




ROAD TRIP

Pennsylvania Department of Aging
Alzheimer's Disease & Related Disorders:
A Focus on Lewy Body and
Frontotemporal dementia



*Ask me about
Frontotemporal dementia...
the other dementia!*





According to the Association for Frontotemporal Degeneration (AFTD), FTD represents a group of brain disorders caused by degeneration of the frontal and temporal lobes of the brain. It is also frequently referred to as Frontotemporal dementia (FTD), Frontotemporal Lobar Degeneration (FTLD), or Pick's disease. FTD's estimated prevalence is around 60,000 cases, and many in the medical community remain unfamiliar with it.





It is vitally important that we recognize Alzheimer's disease as just ONE of the top FIVE dementia related diseases. Respectively, there is Vascular, Frontotemporal, Lewy Body, and Parkinson's disease dementia. These are the less known dementia diseases but equally deserving of my recognition today. As I specifically address Frontotemporal disease, recognize, it is quite different from the other four dementia diseases. Which is why it is quintessential to know which disease is disrupting the life of your loved one.

Frontotemporal dementia differs in three highlighted areas. According to the AFTD, *FTD adversely affects behavior, language, and movement. However, primary memory is usually intact. *Moreover, the age of FTD onset has ranged from 21 to 80, the majority of FTD cases occur in the 45 to 64 age range. Consequently, FTD has a substantial impact on a family's financial status. Consider the ripple affect if you will....the sheer economic burden. *FTD is less common and far less known. It is highly misdiagnosed and typically takes close to 4 years for an accurate diagnosis.

- FAST FACTS...

When you meet one person with FTD; you have met one person with FTD. People vary, so do symptoms.

There is no cure and no medications that slow or stop the progression of the disease.

Life expectancy is approximately 7-13 years after the start of symptoms.

Often misdiagnosed as a psychiatric condition.

Those in the space recognize FTD as a “person diagnosed” versus a “patient.”

FTD primarily causes changes in behavior, personality, language, and movement. Yes, memory is affected.

Unfortunately, symptoms may include: anger, lack of empathy, apathy, poor financial decisions, impulsivity, excessive sweets and carbs, and a lack of filters to name a few symptoms.



According to the CDC and because I behold such a captive audience, I must say, individuals with FTD and the other dementia diseases do experience disparate treatment.

Health disparities can have profound, negative effects on entire populations or individual communities.

Dementia care and support services can vary widely depending on race, ethnicity, geography, and economic factors.

Stigma, cultural differences, awareness, and understanding about the dementia diseases can all be factors leading to health disparities.

Moreover, the ability for a person to get a diagnosis, manage the dementia disease, and be able to access quality health care contributes to health disparities.

Let not the color of one's skin be denied the possibility of being healthy for belonging to a group that has historically been economically and socially disadvantaged.



I have a toolbox with essential tools that help me navigate a given day/night.

What's in your toolbox you may ask?

Hope, a Sense of Humor, Adaptability, Flexibility, Hobbies, Advocacy, Respite, Support System, Intentionality, Word Modification, Legal Documentations, Clinical Trial, Mindset Journey, Exercise, Diet, Sleep, able to differentiate between the disease and the person living with dementia, and finally, He>i.

Is the dementia Journey Easy?

Heavens or H___No!

However, it does become easier as you implement tools from your toolbox into your lifestyle.

**CALL TO ACTION JOURNEY FOR CLINICAL TRIAL
PRINCIPAL INVESTIGATORS & HEALTHCARE
PROFESSIONALS!**



- **Build awareness campaigns around community people & utilization of social media platforms.**
- **Educational workshops discussing dementia and ongoing promotions of brain health.**
- **Brain Health screenings regularly in the community. Train healthcare professionals with cognitive instruments.**
- **All written/print materials must reflect the dominant language(s) of the community.**
- **The clinical architecture must be brought to the community.**
- **Re-examine clinical trial participant exclusionary criteria.**
- **Doctors, PA's , & Nurses: direct families on the dementia journey to local dementia orgs; who can provide resources & time to families. Welcome us!**

- **Workforce development preparation designed to care for racial & ethnic diversity in the dementia space.**
- **Increased diversity among healthcare providers for dementia care to eradicate barriers.**
- **Community relationship building with emphasis on trust prior to clinical trial standup.**
- **Work with governmental leadership & team with businesses & organizations.**
- **Develop Focus Groups driven by the community to ascertain needs.**
- **Advocate for Culturally Competent Services and Support.**
- **Support de-stigmatization, and remember, Words Matter!**



Dr. Debra Tann

Debraondementia.com



229.415.3333

