



Fast Facts about Frontotemporal Degeneration

Frontotemporal degeneration (FTD), also commonly referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Picks disease, is a disease process that causes changes in behavior and personality, language and/or motor skills, and a deterioration in a person's ability to function.

FTD is distinct from other forms of dementia in two important ways:

- **Onset of FTD often occurs in a person's 50s and 60s**; the average age of diagnosis is about 57, which is a full 13 years before the average Alzheimer patient is diagnosed. Thus, FTD can affect work and family in a way dementia in older patients does not.
- The hallmark of FTD is a gradual, **progressive decline in behavior and/or language** (with memory usually relatively preserved). As the disease progresses, these deficits cause significant impairment in social and/or occupational functioning and result in an increasing dependency on caregivers.

FTD affects an estimated 50,000-60,000 Americans (Knopman, 2011; CurePSP, www.psp.org).

FTD represents an estimated 10%-20% of all dementia cases. It is recognized as one of the most common presenile dementias (meaning it occurs in a younger population).

The prevalence world wide is uncertain with estimates of FTD amongst people ages 45 to 64 between 15 - 22 per 100,000 (Knopman, 2011).

Frontotemporal degeneration is characterized by progressive atrophy of several different areas of the brain, particularly the frontal and/or temporal lobes, the parts of the brain that control **“executive functions” such as decision-making, personality, social behavior and language.**

Currently, there are no treatments to slow or stop the progression of FTD. However, research is advancing and initial clinical trials are underway.

The course of the disease ranges from 2 to over 20 years, with a mean course of 8 years from the onset of symptoms.

Because of the nature of these symptoms (and the fact that a patient is often “too young” for dementia to be considered), **FTD is often initially misdiagnosed as a psychiatric problem or movement disorder**, such as Parkinson's disease. Alzheimer's disease is another possible misdiagnosis.

Subtypes of FTD are identified clinically according to the symptoms that appear first and most prominently. Clinical diagnoses include behavioral variant FTD (bvFTD), primary progressive aphasia (PPA) which affects language, and the movement disorders progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD).

Accurate diagnosis is crucial, as some medications used to treat other disorders may be harmful in a person with FTD.

Existing care facilities and programs may not be appropriate for—indeed, many do not accept—younger individuals as patients without additional education and support about FTD