

WHEN THE DIAGNOSIS DOESN'T FIT: CHALLENGES IN DIAGNOSING FTD

INTRODUCTION

Dementia is often missed as a possible diagnosis for a younger person presenting with changes in mood or behavior. Early symptoms of frontotemporal degeneration (FTD) may overlap with conditions such as depression, Parkinson's disease or bipolar disorder and lead to an incorrect diagnosis.

A person developing FTD may not be aware of their changing behavior and therefore may communicate ineffectively with doctors. The individual may continue with unhelpful treatments—or, alternatively, fail to follow up with doctors entirely—until a crisis in employment, in family life or in the community prompts further evaluation.

The role of a savvy informant (a family member, significant other, close friend) is therefore critical to ensure accurate diagnosis of an FTD disorder. Misdiagnosis causes the loss of precious time to plan properly for FTD, compounding the negative impact on the person and family. Awareness of the hallmark symptoms of FTD and access to appropriate care and support are essential to improving quality of life for persons diagnosed with FTD and their families.

THE CASE OF MR. P

BACKGROUND AND EARLY CHANGES

Mr. P grew up in a small town. After leaving to serve in the armed forces, he returned to his wife Jane and baby girl Eva. He worked his way up to manager in a large local clothing store, and was active in the church. Mr. P was well liked and respected in town, and was known as a principled, quiet man who enjoyed long walks. He and his wife had a close marriage. His family had mostly moved away from the town by the time they'd settled there. Jane's family, meanwhile, lived in Europe, where she was originally from.

When Mr. P was 46, he was laid off from his job. He told his wife the store was downsizing. She was concerned about his unemployment, but did not press him for details. He started working from home, turning his hobby of personal investing into a small business, with friends from around town and from church as his clients.

Jane started to notice changes in his behavior. For example, sometimes when she began to tell him about her day at work, he would just walk off. He started taking long, rambling walks, often to other towns, without telling Jane, who would be unable to reach him. The first time this happened, she called the police after he'd been missing for six hours, fearing something might have happened to him. He turned up after a day, seeming unconcerned that he had caused such worry. He was vague about where he had been and told her he "got a ride" back. He did not explain why he left without telling her, or why he never got in touch.

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WHY DIAGNOSIS MATTERS

FTD and related neurological disorders are among the most difficult conditions to diagnose. Their symptoms can overlap with other illnesses such as depression, bipolar disorder, Parkinson's disease, or Alzheimer's disease. While research into diagnostics is advancing, there are not yet any tests that can identify FTD with certainty during the patient's lifetime. The doctor must make a determination based on the person's history, presenting concerns and the results of neurological, neuropsychological and brain imaging tests. A specialist can often make a diagnosis with confidence based on a comprehensive clinical evaluation, but it is generally difficult to get a clear diagnosis from community physicians or psychiatrists.

For many reasons, pursuing a referral to a specialist and comprehensive testing can be burdensome for the individual and their family. They may be uncomfortable challenging a doctor's opinion. The person with the disease may not realize their behavior has changed and may feel that evaluation is unnecessary. Many parts of the country lack a nearby doctor with sufficient expertise. Comprehensive testing may require long travel over multiple appointments, and it can be expensive without being definitive.

Nevertheless, a diagnosis that identifies the specific type of dementia has important explanatory value—especially in FTD.

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Jane grew concerned that her husband's behavior might be due to depression over losing his job.



Accurate diagnosis can guide:

- Prognosis and knowing what to expect.
- Planning for appropriate, effective care, such as therapies, behavioral interventions, and medications.
- The possibility of being involved in research.
- Progress toward a better understanding of the disease and the needs of those diagnosed.

Many people with FTD and their families feel a sense of relief when they get a diagnosis that explains their experience. However, healthcare providers are not always correct. When close family feel a diagnosis does NOT resonate with their experience, it is important to seek a second opinion or ask that the person be seen by a specialist.

Of course, a diagnosis is only the first step. It is essential that people diagnosed with FTD also receive information and resources that will allow them to learn about the diagnosis. They should also get assistance in developing a care team to support them over the course of the disease.

