

Not Too Young: The Most Common Dementia Under 60

Introduction

While dementia is popularly seen as a condition exclusively impacting the elderly, people in their 50s, 40s, 30s and even younger can be diagnosed. The most common dementia affecting people under the age of 60 is frontotemporal degeneration (FTD), which can cause drastic behavioral and personality changes that can

negatively disrupt one's family life, employment situation, and sense of self. Securing an accurate FTD diagnosis for someone under 60 can also be a struggle, as healthcare professionals may not think of dementia at such a young age. The case of José G., who is not yet 50 years old, highlights many of the challenges that behavioral variant FTD can impose on a relatively young family.



The Case of José G.

For years, José G. was a popular figure in his rural Nevada hometown. Elected to several terms as county medical examiner, José seemed to be on a first-name basis with everyone he met in public. He and his wife, Marlana, both in their late 40s, have three children—two sons away at college, and a daughter in high school. Between José's elected position, his job as a hospice nurse, and his wife's real estate job, the couple earned a comfortable living. They enjoyed eating at nice restaurants and spending time with friends, waterskiing at a nearby lake. José volunteered at church and kept in excellent physical condition, running half-marathons several times a year.

Three years ago, José and Marlana went on a cruise to celebrate their 25th wedding anniversary. They seemed to be the youngest people on board by two decades, but they were determined to have fun. So while Marlana thought it odd that José, who typically does not like drawing attention to himself, entered a dance contest, she didn't think too much of it—that is, until José started to disrobe during his routine, eventually stripping to his underwear. The performance was a hit—José even won a trophy—but Marlana was disturbed by how uncharacteristically he had behaved. Her husband was a gregarious person, but hardly an exhibitionist. A woman Marlana met on the cruise made a joke about "liquid courage," but José was a teetotaler and had not drunk a drop of alcohol all night.

The strange behavior continued after the trip. While driving, José would drift into the left lane. Marlana, sitting in the passenger seat, would cry out in fear, but José seemed not to care. He started forgetting words for everyday items—the coffee pot, the toilet plunger—and, while speaking, would frequently trail off mid-sentence. At one point, the couple went out to eat at a restaurant with friends, and José, seemingly upset that the server did not clear the table to his liking, snapped, "Hey, are you too good to pick up our damn dishes?" The rest of the party was mortified.

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FTD OVERVIEW

Frontotemporal degeneration (FTD), which refers to a group of progressive neurological diseases affecting the brain's frontal and temporal lobes, is the most common cause of dementia for people under age 60. The FTD disorders are characterized by gradual deterioration in behavior, personality, language, and/or movement, with memory usually relatively preserved. FTD may also be referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Pick's disease.

Clinical FTD diagnoses include behavioral variant FTD (bvFTD), primary progressive aphasia (PPA), corticobasal syndrome (CBS), progressive supranuclear palsy (PSP), and ALS with FTD. Specific symptoms and the course of disease can vary significantly across individuals, even within the same subtype.

Although age of onset can range from 21 to 80, the majority of FTD cases occur between 45 and 64. The young age of onset substantially increases the impact of the disease on work, relationships, and the economic and social burden faced by families.

FTD is frequently misdiagnosed as Alzheimer's disease, depression, Parkinson's disease, or a psychiatric condition. On average, it currently takes 3.6 years to get an accurate diagnosis. There are no cures or disease-modifying treatments for FTD, and the average life expectancy is 7-13 years after the start of symptoms. ■

first cousin was diagnosed with Alzheimer's in her early 50s, and while her symptoms were significantly different, Marlana couldn't shake the feeling that her husband's brain was changing. José, however, denied that he was acting differently, and seemed uninterested in his wife's concerns. Marlana began taking notes on all of José's new behaviors. She gently suggested that he see a doctor about these changes, but José remained adamant that he was fine. This lack of self-awareness of his behavior was especially troubling to Marlana. [This lack of awareness, known as anosognosia, is a common symptom in FTD. For more information, see the Winter 2019 issue of *Partners in FTD Care*.]

