AFTD The Association for Frontotemporal Degeneration
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FTD Talking Points

- FTD (frontotemporal dementia or frontotemporal degeneration) is the most common dementia for people under 60.
- Onset can occur as early as age 21, with most people diagnosed between 45 and 64.
- The decline happens slowly at first, the length of progression ranging from 7-10 years.
- In the beginning, people often appear physically healthy despite neurodegeneration that is occurring. The most common symptoms are uncharacteristic personality changes, apathy, and unexplained struggles with decision-making, movement, speaking, or language comprehension.
- Approximately 20% of FTD cases are caused by a dozen genes known to cause FTD. We encourage concerned families to speak with a genetic counselor to learn more.
- The most common gene associated with genetic FTD also causes genetic ALS.
- There are five disorders classified as FTD - behavioral variant FTD (bvFTD) and primary progressive aphasia (PPA) are the two most common types.
- FTD’s estimated U.S. prevalence is around 60,000 cases, but experts believe that number is an underestimation.
- FTD is often misdiagnosed as depression, Alzheimer’s or Parkinson’s disease, or a psychiatric condition. It currently takes 3.6 years on average to get an accurate diagnosis.
- There is currently no cure for FTD. However, a growing number of interventions – not limited to medication – can help with managing FTD symptoms and there are clinical trials currently recruiting individuals to test drugs that have the potential to stop or slow disease progression.
- The best way to stay informed about research opportunities, and to provide information to help accelerate clinical trials in FTD, is for people impacted by FTD to join the FTD Disorders Registry at ftdregistry.org.

About AFTD

- AFTD (The Association for Frontotemporal Degeneration), is the country’s leading nonprofit focused solely on FTD. We support families impacted, promote awareness and education, fund research, and advocate for legislative, policy, and regulatory changes to improve the quality of life for people with FTD.
- We are a community-driven organization, and we’re here to help.

Resources

- The Association for Frontotemporal Degeneration: TheAFTD.org
- For guidance and resources regarding FTD, diagnosis, research, care and support, contact AFTD’s HelpLine at 866-507-7222 or info@theaftd.org
- For those concerned that they have or know someone who has FTD, these diagnostic checklists for behavioral variant FTD and primary progressive aphasia can help.