WARNING SIGNS OF FTD...AND THE IMPORTANCE OF EARLY DIAGNOSIS

Accurately diagnosing FTD disorders can be a challenge, even for seasoned physicians. The doctor must collect an accurate history to understand development of the concerns in the context of the particular person's life. People with behavioral variant FTD in particular can sound and seem reasonable and can comport themselves well during a short doctor's visit, even in the face of conflicting testimony from loved ones.

A close family member or friend should go to appointments with the symptomatic person as an informant, to describe their uncharacteristic changes. This may feel forced and imposing, especially earlier on, when functional changes may not be obvious to others. But it's important. If there is no informant, doctors are unlikely to get an accurate history, which can delay diagnosis.

Changes that can be warning signs of FTD include:

BEHAVIORAL CHANGES:

- Apathy, reduced motivation, or decrease in activities or social involvement.
- Decrease in empathy, indifference toward the feelings of family and friends, or unresponsiveness to a family member's distress.

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Jane grew concerned that her husband's behavior might be due to depression over losing his job. He agreed to see a psychiatrist and was placed on an antidepressant. While Mr. P's behavior still seemed different to her, he did not complain of feeling depressed, nor did he seem particularly sad. He continued to take long walks, however, and seemed uninterested in his family and his church. Jane assumed full childcare responsibilities while still working. She worried that he might be having an affair, leading her to become depressed and anxious, though she'd always been an upbeat and positive person. She felt alone in her husband's hometown, so far from her own family.

One day, Jane overheard her husband take a business call from a client. She was horrified to hear Mr. P offering the client an "investment opportunity" that sounded to her like a scam—and even more horrified to hear that he himself had invested in this scam. She went to the bank to discover that their savings account had been cleared out. When she confronted him, he seemed indifferent to the fact that their life savings were now tied up in worthless land in another state. He also seemed not to care that he had done this without consulting his wife.

DEPRESSION OR SOMETHING ELSE?

At this point Jane started worrying that something besides depression or another woman was affecting her husband; she wondered if he had a brain tumor. She was embarrassed about what people in their small town, especially his clients, might be thinking, and she prayed that they were not listening to his financial advice.

She asked her husband to see his doctor. Upon his return, Mr. P said he "checked out healthy." Jane followed up by calling her husband's doctor herself to report that he had been acting out of character, but the doctor assured her that everything seemed fine. Jane grew a little more frantic and questioned whether there was something wrong with *her* judgment. Nevertheless, she scheduled her husband to see a neurologist in the nearest city. She accompanied him on the two-hour journey but did not sit in on the appointment. The neurologist found Mr. P's mental status testing and neurological examination to be normal. A brain scan revealed no strokes or tumors to explain his change. The neurologist suggested that he follow up with his psychiatrist for better treatment of his depression.

By age 49, Mr. P had stopped his financial-planning business; Jane had noticed that he began having trouble recognizing who he was talking to on the phone. He was becoming more withdrawn, and spent a lot of time picking up sticks in the yard. On his walks,

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which were now becoming more circumscribed, he started gathering feathers and broken glass; the house grew increasingly cluttered with these collections. His hygiene suffered. Eva, now in high school, stopped bringing friends over. She and her mother were both bewildered by his behavior, but Eva was also angry at her mother for “putting up with him,” and started rebelling.

A DIAGNOSIS WITHOUT EXPLANATION

Jane was getting more worried about leaving her husband alone while she was at work. At another visit to the doctor, Mr. P was referred for neuropsychological testing, also two hours away. Mr. P and Jane both attended that appointment. In most of the tests, he scored within normal range, except for a slightly lower-than-expected performance in attention and some executive function tasks.

On their own the test results were inconclusive. But, combined with the information Jane provided about her husband’s history, the results convinced the neuropsychologist that Mr. P should be re-evaluated by a neurologist. Mr. P complained about making another long trip for tests he did not think he needed, but at Jane’s urging, he agreed to go.

The neurologist reviewed his previous brain scan, and, without providing any information or counselling about the disease, diagnosed Mr. P with frontotemporal dementia (another name for behavioral variant FTD). Jane left with no guidance about what FTD entailed, what to expect or how to plan, and there was no follow-up appointment scheduled.

Jane asked friends and neighbors to stay with Mr. P while she worked, and sometimes she brought Mr. P with her to her job. Everyone was very kind, since they knew and remembered Mr. P, and they recognized that he now had a disease that changed his behavior.