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Eventually, José went for his previously scheduled yearly check-up with his primary care physician, a good friend of the family. Marlana was able to convince José that she should tag along. She had been worried José’s doctor would simply dismiss her dementia theory—after all, José was a physically fit and accomplished man in his prime. Adding to Marlana’s anxiety, during the visit her husband came across more as the “old José”—the gladhanding county medical examiner—and less as a person who snaps at waitresses and strips in public. Thankfully, Marlana had documented his changes thoroughly, and emailed the doctor her notes and explained her concerns before the appointment. Additionally, during the visit she sat behind José and gave nonverbal cues to the doctor whenever José said something misleading or incorrect.

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Between Marlana’s notes and his own observations, the physician became concerned, and recommended that José see a neurologist. Eager to disprove his wife’s theory, José agreed to go. The neurologist, however, made a diagnosis of behavioral variant FTD (bvFTD) with short-term memory loss. A follow-up appointment with an FTD specialist at a well-regarded academic medical center several states away confirmed the diagnosis. José was stunned, but accepted the doctors’ expert opinions. At their advice, José immediately resigned from both of his jobs. Shockingly, he found himself retired before the age of 50.

José and Marlana decided that she would continue to work while he stayed home. Neither felt that José needed at-home care—he was more than capable of taking care of his basic needs, and now that he knew his behaviors were the result of a brain disease, both he and Marlana felt a small sense of relief.

The relief did not last long. José, left alone all day, began compulsively eating whatever he could get his hands on, the unhealthier the better. Within a few months, he had gained nearly 30 pounds. He no longer felt young and active—his FTD had made him feel sluggish. He couldn’t even go for a drive: Following a close call when behind the wheel, an increasingly concerned José agreed to cede his car keys to his wife.

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CREATING WELL-BEING WITH PERSON-CENTERED FTD CARE

Mary O’Hara, LCSW

José G., the subject of this issue’s case study, had a rich social and family life, full of accomplishment and connection. But soon after his diagnosis, he lost his job, his elected appointment, his car, his hobbies, his financial independence, and many of his relationships. Consequently, José lost his sense of identity, control, meaning, and purpose. Due to understandable concerns about his abilities, safety, and judgment, many of the things most important to José were taken away.

Because of FTD’s unpredictable symptoms, family or paid caregivers may naturally focus on minimizing the impact of new behaviors and compensating for new impairments to keep the person diagnosed safe. Safety, however, does not necessarily have to come at the expense of maintaining engagement, connection, and meaning in their life.

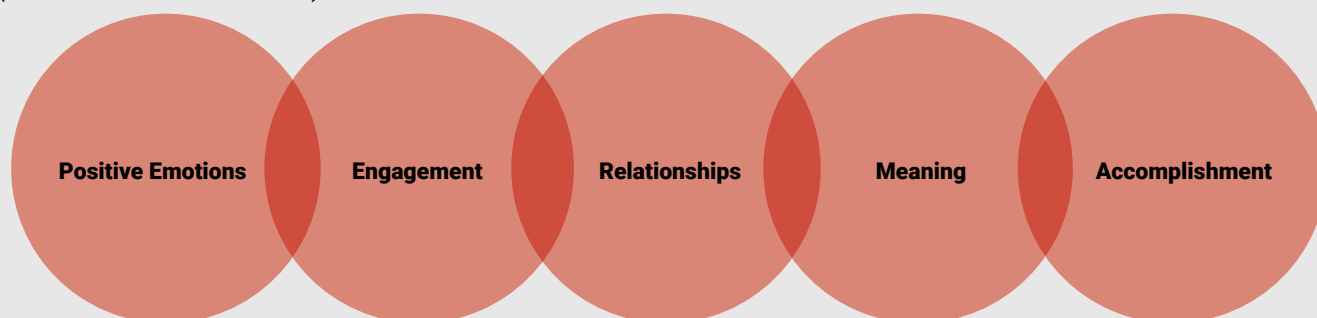
Person-centered FTD care should focus on what is still possible for the individual diagnosed. Doing so can mitigate some of the shame and social stigma often associated with a diagnosis: Seeing a person with FTD for what they can still do

enables families, care providers, and communities to be more supportive and welcoming. Defining a person with FTD by what they have lost due to their disease risks marginalizing, stigmatizing, and isolating them further.

