FTD FACT SHEET

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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FTD FACT SHEET

Frontotemporal degeneration (FTD) is the most common form of dementia 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. **Different symptoms**

   FTD brings a decline in behavior, language or movement, while memory usually remains preserved.

2. **Typically Strikes Younger**

   Although the age of onset ranges from 21-80, the majority of FTD cases occur between 45-64. Therefore, FTD's economic impact on families is substantially greater than that imposed by Alzheimer's.

3. **Less common and still far less known**

   FTD is a rare but underdiagnosed disease that affects 60,000+ in the U.S. alone. It is frequently misdiagnosed as Alzheimer's, Parkinson's disease, or a psychiatric condition like depression. On average, it takes 3.6 years to get an accurate diagnosis.

FTD 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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FTD OVERVIEW

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

FTD is a progressive disease; as time passes, symptoms are seen more frequently, and grow more intense. The length of progression varies from 2 to over 20 years. Often, the first indications of FTD are overlooked or dismissed as someone simply misspeaking or acting out of character, maybe because they are having a bad day. But as one's FTD progresses, it becomes increasingly difficult to plan or organize activities, behave appropriately in social or work settings, and care for oneself, resulting in increasing dependency. Changes to one's behavior and personality, along with difficulties in language and movement, are FTD's hallmark symptoms – unlike Alzheimer's disease, which is primarily characterized by memory loss.

As FTD progresses, it predisposes an individual to physical complications such as pneumonia, infection, or injury from a fall, with an average life expectancy of 7 to 13 years after the start of symptoms.

FTD is often misdiagnosed as a different dementia (such as Alzheimer's), some other type of neurological disorder, or a psychiatric problem such as depression. AFTD has created diagnostic checklists to help families get an accurate diagnosis by identifying red flags to physicians. Diagnosing FTD requires a thorough history, verified by a care partner or caregiver, and a neurological examination.

FTD Subtypes (Ordered by Prevalence)

BEHAVIORAL VARIANT FTD (bvFTD)

Behavioral variant FTD is the most common form of FTD, responsible for about half of all cases. BvFTD is also frequently referred to as frontotemporal dementia or Pick's disease, and is identified by personality changes, apathy, and a progressive decline in socially appropriate behavior, judgment, self-control, and empathy. People with bvFTD typically do not recognize the changes in their own behavior, or exhibit awareness or concern for how their behavior affects others.

FTD OVERVIEW

PRIMARY PROGRESSIVE APHASIA (PPA)

PPA is the second most common type of FTD, characterized by a gradual loss of the ability to speak, read, write, or understand what others are saying. Experts further organize PPA into three groups based on which language skills are most affected:

- **Nonfluent/agrammatic variant PPA**, or progressive nonfluent aphasia, makes producing speech difficult. While the person diagnosed can still recall the meanings of individual words, their speech becomes slow and effortful. They may omit words, use incorrect word endings, and/or mix up the order of words in sentences.
- **Semantic variant PPA**, or semantic dementia, causes one to "lose" the meanings of words and struggle to recall the names of objects. Speech becomes vague and difficult to understand because many words are omitted or substituted.
- **Logopenic variant PPA** makes it difficult to remember words while speaking, causing slow and hesitant speech, although the understanding of words' meanings remains intact. Persons diagnosed may also have short-term memory problems and repeat phrases and sentences.

ALS AND FRONTOTEMPORAL DEGENERATION

Also known as FTD with motor neuron disease (MND), this subtype causes difficulty with walking, standing, using one's hands, speaking, swallowing, or breathing. Other motor symptoms may include muscle weakness, atrophy, twitching, or slurred speech. BvFTD symptoms (such as changes in behavior, personality, and language skills) are often noticed first. Less commonly, symptoms of the nonfluent agrammatic and semantic variants of PPA are seen.

There are several gene variants known to cause FTD, ALS, and ALS with FTD, but the most common gene is *C9orf72*. Since both FTD and ALS can occur in the same person, FTD and ALS researchers often collaborate in their work.

CORTICOBASAL SYNDROME (CBS)

In addition to the frontal and temporal lobes of the brain, several regions deeper in the brain that initiate, control, and coordinate movement are affected in CBS, which presents as a decline in motor function very similar that found in Parkinson's disease (and is sometimes referred to as atypical Parkinsonism). Movement difficulties in CBS often begin on one side of the body but will spread to the other side. As the disease progresses, changes in behavior and language skills common to bvFTD and PPA may appear.

PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

PSP symptoms also resemble those seen in Parkinson's disease. Its earliest motor symptoms are muscular stiffness in the neck and trunk, along with poor balance and more frequent falls. A red flag for PSP is an inability to easily point one's eyes upward; eye movement becomes even more restricted from there, and even opening and closing one's eyes becomes difficult. PSP can also affect overall coordination, along with movement of the mouth, tongue, and throat. In addition to motor symptoms, people with PSP may exhibit changes in behavior and language skills common to bvFTD and PPA, particularly as the disease progresses.

FTD OVERVIEW

FTD & Genetics

When a person is diagnosed with FTD, their relatives may worry that they could develop it themselves. AFTD strongly recommends talking to a genetic counselor to help you assess your risk by evaluating your personal and family health history. Genetic counselors are trained to guide you through this process and provide support as you consider genetic testing.

How does FTD develop? There are several ways that FTD cases can be characterized:

- **Sporadic FTD** – In approximately 60% of people diagnosed with FTD, there is no family history of FTD or any other neurological condition. We refer to FTD cases where the cause is not clearly understood as "apparently sporadic FTD." A genetic evaluation should still be considered, as a genetic cause of FTD can be identified in a small percentage of apparently sporadic FTD cases.
- **Familial FTD** – Approximately 40% of people diagnosed with FTD have a family history of one or more blood relatives diagnosed with FTD or a related condition (such as ALS), a mental health condition like depression or anxiety, progressive challenges with language or movement, or another dementia.
- **Genetic FTD** – In a portion of those with familial FTD, a genetic variant (or mutation) can be identified as the cause: an affected parent has passed a genetic variant associated with FTD to their child. All known genetic forms of FTD are inherited in an autosomal dominant manner, meaning the child of a person with FTD has a 50% chance of inheriting the FTD-causing variant. Variants in more than a dozen genes can cause FTD; however, the most common genes are *C9orf72*, *GRN*, and *MAPT*.

ASK FOR A REFERRAL TO A GENETIC COUNSELOR

Your neurologist or the AFTD HelpLine can assist you in finding a genetic counselor or other healthcare professional experienced in the genetics of adult neurological conditions.

FTD OVERVIEW

Life With FTD

There are currently no approved treatments for FTD, but steps can be taken to manage symptoms.

FOLLOW A DAILY ROUTINE

Many people with FTD, as well as their care partners, benefit from following a regular daily routine. Predictable patterns and activities – meals, household tasks, physical activity, hobbies, social interaction, spiritual development, a regular sleep schedule – provide an important framework for both the person with FTD and the caregiver.

Since the course of FTD is unpredictable, both care partners and persons diagnosed should try to remain flexible. While you may not be able to do things as quickly or easily as before, elements of your routine can be adapted to your changing needs and still provide enjoyment. As symptoms progress, however, you may need to discontinue some parts of your routine.

ENGAGE IN ACTIVITIES

It is also important for people with FTD to stay engaged in activities they find fun and stimulating. An activity can be as simple as listening to music or watching the birds outside, as long as it brings enjoyment. If competitive poker or bridge was a favorite social hobby, playing a more casual or simpler version (with fewer rules, if needed) can engage the person, connect them with their past, and provide a meaningful way to interact with others. However, if an activity stops being enjoyable and starts causing frustration as one's abilities change, it is time to reevaluate and adjust.

ADJUST YOUR CAREGIVING MINDSET

Since people with FTD often cannot be expected to change their behavior, care partners and caregivers must adjust their own expectations when it comes to managing symptoms. Confronting a person diagnosed and trying to correct their actions after the fact is usually less successful than trying to prevent these behaviors before they happen. Try to notice what triggers certain symptoms (such as aggressive or disinhibited behavior) and avoid them if possible. Such triggers could include: certain activities of daily living, the presence of other individuals, certain times of day, and specific environmental factors (noisy and/or unfamiliar places, other visual triggers).

AFTD Is Here to Help

You don't have to face the FTD journey without help. AFTD has support groups and educational resources you can use to teach yourself and others about this disease. Visit our website at **theaftd.org**, or contact the AFTD HelpLine at **866.507.7222** or **info@theaftd.org** to learn more.

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AFTD RESOURCES

AFTD Website

- Learn about FTD symptoms, genetics, approaches to care, research opportunities, and updates.
- Sign up for our newsletters and emails to stay informed about expanding research, advocacy, and support efforts.

www.theaftd.org

AFTD HelpLine **866.507.7222 toll-free** or **info@theaftd.org**

AFTD's most important direct service to persons with FTD, care partners, and professionals, the HelpLine is staffed by social workers Monday–Friday during regular business hours.

Diagnostic Checklists

If a friend or family member is concerned they might also have FTD, you can share the checklists AFTD developed to help identify red flags for the two most common types of FTD - behavioral variant FTD (bvFTD) and primary progressive aphasia (PPA). They are available in six languages: English, Dutch, French, Italian, Polish, and Spanish.