At age 52, Mr. P started walking around the house naked, even in front of neighbors and his daughter. This behavior was particularly difficult for Jane to understand and to manage. While she knew he had FTD, she did not know if there were any medicines or treatments for his troubling behaviors.

Jane contacted neurologists at the hospital of a large regional medical center 90 minutes away for advice. The doctor confirmed Mr. P’s diagnosis, but did not offer any helpful treatments or advice. Not long after that appointment Jane made the difficult decision to place him in a nursing home, with financial help from Mr. P’s family and church congregants. Jane and Eva were able to start repairing their relationship, and visited Mr. P regularly. The nursing home staff knew Mr. P’s diagnosis but had not served anyone with FTD before.

His disease progressed to a severe stage; he could no longer communicate verbally. Nearly two years into Mr. P’s stay, a researcher visited the nursing home. While Mr. P could not participate in the study, Jane appreciated the opportunity to speak with someone with experience and an interest in FTD.

Two months later, Mr. P died suddenly. No autopsy was performed. Jane reported that his death left her with an empty loss that was worse than having him alive, even though he was no longer the person he had been.

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- Disinhibited behaviors: doing or saying rash things, approaching strangers, making sexually inappropriate jokes, doing/saying things that embarrass you, making ill-advised purchases, etc.
- Compulsive behaviors: eating only certain foods, walking certain paths, following a rigid routine, hoarding certain items, repeating “catchphrases,” rubbing hands, folding and refolding laundry, etc.
- Changes in eating: eating a lot more, craving certain foods (especially sweets or carbohydrates), attempting to eat non-food items.
- Criminal behaviors such as shoplifting or fraud.
- Changes in mood including feeling more anxious, suspicious or depressed.
- Changes in judgment and decision-making.
- Decreased attention to personal appearance and self-care.

LANGUAGE CHANGES:

- Hesitant, more effortful speech.
- Speech that sounds weak or imprecise.
- Difficulty generating or recognizing familiar words.
- Making word or sound substitutions, like *fable* for *table* or *sheep* for *cow*.
- Difficulty understanding common words or understanding others when they speak.
- Uncharacteristic trouble with grammar or spelling.
- Any increase or decrease in speech output.

MOTOR CHANGES:

- Tremors.
- Slowness or rigidity in gait.
- Trouble with balance, unexplained falls.
- Muscle weakness.
- Unusual positioning of hands, arms, legs.
- Incontinence.
- Changes in sexual function.



Questions for Discussion

What changes in Mr. P caused Jane to feel this was different from depression?

It is not uncommon for unexplained symptoms to be diagnosed as a mood disorder, such as depression. But increasingly Jane became aware of uncharacteristic behavioral changes that made her question the initial diagnosis. Mr. P took frequent long walks without telling her where he was going. His judgment declined; he fell prey to a real estate scam and jeopardized their future finances. He showed a notable lack of concern for Jane's emotional needs: specifically, her anxiety over his health and Eva's rebellion. Once depression was established as the diagnosis, there was a tendency to ascribe all Mr. P's unexplained changes to it, and to simply continue treating him as a depressed person. But Jane did not sense depression in Mr. P, and he never complained about being depressed himself.

What did Jane do that facilitated getting the diagnosis?

Her concerns persisted as Mr. P's behavior continued changing and the ongoing treatments for depression did not help. After recognizing that he had fallen for a scam, she followed up with the bank and confirmed their savings were gone. She noted the increasingly odd collections of sticks, feathers and broken glass, and his poor hygiene. She was upset by Eva's angry rebellion. Jane tried repeatedly to find other medical explanations, but the doctors saw no obvious issues in brain scans or neurological exams, and were unfamiliar with FTD. Finally, she attended a neuropsychological exam and shared with the doctor the history of Mr. P's symptoms. She reflected on the past: Five years ago Mr. P was a manager of a store, and things had progressed to where he no longer took part in any goal-oriented activity and instead collected animal parts. Together these pieces prompted referral to a neurologist who recognized and diagnosed FTD, but who provided Jane with no education or information about the disease.

What particular evaluations helped to make the diagnosis of FTD?