PERSON-CENTERED FTD CARE

Investigate	Investigate what brings meaning
Involve	Involve the person diagnosed
Listen	Listen for what matters most
Enlist	Enlist the help of others
Celebrate	Celebrate accomplishments

(see PERSON-CENTERED, next page)

(PERSON-CENTERED, continued)

The PERMA model of well-being, designed by the psychologist Dr. Martin Seligman, is applicable here. (PERMA stands for Positive emotions, Engagement, Relationships, Meaning, and Accomplishment.) Dr. Seligman designed PERMA to help shift one's thinking from a loss model, focusing on what is taken away, to a more positive model aimed at what one can "bring in." While not developed for dementia, PERMA can be adapted to help family and professional caregivers see what remains possible in the life of a person with FTD, and how they can introduce greater engagement, connection, or meaning.

Positive Emotions: Identify what brings out the most positive emotions and experiences for the person. Even if José could no longer waterski or drive the boat, he might still look forward to spending a day with others out on the water. This concept also prioritizes monitoring, addressing, and treating changes in mood. For José, art therapy could be a fulfilling way to express his emotions.

Engagement: Engagement involves finding activities that both challenge the person diagnosed and are suitable for their cognitive abilities, while also maintaining safety. José's daily walks with his fellow churchgoers kept him safely engaged outside of the house while also minimizing the risk of him overeating if he were left home alone all day.

Relationships: FTD can be a very isolating experience, and may cause some friends to fall away due to their discomfort with it. But if they learn how to respond to FTD's symptoms, they may be more likely to adapt and stay connected. Many newly diagnosed individuals can also form new relationships by connecting with others living with a diagnosis, whether online or in person.

Meaning: While it is impossible to fully replace the meaning derived from a former job or newly inaccessible hobby, new, different sources of meaning can be found. For example, José may find meaning by spending time with his former colleagues, volunteering in an appropriate capacity at his church, or tending a community garden. Understanding what the person diagnosed most values can help to re-establish sources of meaning in their lives.

Accomplishment: Working on or finishing a task, no matter the size, can lead to feelings of accomplishment. Even daily routines provide regular opportunities for small but meaningful accomplishments. José might feel accomplished by returning to running with a friend.

Applying the PERMA model to create well-being with a person diagnosed cannot be accomplished by care partners and caregivers alone. They need support—from their family, friends, community, and the health system. The person diagnosed may resist attempts to introduce new activities or routines. Deciding how much to push and when to back off can be challenging for caregivers. Families therefore need help from their support system in introducing these concepts. While the PERMA approach asks more of our communities, it also offers much more to a person living with a new diagnosis—and can offer family members greater support by reducing distress, worry, and much of the guilt associated with FTD caregiving. ■

PERMA can help family and caregivers see what is still possible in the life of a person with FTD.

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Money problems surfaced next. José lived in Nevada, and several small casinos were in walking distance from his house. Alone all day, José found himself lured into the casinos several times a week. Over the course of several months he had secretly gambled away the majority of his and Marlana's life savings. Worst of all, while José was often recognized by friends at the casinos, no one pegged him as a reckless gambler or tried to stop him—after all, he was young and ostensibly in his prime earning years, and relatively few people knew he was living with bvFTD.

Marlena was infuriated when she learned that José had gambled away their savings. Worse, he did not seem to care that he had done so, nor did he care about how he dressed or what he said to people; he began getting into confrontations with strangers in public. Even more frustrating, José seemed, to a certain extent, to recognize that he was acting impulsively, and that his impulsivity got him into trouble—yet his FTD prevented him from summoning the discipline that had so recently afforded such a comfortable lifestyle for him and his family.

Because he is aware of his condition, José felt acutely what he perceives to be the loss of his personhood. One day he overheard a phone conversation in which his wife referred to their home as “my house” instead of “our house.” The comment made him realize that he is actively grieving his former life. José was not yet 50 years old; he felt he should still be earning a living, helping to provide for his family, and maintaining the responsibilities of his old life. Instead, his credit and debit cards have been taken from him and he depends on his wife to make nearly every substantive decision on his behalf.

However, after having numerous heart-to-heart talks, brainstorming, and consulting AFTD's website, José and Marlana were able to come up with ways for José to find some purpose. She found a local psychologist who worked with José to help him process his feelings of loss. Through their local church, she found fellow members who volunteered to come and walk with José every day. And through AFTD, the entire family found options for both online and in-person support groups. Marlana and the couple's daughter began attending a support group for family caregivers, while José got involved in an online group with others who shared his diagnosis and many of his symptoms, helping him realize he was not alone in his journey. ■

After having heart-to-heart talks, brainstorming, and consulting AFTD's website, José and Marlana found ways for José to seek purpose in life with FTD.

