

FTD FACT SHEET



Frontotemporal degeneration (FTD) is the most common form of brain disorders for people under 60.

FTD represents a **group of brain diseases** caused by degeneration of the frontal and/or temporal lobes of the brain. It is also frequently referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Pick's disease.

Not all dementia is Alzheimer's. FTD differs from Alzheimer's in three important ways:

1. It has different symptoms.

Uncharacteristic personality changes, apathy, and unexplained struggles with decision-making, movement, speaking or language comprehension are the most common symptoms. Often people appear physically healthy despite the neurodegeneration.

2. It typically strikes younger.

Most FTD cases occur between the ages of 45 and 64, causing a substantially greater impact on work, family, and finances than Alzheimer's.

3. It is often misdiagnosed.

FTD's estimated U.S. prevalence is around 60,000 cases, and many in the medical community remain unfamiliar with it. FTD is frequently misdiagnosed as Alzheimer's, depression, Parkinson's disease, or a psychiatric condition. On average, it currently takes 3.6 years to get an accurate diagnosis.

FTD CLINICAL SUBTYPES

FTD subtypes are identified by the symptoms that appear first and most prominently.

- **Behavioral variant FTD (bvFTD)** typically presents with uncharacteristic behaviors like socially inappropriate behavior, apathy, hoarding, and compulsiveness.
- **Primary progressive aphasia (PPA)** typically presents with problems with speech and the ability to communicate.
- **Progressive supranuclear palsy (PSP)** and **corticobasal degeneration (CBD)** typically present with balance or movement issues.
- **FTD-ALS** - Researchers have identified a connection between FTD and amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease).

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WHAT TO EXPECT AFTER DIAGNOSIS

Today, there is no cure for FTD. Experimental treatments to slow or stop disease progression are currently in trials, while a growing number of interventions are available to help manage FTD's symptoms and maximize quality of life.

The progression of behavioral, language-, and/or movement-related symptoms varies by individual. As the disease progresses, persons with FTD experience increasing difficulty in understanding, communicating with others, or relating to loved ones.

These deficits cause problems in social and/or occupational functioning that result in an increasing dependency on caregivers. Families should work quickly to identify a team of knowledgeable professionals who can help with coordinating care and legal and financial issues.

Over time, FTD predisposes individuals to physical complications such as pneumonia, infection, and fall injuries. The average life expectancy is 7 to 13 years after the start of symptoms; the most common cause of death is pneumonia.

AFTD IS HERE TO HELP

Contact our HelpLine at **866.507.7222**, or by email at **info@theaftd.org**. Visit our website (**www.theaftd.org**) to find more information and ways to connect with support groups and other vital resources.

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