Over the years, Mr. P had a variety of mental status evaluations and brain scans to look for stroke or tumor. These were all within normal limits. While the neuropsychological testing was within normal range in most areas, it detected a slightly lower-than-expected performance in attention and some executive function tasks. This finding, together with the history of Mr. P's symptoms that Jane provided, prompted referral to a neurologist with more experience reading brain scans. He was able to detect subtle changes or atrophy in frontotemporal regions that indicated FTD.

How did the delay in getting a diagnosis affect Mr. P and his family?

Mr. P's relationships with Jane and Eva were negatively affected by his unexplained loss of interest in them. Eva thought her mother was weak for "standing by her man" as his behavior changed. The progressive nature of the undiagnosed and incorrectly treated symptoms over time contributed to Jane experiencing depression and anxiety. His declining judgment compromised the family's finances, which Jane could have kept safe had she known what to expect with FTD. There was no opportunity to plan for care needs outside of the home since Jane was not aware of how FTD's progressive nature might present itself over time. While neighbors and friends came to understand that Mr. P was ill, the family never had support from anyone who was familiar with FTD and could have helped them understand and prepare for his changes.

OTHER COGNITIVE CHANGES:

- Trouble making and carrying out plans.
- Difficulty sustaining and redirecting attention.
- Decline in judgment and decision-making.
- Trouble with problem-solving.
- Getting lost in familiar neighborhoods.
- Not knowing what to do with familiar objects.

Thinking back, is the individual's functioning the same as before? If the person is working, can they still perform all their duties as well? Can they manage finances? Can they cook, shop, and/or dress themselves? When did changes first appear?

Does the person diagnosed with depression look sad or cry frequently, or seem happy or content? Do their symptoms improve during treatment for depression? Does the condition that has been diagnosed typically begin at this age? Bipolar disorder or schizophrenia typically start in young adults.

FTD symptoms, which can overlap with psychiatric and other disorders, often lead people to doctors and treatments that may not be helpful and delay understanding of the true challenge.

On average, it takes 3.6 years to get an accurate FTD diagnosis. Delays compound the potential negative impact of symptoms and changes due to the disease. Delays can disrupt relationships, sometimes leading to divorce because of confusing or hurtful changes in a partner's behavior. Employment is jeopardized when declining job performance leads to termination before FTD is identified as the cause. And the best opportunity for the person with the disease to participate in legal and financial planning is in FTD's early stages.



Empowering people who are possibly facing FTD to advocate and share information effectively with healthcare providers can improve the overall diagnostic experience.

FINDING A PHYSICIAN WITH EXPERIENCE IN FTD

Many primary care physicians and community neurologists are uncomfortable making a diagnosis of FTD. Given FTD's uncommon nature—notably its often young age of onset—and the implications of an incorrect diagnosis, it is good to ask for a referral to a specialty center in cognitive disorders for evaluation if FTD is suspected or other diagnoses do not adequately explain the symptoms. Most of these centers are directed by neurologists, though an interested geriatric psychiatrist or geriatrician may also be appropriate. Psychiatrists are helpful when behavioral or emotional problems are predominant. Geriatricians are desirable for older FTD patients with concurrent medical comorbidities.

Neurologists and behavioral neurologists who specialize in the diagnosis and/or clinical care of FTD are rare. AFTD lists US and Canadian medical centers on its website by geographic region (www.theaftd.org/get-involved/regions). Many of the centers listed are directed by a neurologist and will have medical staff, including neurologists, with a special interest in FTD. These centers are devoted to understanding FTD and related diseases, and are engaged in research into the causes and potential treatments. They are among the most experienced in diagnosing the disease. These centers primarily see patients for an initial diagnostic evaluation or second opinion with subsequent appointments often based on enrollment in a research project. They may not offer routine office visits or provide ongoing clinical care.

Physicians with experience in FTD are even harder to find in rural or underserved areas. Neuropsychologists can be a good resource; they may be more accessible than neurologists in some areas.

The best way to find a local physician and other professionals with experience in FTD is through networking. Contact the AFTD HelpLine to see if staff are aware of a doctor in your area. While AFTD does not endorse or recommend local doctors, this information can provide a starting point for your search. Information about local resources may be available through an FTD support group facilitator. Contact information for facilitators is listed on AFTD's Regional Resources page.