MENTAL HEALTH MATTERS: FINDING THE RIGHT EMOTIONAL SUPPORT

Some people with FTD are aware of their losses, and can express their feelings and their struggles to cope with these changes. Others have lost this awareness and may appear apathetic or unaffected by the diagnosis. In either case, the person with FTD must adapt to a different life that can feel uncertain, empty, unfamiliar, and lonely.

Those with insight into their experience may benefit from speaking with a mental health professional—ideally one with experience working with neurological disease—to help name their feelings, including depression and anxiety, and process their loss. Alternatively, professional therapeutic interventions using art, music, or dance offer the chance to express and process emotions without words, while structured physical activities (walking, yoga, basketball, golf) in low-stimulus environments can provide positive ways to channel frustration and other emotions. Numerous studies have shown the positive impact of both physical activity and the creative arts on one's cognition and mood—and they can be as beneficial for caregivers as they can for persons diagnosed. As awareness of this positive impact increases, many neurology offices, research centers, and local community services are more able to refer families to local providers of such therapies.

If a person with FTD is not expressing emotions about their loss, do not assume those emotions are not present. These unexpressed emotions can often present as disruptive behaviors. But addressing the underlying emotion can help minimize behaviors. Their mental health and wellness may well benefit greatly from more engagement, support, and connection.

It can be confusing and overwhelming for those caring for someone with FTD to know what approaches to care are best, what to prioritize, and how to balance their own needs with the changing needs of the person diagnosed. One important care goal is to connect families with professionals and experts at every stage of the illness to help them navigate the disease in a way that supports the best life of both the person diagnosed and the family members managing their care. ■

REDUCING FINANCIAL RISK IN FTD

FTD is uniquely able to wreak havoc on a family's finances. Its symptoms may include impaired judgment, impulsive behaviors, poor decision-making skills, apathy, disinhibited behavior—all of which can lead to financial calamity. The person with FTD may fall prey to financial scams, compulsively gamble, ignore their bills, fail to pay taxes, spend beyond their means, get fired from their job, or, if self-employed, mismanage their own business. Because FTD is often a young-onset dementia, most commonly occurring between ages 45 and 64, families affected have or are taking on more debt (paying off a mortgage, taking out loans for college tuition) or are working and saving for retirement. The impact of financial instability at this time can be ruinous to the family for years to come.

While primary care providers and financial institutions increasingly recognize changes in financial decision-making as an early sign of cognitive decline, the younger age of onset, symptoms, and challenges in diagnosis create especially complex dynamics.

Some steps that families can take to mitigate financial risks as symptoms emerge or if FTD is suspected:

- **Monitor financial accounts**, including checking, savings, credit cards, and 401Ks and other retirement accounts, for unusual behaviors.
- **Communicate your concerns** with trusted family members, associates, and financial institutions.
- **Request medical leave** from a human-resources representative (if the person is still employed and is undergoing evaluation) to protect their employment status and prevent them from losing disability or retirement benefits.
- **Coordinate** with their accountant and/or business partners (if the person owns their own business) to establish necessary monitoring or safeguards of business finances and accounts.

Throughout this process, the person exhibiting symptoms should be included to the greatest extent possible.

Once a formal FTD diagnosis has been established, the primary care partner should take the following steps to reduce financial risk:

Prepare to educate others on FTD. Gather print information, reliable websites, and other resources that speak to your experience to share with others who are not familiar with FTD.

Continue to monitor financial accounts—not because of a lack of trust, but because FTD symptoms and behaviors will continue to progress in ways that will change the individual's prior abilities. Preventing serious risk is key.

Establish a Power of Attorney. Power of Attorney (POA) is a written document authorizing someone—usually a family member—to make financial, legal, and healthcare decisions for another person.

Consider your specific family situation. A degree of complexity can arise if the person with FTD lives alone without family support, has young children, or is in a second marriage (or beyond). Encourage family members to learn about FTD, work together to choose the POA, and coordinate finances and care. Meeting with a neutral family mediator may be helpful.

