

**Dear Provider,**

## **My loved one has frontotemporal degeneration (FTD)**

Although we are coming to see you about an issue that may be routine for you or your practice, this letter will help you better understand our situation and some of the challenges we are facing related to a diagnosis of 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 us

Please consider us 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 us with the best possible care, 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](http://www.theaftd.org)).
- 2. Include me in any decisions about my family member's care or services.** As the primary care partner, it is critical that I am involved in order for you to work effectively with my family member/companion and 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 my loved one and myself. This is a very difficult situation for us and our family. Having professionals make an effort to understand what our family is going through is so helpful to us. Your patience and willingness to spend some extra time learning about FTD give us a sense of relief – and it is greatly appreciated.

Sincerely,

For more information:

[www.theaftd.org](http://www.theaftd.org)

[www.aftdkidsandteens.org](http://www.aftdkidsandteens.org)

[info@theaftd.org](mailto:info@theaftd.org)

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