Managing FTD symptoms is a challenge. A person with FTD and their family members are served best by developing a collaborative working relationship between a primary care physician and a cognitive/behavioral neurologist or psychiatrist, along with a neuropsychologist with expertise in non-pharmacologic modes of behavior management. Resources for healthcare professionals (www.theaftd.org/understandingftd/healthcare-professionals) are available on AFTD's website, including diagnostic criteria for behavioral FTD, subtypes of PPA, relevant medical journal articles and a downloadable "Primer on Frontotemporal Dementia" from the University of California, San Francisco. AFTD's booklet, *The Doctor Thinks It's FTD. Now What?*, gives physicians a resource to give to families as a starting place.

Partners in FTD Care Advisors

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts and family caregivers. Advisors include: Sandi Grow, RN, caregiver • Lisa Gwyther, LCSW, Duke Family Support Program • Barbara Harty, GNP, UNTHSC • Susan Hirsch, MA, HCR ManorCare • Jill Shapira, PhD, RN • Rebekah Wilson, MSW, Alzheimer's Tennessee

AFTD extends special thanks to this issue's special guest contributor, Maya Lichtenstein, MD, MHSc, a behavioral neurologist with Geisinger Health System in Pennsylvania. Dr. Lichtenstein works as part of a multidisciplinary team that diagnoses and cares for patients with dementia and their families.

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WORKING PRODUCTIVELY WITH FAMILIES WHO HAVE BEEN FRUSTRATED BY DELAYED DIAGNOSIS

Q: A 58-year-old man with behavioral FTD moved into our dementia assisted living community last month. The staff is steadily getting to know him. His wife is having a more difficult time with the adjustment. She resists the administrator in care planning meetings, refuses to consider medication changes, and corrects everything the residential staff does. How can we build a good partnership with her?

A: Creating a positive working relationship starts with understanding the experiences of the family in obtaining a diagnosis, an arduous journey that can strain relationships and cause emotional damage.

Family members of people with FTD—especially significant others—often carry frustration, anger and guilt that is difficult to express or even acknowledge. The symptoms that change a loving confidant into a stranger can leave families feeling confused and hurt. Repeatedly arranging evaluations that lead to misdiagnoses and unhelpful treatments is physically and emotionally grueling. Interactions with healthcare professionals can be frustrating: Physicians unfamiliar with FTD may refuse to meet with family members without the patient present, and may discount their concerns if they cannot directly observe them in limited contact with the patient. Doctors may even blame the caregiver for causing problems in the relationship. When families finally find a doctor who is aware of FTD and can confirm the diagnosis, they are too often given little help or support.

While diagnosis can provide momentary relief, it is typically followed by more frustration and anger. Family members may project their anger onto the person with FTD, which can add to feelings of guilt for not being more understanding or patient with an ill person. They may also direct anger at physicians and other providers.

After an FTD diagnosis, healthcare providers have an opportunity to help the person and their family build a foundation for the best possible care and quality of life. To

capitalize on this opportunity, providers should be aware of possible anger and frustration with the healthcare system. Identify the person most able to develop rapport with key family caregivers. Allow these family members to express anger and frustration with the diagnostic process and with the lack of care available. Spend extra time with them and make sure staff is responsive to their needs in order to build trust.

In the scenario outlined by the question above, the administrator reached out to the resident's wife when she visited, outside of care planning meetings. In a series of visits over coffee, the woman described her husband's uncharacteristic behavior over the course of several years, which involved embarrassing incidents with family and friends, an accumulation of debt, theft and an affair. They visited seven doctors in over three years, but no one could adequately explain his behavior, and none of the drugs he tried for depression, anxiety, and bipolar illness worked to curb it. Three of the doctors they had seen said that, based on behavior, something might be wrong with his frontal lobe, but they were at a loss as to his specific diagnosis. A referral to a specialist at an academic medical center finally identified FTD.

Over the course of several relaxed conversations, she said she felt anger at her husband because of how he treated her and the family, leaving her with serious legal and financial issues; she also felt guilty for this anger. She resented the doctors for failing to diagnose him sooner. His eventual diagnosis was a relief, she said, but because it came after he lost the ability to communicate, she felt cheated. And above all she felt stress of managing his care while supporting their three children.

Gradually, she began to trust the facility administrator and staff, and care planning became more collaborative. She got connected to AFTD and began to participate in a local FTD caregiver group. Ongoing mutual support from peers gave her the opportunity to learn care-management tips, process her emotions, and share her experiences to help others.

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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