

CHALLENGES IN DIAGNOSING FTD

There are multiple challenges to diagnosing FTD in a timely way. The doctor must know the full context of the individual's behavior and language changes, and be aware that not all dementia is Alzheimer's disease. Ensuring that these challenges are met often requires advocacy.

CONVEYING CONCERNS TO DOCTORS

- Know the warning signs of FTD. [See the sidebar on page 2.] Many language and behavior symptoms of FTD overlap with other disorders such as depression, anxiety, bipolar disorder, Parkinson's or Alzheimer's.
- Have a family member or friend go along to doctors' appointments. Because the person affected may not be aware of their changing behavior, input from another "informant" is important.
- Speak up. Patients and families may be uncomfortable challenging a doctor who says there's nothing wrong. You know the person best and are their advocate.
- Write down troubling changes and when they started. The evolving history of symptoms is important for diagnosis. The individual, along with their co-workers, family and friends, may each notice something that seems odd, but not have the full picture.
- Give specific examples of how changes in the person's behavior have negatively impacted their ability to function in work, family and social settings. Examples: a professional chef who is unable to complete a familiar recipe, or a financial advisor who becomes frustrated and angry balancing his personal checkbook.
- Tell the healthcare provider when symptoms do not improve, or continue to get worse, with a prescribed treatment. Initial diagnoses are often incomplete.
- Be persistent when conveying that something seems seriously wrong with the person's ability to function as before.
- Ask for a referral to a specialist. Look for a behavioral neurologist who is familiar with the range of neurocognitive disorders, including FTD. In rural areas, there may be more neuropsychologists available than neurologists; a psychiatrist or geriatrician may also be helpful.
- Learn about the tests used in a comprehensive evaluation to understand how the doctor determines a clinical diagnosis. Visit the Evaluation and Diagnosis page on the AFTD website for more information.
- Seek a second opinion with an expert; consult the AFTD website for major FTD research centers, or contact the HelpLine (info@theaftd.org or 866-507-7222) for other resources.
- Coordinate care for treatment even while you are clarifying the diagnosis. Address the symptoms that are most troubling or urgent while pursuing a diagnosis.

ANOSOGNOSIA: WHEN THE PERSON AFFECTED DOES NOT SEE A PROBLEM

Anosognosia is a lack of awareness of one's own condition. It can be a symptom of FTD. The person with FTD is not being manipulative or deceitful; they are simply unaware of their changing behavior, which complicates evaluation and diagnosis. In such a case:

- Go with the person to all doctors' appointments.
- Arrange to talk with the doctor apart from the patient. (This is particularly important if the doctor knows about FTD.) Send a note to the doctor prior to the appointment, or pass a note to a nurse during the visit indicating that you want private time with the doctor.
- Be creative and persistent. The doctor may resist family efforts to speak alone, as insurance reimbursement policy dictates the patient must be present for a doctor to bill.

- Stand or sit behind the person affected in the exam room to mime disagreement with the person's reported history.
- Leave the doctor a list detailing how the person is functioning in daily activities.
- The person with FTD often sees a clear bill of health from the doctor as proof the caregiver is the problem. People with FTD are more likely to remember prior evaluations and resist the caregiver's efforts for additional evaluation. It is important that family caregivers have support.
- Consider creative, indirect ways to have the patient seen by a doctor if they resist. Enlisting the doctor's assistance ahead of time, schedule an appointment for another family or friend, and ask the person affected to help that person go to the appointment. Some individuals will agree to see the doctor "to keep insurance benefits" or to refill medications they take for another condition. Keep the explanation as simple as possible.

AFTER THE DIAGNOSIS

- Create a care team of healthcare practitioners, including a primary care physician and a neurologist, psychiatrist or geriatrician familiar with medications for dementia's behavioral and psychological symptoms.
- Use information from the evaluation to guide care. Brain imaging and neuropsychological exam results can identify areas of intact and impaired thinking.
- Visit AFTD's website and sign up for newsletters and updates on resources, supports and FTD research.
- Contact the AFTD HelpLine (info@theaftd.org or 866-507-7222) for information, or to ask trained staff your questions about the disease, managing care and maintaining quality of life.
- Learn about FTD (and, if identified, the particular subtype: behavioral variant FTD, primary progressive aphasia, etc.) and the functions of the frontal and temporal lobes of the brain to understand changes in behavior, language and motor skills.
- Connect with FTD-specific support. In the absence of treatment to slow progression, support from peers provides emotional support, problem-solving and access to resources.
- Sign up with the FTD Disorders Registry to stay current with the latest research and to learn about opportunities to participate in studies.
- Encourage collaboration and education.
- Request that the diagnosing physician send a copy of the evaluation summary to any doctor who saw that patient previously, to educate those not aware of FTD and improve referral to specialists.
- Delays in diagnosis and misdiagnoses may leave caregivers frustrated, angry and mistrusting of treatment recommendations. It may require time to develop trust.
- Encourage doctors and community providers to sign up for AFTD's *Partners in FTD Care* newsletters by emailing partnersinFTDcare@theaftd.org.
- Follow up with the original doctor(s) with information from AFTD about warning signs, clinical criteria and differential diagnosis to help them be better prepared next time.

Be persistent when conveying to the doctor
that something seems seriously wrong.

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