

What to Do About... FTD, the Most Common Dementia Under 60

Frontotemporal degeneration is most commonly diagnosed between the ages of 45 and 64, and is the most common dementia under age 60. Since most people—including healthcare professionals—rarely suspect dementia in people that young, securing a diagnosis can be extremely difficult. And post-diagnosis, younger people and their caregivers face unique challenges, particularly relating to financial management, ensuring safety, and finding emotional support. Following are some strategies to keep in mind if families suspect, or have confirmed, that FTD has become part of their lives.

Tips for Families Pursuing a Diagnosis

- Take detailed notes of unexplained changes in behavior, personality, language, and movement/balance, before consulting with a physician. Be as specific as possible, including when changes were first noted, how frequently they arise, and the ways they negatively impact their ability to function in work, family, and social settings.
- Reevaluate treatments for depression, anxiety, or other conditions if they are not producing benefits.
- Visit www.theaftd.org/for-health-professionals/partners-in-ftd-care and download the “Changes in Behavior Chart” to use as a guide to describing behaviors, as well as the Summer 2017 issue of *Partners in FTD Care*, about challenges in diagnosing FTD.
- Attend doctors’ appointments with the person experiencing symptoms to ensure accurate reporting of concerns. Sit slightly behind the individual during the doctor’s appointment and use nonverbal cues—such as shaking your head—to indicate to the physician that what they are saying is untrue.
- Set up a conversation with the doctor in which the person affected is not present. Your notes will come in handy here.
- Ask for a referral to a specialist—for example, a behavioral neurologist familiar with FTD. In rural areas, there may be more neuropsychologists available than neurologists; a psychiatrist or geriatrician may also be helpful.
- Advocate for a comprehensive diagnostic evaluation.
- Take action to address risky behaviors and ensure safety as needed while pursuing a diagnosis.
- Visit AFTD’s website and contact the HelpLine for individual information and guidance.

Diagnostic Information for Healthcare Providers

- Learn the signs and symptoms of FTD, the most common dementia in people under 60.
- Listen. Tune in to what the individual and their family members think and feel about the situation. Understanding their history of symptoms and changes in their behavior is essential for accurate diagnosis and proper care.
- Learn the diagnostic criteria for behavioral variant FTD, primary progressive aphasia, and the related movement disorders of PSP and CBS.
- Know that people with ALS often experience cognitive impairment, and that some people with ALS fit diagnostic criteria for FTD as well.
- Refer the person affected for a neurological evaluation or to an FTD specialist if they show “red flags” for FTD. Do the same for people who are being treated for depression or midlife crisis who show no improvement or worsening symptoms.
- Learn common misdiagnoses: bvFTD is often mistaken for depression, bipolar disorder, a personality disorder, drug or alcohol dependence, late-onset schizophrenia, or other dementias.
- Refer patients with suspected FTD to multi-disciplinary specialty centers with experience in FTD for further testing and diagnosis.
- Help families access timely referrals and necessary resources for evaluation and post-diagnosis support and care planning. The period before diagnosis and immediately after are extremely challenging and overwhelming for families.
- Visit AFTD’s website—specifically the section “For Healthcare Professionals”—if you are not familiar with FTD. Contact the HelpLine for individual information and guidance.

Ways Families Can Provide Emotional Support to the Person Diagnosed

- Adjust your expectations of the way the person diagnosed performs activities or tasks that they once found easy. Do not rush them or point out if they are doing something incorrectly.
- Create a productive daily routine with individualized activities based on the person's interests and current abilities. Include a variety of activities (gardening, walking, painting, etc.). Following a predictable routine benefits both the person with the disease and their care partners.
- Pay attention to noise and stimulus levels. People with FTD have difficulty processing too much sensory stimulation and may become confused or overwhelmed.
- Allow ample time to rest.
- Consult with an occupational therapist (OT) to complete a functional assessment and identify strategies to promote activity engagement as interests and abilities change.
- Create an individual plan: when to engage in a particular activity, how to set it up, how to simplify steps to complete it, and how to monitor it safely.
- Begin an activity with the person and stay with them until they are engaged. A person with FTD cannot always initiate an activity, but once started, they may independently continue.
- Modify past interests to reflect the current level of ability, e.g. if they enjoyed playing basketball, provide a small basketball hoop.
- Be creative. The more personalized the approach, the more effective it will be.

Financial Considerations in FTD

- Recognize that making unwise financial decisions is very often one of the first signs a person may have FTD. Understand that it is not the person but the disease causing poor judgment, impaired planning, and disinhibited behavior.
- Monitor financial accounts. Set up alerts on unusual spending. Watch for repetitive or compulsive behaviors such as gambling, purchasing unusually large amounts of certain items (from cartons of ice cream to cars), or excessively generous charitable giving.
- Secure the family's financial safety by limiting access to credit cards, money, and the internet. Use rechargeable gift cards or credit cards with low credit limits to monitor and limit spending.
- Request medical leave from a human-resources representative (if the person is still employed and is undergoing a diagnostic evaluation) to protect them from losing disability or retirement benefits.
- Coordinate with the person's accountant and/or partners if they are self-employed or own a family business.
- Complete legal forms, including durable power of attorney, healthcare power of attorney and advance directives.
- Educate financial institutions (and the person's financial advisor, if applicable) on FTD, and investigate possible checks and balances that can be placed on accounts.
- Encourage use of AFTD's Provider Letter as a template to personalize to inform key stakeholders of the situation and request assistance. Download the Provider Letter at www.theaftd.org/living-with-ftd/resources.