

Dear Provider,

Information on frontotemporal degeneration (FTD)

Although I am coming to see you about an issue that may be routine for you or your practice, this letter will help you better understand my diagnosis and some of the challenges I am facing related to living with frontotemporal degeneration (FTD).

What is FTD?

FTD is the most common form of dementia for people under 60. FTD represents a group of brain disorders 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.

FTD differs from Alzheimer's disease in a number of ways. It brings a gradual, progressive decline in behavior, language or movement, with memory usually relatively preserved. 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. FTD's estimated U.S. prevalence is around 60,000 cases (Knopman 2011, CurePSP), 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.

The FTD disorders include: behavioral variant FTD (bvFTD), primary progressive aphasia (PPA) (nonfluent/agrammatic, semantic and logopenic variants), ALS with frontotemporal degeneration, corticobasal syndrome (CBS or CBD), and progressive supranuclear palsy (PSP).

While the disease may present with the symptoms listed below, each individual's experience is highly variable. Specific symptoms and the rate of progression are difficult to predict. At present there are no treatments to slow or stop progression of the disease. FTD often involves:

- Significant changes in behavior and personality
- Loss of empathy
- Decline in executive function (planning, organizing, decision making)
- Poor judgment
- Apathy and withdrawal from favored activities and people
- Inappropriate social behaviors
- Halting speech or difficulty understanding words or sentences
- Motor and movement problems similar to the symptoms of Parkinson's and/or ALS

How you can help

Please consider my care partner and I a team that needs to make choices and decisions together. Some people with FTD are able to express their wishes and participate in care planning with support. Others, however— especially people with impairment in the frontal lobe common to behavioral FTD— may lack the self-awareness and judgment to be reliable informants or independent agents on their own behalf.

In such cases, the individual may not realize there is anything wrong, may appear to be functioning normally and may seem capable of understanding and making choices. **In order to provide me with the best possible care or service, I urge you to:**

- 1. Learn about this most difficult and poorly understood disorder.** Contact The Association of Frontotemporal Degeneration (AFTD) for information about the disease and appropriate care and medical treatments to manage symptoms and maximize functioning. AFTD is a nonprofit organization whose sole mission is to advocate for people affected by frontotemporal degeneration (www.theaftd.org).
- 2. Include my care partner in any decisions about the care or services you are providing.** In order for you to work effectively with me, it is critical that you include my care-partner before any final decisions are made. Without our shared perspective, your recommendations may not be fully informed and follow-through may be jeopardized. Please do not consider any decision as final unless **BOTH of US** have been involved in the process.

Thank you for taking the time to read this, and for the assistance you are providing. This is a very difficult situation and having professionals make an effort to understand FTD is so helpful. Your patience and willingness to spend some extra time learning about this disorder provides a sense of relief – and it is greatly appreciated.

Sincerely,

For more information:

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