AFTD Support Groups

AFTD offers groups for care partners or people diagnosed with FTD that are available in person or online to facilitate peer learning in a safe environment.

Newly Diagnosed Checklist

An FTD diagnosis can be overwhelming in many ways. AFTD's Newly Diagnosed Checklist guides persons diagnosed and their families on steps to take to help adjust to the changes ahead.

Help & Hope

A weekly e-newsletter for people on the FTD journey. Issues provide advice on support strategies, the lived FTD experience, and updates on FTD advocacy, research, and AFTD volunteer opportunities.

Provider Letters and FTD Awareness Cards

Sample provider letters inform healthcare professionals about FTD's symptoms and ways they can help you. Printable FTD awareness cards let others know what FTD is and how it may impact behavior in a public setting.

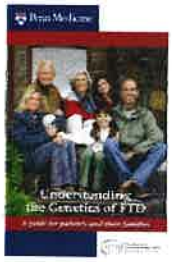
Comstock Grant Program

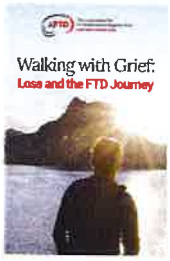
The Comstock Grant Program provides financial assistance to offset the cost of respite for family caregivers and for travel to an AFTD conference. Persons diagnosed with FTD can apply for a Quality of Life Grant for goods or services that enhance their daily life. All grants are $500.

Partners in FTD Care

Developed by clinicians and caregivers, this publication promotes greater knowledge and understanding of FTD and shares best care practices. We encourage you to share these with your healthcare professionals.

AFTD RESOURCES





FTD Documentary and Booklets

The Doctor Thinks It's FTD. Now What?
Learn strategic approaches to an FTD diagnosis and how to prepare for the changes it brings.

It Is What It Is
A documentary and short booklet featuring four families as they confront FTD.

Understanding the Genetics of FTD
Read about the role of genetics in FTD. By AFTD and the University of Pennsylvania Center for Neurodegenerative Disease Research.

What About the Kids?
Helps parents who have children living at home with practical guidance on adjusting to a parent's FTD diagnosis.

Walking With Grief
Discover information, strategies, and first-hand accounts to deal with the grief that may arise with FTD.

Follow Us on Social Media

The Association for Frontotemporal Degeneration

- Join AFTD's Closed Facebook group - members share their experiences with peers: **facebook.com/groups/52543721114**
- Request to join AFTD's "secret" Facebook group for young adults in their 20s and 30s by emailing **aftdfacebook@theaftd.org**.

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What is Frontotemporal Degeneration (FTD)

and how does it differ from Alzheimer's?

FTD is the most common form of dementia for people under age 60. FTD represents a group of brain disorders caused by damage to neurons (nerve cells) in parts of the brain called the frontal and temporal lobes.

1) Different symptoms.

FTD brings a gradual, progressive decline in behavior, language or movement, with memory usually relatively preserved.

2) It typically strikes younger.

Although age of onset ranges from 21 to 80, the majority of FTD cases occur between 45 and 64. Therefore, FTD has a substantially greater impact on work, family, and the economic burden faced by families than Alzheimer's.

3) It is less common and still far less known.

FTD's estimated U.S. prevalence is around 60,000 cases (*Knopman 2011, CurePSP*). Many in the medical community remain unfamiliar with it, so 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.

What are the different kinds of FTD disorders?

FTD disorders can be identified according to the symptoms that appear first and most prominently, whether in behavior, changes in the ability to speak and understand language, or in movement.

Progressive Behavior/ Personality Decline

Behavioral Variant FTD (bvFTD)

Also called:
- Frontotemporal Dementia
- Pick's Disease

Progressive Language Decline

Primary Progressive Aphasia (PPA)

Has three clinical subtypes:
- Nonfluent/Agrammatic
- Semantic
- Logopenic

Progressive Motor Function/ Movement Decline

Corticobasal Syndrom (CBS)

Progressive Supranuclear Palsy (PSP)

Amyotrophic Lateral Sclerosis with FTD (ALS-FTD)

FTD also imposes a more severe economic burden on families: Approximately $120,000 per year, nearly double the amount associated with Alzheimer's, according to a 2017 study funded and co-written by AFTD and published in Neurology.

Where can I find help?

AFTD

The Association for Frontotemporal Degeneration's mission is to improve the quality of life of people affected by FTD and drive research to a cure.

Learn more about the different types of FTD and get connected with information, resources and support by visiting **www.theaftd.org** or connect for specific questions with AFTD's HelpLine: **info@theaftd.org**, and by phone at **1-866-507-7222**.