive testing, and brain imaging.

The assessment usually includes a detailed history. Because FTD can reduce insight, a clinician may ask a family member or another person who knows you well about changes in behaviour, communication, work, or daily life.

Tests of thinking and language examine skills such as planning, attention, word meaning, speech, memory, and problem-solving. A general physical and neurological examination looks for movement changes, weakness, abnormal reflexes, or other possible explanations.

Blood tests may check for treatable causes of similar symptoms, such as thyroid problems, vitamin deficiencies, infection, or the effects of other medical conditions. These tests do not diagnose FTD.

An MRI scan may show shrinkage in the frontal or temporal lobes. However, an early scan can appear normal, and a scan alone cannot establish the diagnosis. A PET or SPECT scan may sometimes help by showing reduced activity or blood flow in particular brain regions.

Further testing may be used when Alzheimer's, a psychiatric condition, a sleep disorder, or another neurological condition is possible. Genetic counselling and testing may be offered when the history suggests an inherited form. Genetic results can affect relatives as well as the person being tested, so counselling is important before testing.

Treatment and management

There is currently no cure or treatment that stops FTD from progressing. Management focuses on symptoms, communication, independence, comfort, and safety.

A clinician may consider medication for specific symptoms such as compulsive behaviour, agitation, low mood, or anxiety. These medicines do not treat the underlying brain changes. Antipsychotic medicines require particular caution because they can cause serious side effects in people with dementia.

Medicines commonly used for Alzheimer's do not have the same established benefit in FTD and can sometimes worsen behaviour. Medication decisions should be based on the person's symptoms and overall health.

Non-drug support is central to care:

Communication aids may include picture boards, written choices, gesture, or electronic devices. It is often helpful to introduce these before speech becomes severely limited.

Practical planning should begin while the person can take part in decisions. This may cover driving, employment, finances, legal authority, future care, and preferred medical treatment. Local rules determine how driving fitness is assessed and when licensing authorities must be informed.

- Speech and language therapy can support communication and assess swallowing
- Occupational therapy can simplify routines and make daily activities safer
- Physiotherapy can help with mobility, stiffness, balance, and falls
- Dietitian support may help with weight changes or swallowing difficulties
- Predictable routines and a calm environment may reduce distress
- Carer education, respite care, and support groups can reduce isolation

Complications

Reduced judgement can lead to unsafe spending, scams, road risks, conflict, wandering, or inappropriate behaviour. Loss of empathy and insight can place significant strain on close relationships.

Eating changes may cause weight gain, while swallowing problems can lead to weight loss, dehydration, choking, or food entering the lungs. Movement problems increase the risk of falls, injury, and reduced mobility. People with associated muscle weakness may later develop breathing problems.

As the condition advances, help is usually needed with washing, dressing, eating, medication,

and other daily tasks. Caregiver exhaustion, grief, anxiety, and depression also deserve attention and support.

Prevention

There is no proven way to prevent FTD. Inherited forms cannot be prevented through diet, exercise, supplements, or other lifestyle changes.

General measures such as regular activity, avoiding smoking, treating high blood pressure, and staying socially connected support overall health, but they have not been shown to prevent FTD specifically.

If FTD appears to run in your family, genetic counselling can explain testing options, possible results, and what those results could mean for relatives and family planning.

Living with it and what to expect

FTD progresses over months and years, but the order and pace of changes are not the same for everyone. Symptoms usually spread beyond the area first affected. Someone who begins with language problems may later develop behavioural or movement changes, while someone with early behavioural changes may later lose speech and daily living skills.

Abilities can be uneven. A person may still remember events or complete familiar tasks while making decisions that are unsafe. Symptoms may also seem better in a structured setting than they do at home.

Most people eventually need increasing supervision and hands-on care. Swallowing, mobility, continence, and communication may become more difficult. FTD shortens life expectancy, especially when significant muscle weakness or breathing problems develop, but an individual timeline cannot be predicted from the diagnosis alone.

Regular reviews can adjust support as needs change. Planning ahead can help preserve choice and reduce rushed decisions. Many people continue to enjoy music, familiar activities, gentle exercise, humour, food, nature, and time with people they trust, even when communication becomes limited.

When to get medical help

Arrange a routine medical appointment if you or someone close to you develops gradual,

persistent changes in personality, judgement, language, organisation, or ability to manage daily tasks. Similar symptoms can have other causes, including depression, medication effects, sleep problems, thyroid conditions, or another neurological condition.

During follow-up, report new falls, weight change, swallowing difficulty, increasing weakness, major behaviour changes, or rising caregiver strain. These changes may require a review of treatment, equipment, nutrition, or the care plan.

Seek urgent medical help for repeated choking, a sudden inability to swallow, new breathing difficulty, a serious fall, rapid worsening, or acute confusion. Sudden confusion is not a typical gradual change from FTD and may be caused by infection, medication, pain, or another medical problem.

Call emergency services if there is severe breathing difficulty, ongoing choking, a major injury, suicidal intent, violence or behaviour creating immediate danger, or stroke signs such as sudden facial drooping, one-sided weakness, or abrupt speech loss. FTD progresses gradually; sudden neurological symptoms need emergency assessment.

Common questions

Is frontotemporal dementia the same as Alzheimer's?

No. They affect the brain in different patterns. FTD often begins with behaviour, language, or movement changes, while Alzheimer's more often begins with difficulty learning and remembering new information. Later symptoms can overlap, so specialist assessment is important.

Is frontotemporal dementia inherited?

Sometimes. A genetic change can be identified in some families, but many people have no clear family history. A genetic counsellor can help assess the family pattern and explain the benefits and limits of testing.

Does frontotemporal dementia affect memory?

It can. Memory may be less affected early on than judgement, behaviour, or language, but it often becomes more difficult as the condition progresses. Poor planning or attention can also look like forgetfulness.

How fast does frontotemporal dementia progress?

Progression differs between people. Changes usually build over years rather than appearing all at once. The symptom pattern, movement or breathing involvement, other health conditions, and complications all influence the course.

Can someone with frontotemporal dementia live alone?

Some people can live alone early on with support, but impaired judgement may create risks before physical abilities decline. Regular review of cooking, money, medication, driving, communication, and emergency safety helps determine what support is needed.

Does a person with frontotemporal dementia know they have it?

Some people understand their changes, especially early in a language-led form. Others have reduced insight and may sincerely believe that nothing is wrong. This lack of awareness is a symptom of brain changes, not simple denial.

Sources

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- NHS: Frontotemporal dementia
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