

it is **WHAT** it is

Frontotemporal Degeneration:
Tragic Loss, Abiding Hope



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

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Frontotemporal degeneration (FTD) attacks and ultimately destroys the parts of the brain that control language, behavior and personality – the very qualities that make us who we are.

Unlike Alzheimer’s disease which primarily affects memory, FTD results in withdrawal from loved ones through losses of empathy, language, the ability to inhibit behavior, and the ability to consider the needs of others.

At this time, there are no medical treatments and no cures for this devastating group of diseases. But there are many reasons for hope.



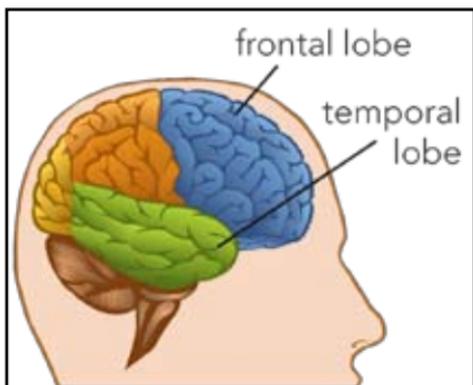
Increased awareness is critical. Early diagnosis, improved access to education, services and supports, and finding a cure all depend on better awareness of FTD.



It Is What It Is introduces viewers to the impact of FTD and challenges them to help change the future for everyone affected by these diseases.

What is Frontotemporal Degeneration?

Frontotemporal degeneration (FTD) is a disease process that affects the frontal and temporal lobes of the brain. It causes a group of brain disorders that are characterized by changes in behavior and personality, language and/or motor skills, and an inevitable deterioration in a person's ability to function.



Terminology about these diseases is evolving. The terms “frontotemporal dementias,” “frontotemporal lobar degeneration” and “Pick’s disease” are also used to describe this group of disorders. While confusing, the changing language reflects the rapid pace of scientific discovery.

FTD at a Glance

- The average age of onset is 56 years (range 20’s-80’s).
- Up to 50 percent of people diagnosed are younger than 65; many are at the height of their professional careers and still have children at home.
- Life expectancy averages 8 years from the start of symptoms, but ranges from 2-18 years.
- FTD accounts for 10-20 percent of all dementias and is nearly as common as Alzheimer’s disease in people under 65.

- Clinical diagnoses include: primary progressive aphasia (PPA), behavioral variant FTD (bvFTD), progressive supranuclear palsy (PSP), and corticobasal syndrome (CBS).
- It is difficult to know with certainty the number of people affected. Most reliable estimates indicate approximately 50,000-60,000 people in the U.S. have an FTD disorder.
- Whereas 50 percent of cases have some family history of similar disorders, researchers have only identified definite genetic mutations in a smaller group, 10 percent of all cases.
- Men and women are affected equally.
- An early age of diagnosis and specific features of the disease can contribute to a greater burden on caregivers than Alzheimer's disease.

Getting a Diagnosis



Obtaining a diagnosis is often difficult because symptoms start slowly and can resemble several other neurological and psychiatric disorders. Bipolar disorder, depression or Parkinson's disease, are common misdiagnoses.

At this time there is no blood test or other single test that can confirm a diagnosis of FTD. Diagnosis requires a comprehensive clinical evaluation including medical, neurological, and neuropsychological tests and brain imaging such as MRI or PET scans.

An experienced clinician can often make a diagnosis with confidence, but some patients see several doctors before FTD is recognized. Frontotemporal degeneration can be diagnosed definitively only upon examination of the brain tissue at autopsy.



Clinical Presentations and Symptoms

Frontotemporal disorders are identified by the symptoms that appear first and most prominently. As the disease progresses, more of the brain becomes involved, affecting additional areas of functioning.

Language Symptoms

People may develop problems with language, including the ability to speak fluently, understand language, read, and write. This is known as primary progressive aphasia (PPA) and there are several forms. Some people become hesitant in their speech and begin to talk less, but appear to retain the meaning of words longer. For other people, the ability to understand words and recognize objects deteriorates but they are still able to speak fluently.

Behavior Symptoms

Behavioral variant FTD (bvFTD), also known as frontotemporal dementia or Pick's disease, is characterized by loss of empathy and inappropriate social behavior. People gradually become less involved in routine daily activities and withdraw emotionally from others. Unusual behaviors may include swearing, overeating or drinking, impulsivity, repetitive behavior, sexually inappropriate behavior or deterioration in personal hygiene habits. The person may show little awareness of these behavior changes and little or no concern for their effect on others.

Movement Symptoms

Two disorders are characterized by problems with motor skills and movement. Corticobasal syndrome (CBS) begins with a decrease in movement on one side of the body and muscle rigidity with a tremor. Progressive supranuclear palsy (PSP) causes problems with control of gait and balance. The inability to coordinate eye movements is a characteristic symptom of PSP. Problems similar to those seen in Parkinson's disease or ALS may also be seen.

