

In-depth overview of Frontotemporal dementia (FTD)

By: Amy Sobrino, MSW, LSW, Co-founder of Effingham Area Alzheimer's Awareness

In previous articles, we have discussed what dementia exactly is, as well as the many different types of dementia. It's helpful knowing that dementia is an umbrella term that describes a set of symptoms, such as memory loss, personality changes, poor judgment, and language processing issues. We've explored various types of dementia including Alzheimer's disease, Lewy Body dementia, and most recently, vascular dementia. This month's *Memory Moment* focuses on an in-depth overview of Frontotemporal dementia (FTD).

During presentations or conferences, I often start by asking the attendees what they think of when it comes to dementia. I share that when I think of dementia, I think of an older adult who has a progressive dementia like Alzheimer's disease. Symptoms like memory loss come to my mind. Most participants share the same viewpoint and agree with my perception. While this perception does capture a lot of people living with dementia, it does narrow our view of what dementia 'looks like'. This is dangerous because we miss other types of dementia that may affect younger people or have different symptoms. Frontotemporal dementia is one of these types that can look a lot different from other types of dementia.

About 10-20% of all dementias is FTD. This disease typically affects younger adults, most commonly between the ages of 45-64. Although the diagnostic process is not easy for any type of dementia, FTD is especially challenging as it is often misdiagnosed as a different type of dementia. It may take 6 months to 2 years+ to get an official diagnosis. The progression of FTD is usually quicker than a dementia like Alzheimer's, with the average person living 7-9 years after diagnosis.

As the name suggest, Frontotemporal dementia affects the frontal and temporal portions of the brain. FTD itself is an umbrella term, with different variations depending on the area of the brain affected. Beginning symptoms are typically changes in behavior, language, or motor skills – not memory, like other dementias such as Alzheimer's disease. People living with FTD commonly have impaired judgment and impulse control that might result in poor life decisions, affecting areas of life such as finances, work, or relationships. Many families report marital and relationship problems prior to an official diagnosis. As the disease progresses, it is more challenging for a person to continue working successfully, maintain connections/relationships, and remain independent with their routine. Because FTD is a progressive disease, a person needs complete care as the disease continues.

Although there are many differences between dementias like Alzheimer's and frontotemporal dementia, management of these symptoms looks very similar between the diseases. Research has shown that maintaining a good daily routine and having engagement in the form of socialization, activity, and exercises is key. Caregivers also

benefit from dementia specific training to help modify their approach to supporting the person they're caring for.

Much of the information in this article has been condensed from the Teepa Snow: A Positive Approach (www.teepasnow.com) and Association for Frontotemporal Degeneration (www.theaftd.org) websites, which have valuable resources and guidance for families dealing with this disease. Our Forget-Me-Not Resource centers housed in local libraries in Coles, Clay, Cumberland, Effingham, Fayette, Jasper, and Shelby counties, also have valuable books and DVDs devoted to frontotemporal dementia.

For more information about Memory Moment articles & Effingham Area Alzheimer's Awareness, check out their website at www.effinghamalz.org. If you are a caregiver & have specific questions or situations you would like information on, please feel free to call Shannon Nosbisch at 217-663-0010 or Amy Sobrino at 618-363-8372.