Cognitive and Emotional Symptoms

Damage to the brain's frontal and temporal lobes affects complex thinking and reasoning. These problems in "executive functions" affect a person's ability to plan, organize and execute activities, while emotional changes impact relationships. Symptoms may include distractibility, inflexibility, reduced initiative, apathy, poor judgment, and abrupt mood changes. Although memory is usually preserved for a while, some patients have impaired memory later on.

Progression and Increasing Demands of Care

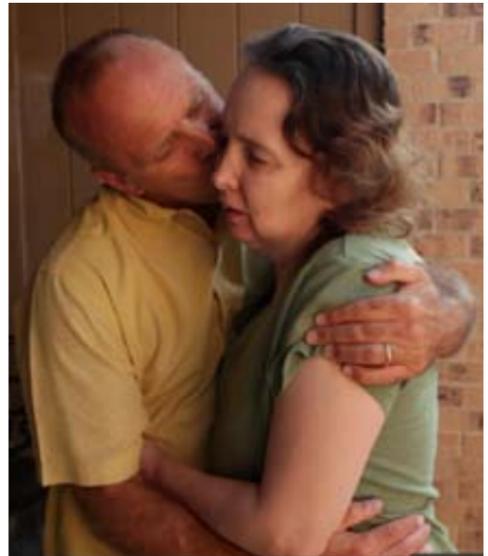


An early diagnosis may allow the patient and family to make important legal or financial decisions together and adjust their plans for the future. When getting a diagnosis is prolonged, this valuable time is lost.

Patients initially may experience symptoms from one area (behavior, language, or movement), but over time many acquire symptoms from the other areas as well. As the disease progresses, people may experience increasing difficulty in their ability to plan or organize activities, interact with others, behave appropriately in social or work settings, and care for themselves.

Many marriages and family relationships are torn apart before an official medical diagnosis is made, and many affected individuals will lose their jobs. The toll of the disease inevitably increases significantly.

The average life expectancy is eight years, but can vary from two to 18 years based on the specific disorder. Variation in the rate and course of progression make it difficult for patients and families to know what to expect.



Research Offers Great Hope

The pace of research into frontotemporal degeneration is increasing rapidly. Scientists are energized by advances in understanding these disorders and the first drugs for FTD are entering clinical testing. It is a time of great activity and great hope.



Funding for continued research is critical. Participation of patients and families in studies is essential. A cure will only be found through partnerships between families and physicians, scientists and funders, and policy makers and the public.

Together We Can Change the Future of FTD

It Is What It Is portrays the devastating loss caused by frontotemporal degeneration. The courage and devotion of these families and all families affected with FTD, compel us to respond.

Get involved. Learn about frontotemporal degeneration and join AFTD in our mission.

Reach out to families who are affected; don't let them face this alone. A simple act of kindness from you may breathe life into their day and brighten their outlook.

Raise awareness through your work, church or school.

Teach health professionals about the needs of individuals with FTD and their families to improve access to appropriate services.

Support AFTD.

Our mission is focused entirely on the care and cure of these diseases.



Visit www.theaftd.org to learn more about frontotemporal degeneration and advances in research.

Potential Uses for This Film



It Is What It Is portrays the impact of FTD on patients and families. The film does not elaborate on clinical aspects of the disorders or address reasons for hope, so it is most effective when presented by someone familiar with FTD.

These powerful images will open the door for discussion. Share it with:

FTD patients and caregivers - While it may evoke poignant emotions, many find comfort and strength in knowing they are not alone.

Family, friends, and colleagues - Show others some of what it means to confront FTD in ways that words alone cannot describe.

Doctors - Primary care physicians and neurologists are the key to early diagnosis.

Health and social service providers - Introduce them to FTD and challenge them to respond to the needs of patients and families.

The public and policy makers - FTD is a rare disease. Advocacy is needed to increase research funding and improve access to services.

To discuss ways to use this film or incorporate it into a presentation, contact info@theaftd.org or 866-507-7222.

About AFTD

The Association for Frontotemporal Degeneration (AFTD) is a not-for-profit organization created in 2002. AFTD's mission includes promoting public awareness of the diseases; providing information, education and support to people diagnosed with an FTD disorder, their families and caregivers; educating health professionals; and promoting and funding research into treatments and ultimately a cure.

For more information visit www.theaftd.org or call 866-507-7222.

AFTD envisions a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.

About thinkfilm, inc.

Joseph Aloysius Becker is a writer, director, producer, and founder and CEO of thinkfilm, inc. (www.thinkfilm-inc.com). thinkfilm has produced hundreds of movie, TV, commercial, and corporate projects and is respected for its work on the Emmy Award-winning series The West Wing and HBO's K-Street. Becker has also directed numerous documentary films for the Discovery Channel on topics as diverse as sharks, Native Americans and a five-part series on the brain.



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