Consult with an elder law attorney and develop a plan to transition financial and legal capacity. Review or establish legal documents, make long-term care plans, and ensure that the beneficiary information on all accounts is current and that assets are properly titled. Laws may differ between states. To find a licensed elder law attorney in your state, consult the National Academy of Elder Law Attorneys (www.naela.org).

Identify and inform relevant outside parties. Inform the person's tax accountant, bank representatives, and other relevant parties about their diagnosis and its risks to sound financial decision-making. The earlier you communicate these concerns, the better prepared you will be to protect their assets.

Learn FTD behavioral interventions and strategies. FTD can impair self-awareness and judgment, which makes it impossible for the person diagnosed to reliably recognize potentially harmful behaviors and take steps to change them. Environmental and behavioral interventions are therefore critical to reducing financial risk. While necessary, these steps are often challenging for care partners and may be resisted by the person with the disease.

For example:

- Limit access to their various accounts.
- Work with banks to obtain the lowest possible credit limit on credit cards.
- Give the person with FTD debit cards with fixed maximum balances for everyday spending. Visa gift cards with fixed balances can also be used.
- Limit and monitor cell phone data. Block unknown numbers on incoming phone calls.
- Limit risky internet use by placing the computer in a shared space in the home or use parental controls to reduce and limit internet access. Ensure spam filters are in place for emails.

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- Register for the National Do Not Call Registry (www.donotcall.gov) and opt out of pre-screened credit card and insurance offers via postal mail (www.consumer.ftc.gov/articles/how-stop-junk-mail).
- Place fraud and identity theft alerts on the person's credit reports, and apply credit or security freezes to limit their ability to apply for new credit.

Encourage participation in FTD peer support groups. Others who have had FTD in their lives can impart wisdom gleaned from their direct experience. Learning strategies and problem-solving approaches while gaining a sense of understanding and emotional support can make support-group attendance one of the best ways to cope with the challenges that FTD presents. ■



DISINHIBITION IN FTD

By Esther Kane, MSN, RN-CDP, AFTD Director of Support and Education

Disinhibition is a hallmark feature of behavioral variant FTD (bvFTD) (Raskovsky et al., 2011). The diagnostic criteria for probable bvFTD requires a decline in social cognition and/or executive function and at least three of the following symptoms: disinhibition, apathy, loss of empathy, compulsive/ritualistic behavior, and hyperorality, the tendency to insert edible or inedible objects into the mouth. Professionals not familiar with FTD, however, may fail to recognize the emergence of disinhibited behaviors as a symptom of dementia (Balasa et al., 2015).

People exhibiting disinhibition act impulsively, without considering the consequences or repercussions of their actions. Socially inappropriate behavior, loss of manners, and impulsive, rash, or careless actions are all examples of disinhibited behavior (Raskovsky et al., 2011). (In this issue's case study, José exhibits socially inappropriate disinhibited behaviors when he begins publicly stripping on a cruise.) Disinhibition also poses a threat to the physical safety of the person diagnosed. The combination of impulsivity and poor judgment can lead to the person diagnosed misusing dangerous objects such as guns, vehicles, or power tools, and has also been associated with an increased suicide risk.

It is important to acknowledge that any of the behaviors described below can be part of an individual's established personality. These behaviors become alarming when they reflect a notable change from the person's usual personality, which can be caused by a disease process.

Socially inappropriate behavior

Examples of behaviors that violate social norms include inappropriately approaching, touching, or kissing strangers; verbal or physical aggression; public nudity or urination; inappropriate sexual behaviors; and criminal behaviors, such as shoplifting, traffic violations, financial mismanagement, or sexual advances. Studies have shown that new onset of criminal behavior in an adult should be considered an indicator of possible FTD.

(see *DISINHIBITION*, next page)

*(DISINHIBITION, continued)***Loss of manners or decorum**

This category includes a range of behaviors that violate social graces. Examples include inappropriate laughter, cursing or loudness, offensive jokes and opinions, or crude and/or sexually explicit remarks. People may also display a general lack of etiquette, loss of respect for other's personal space, and a lack of response to social cues. Some people with FTD exhibit poor hygiene or grooming or impolite physical behaviors.

Impulsive, rash, or careless actions

The revised diagnostic criteria for FTD acknowledge that not all behavioral disinhibition leads to obvious breaches in social or interpersonal conduct; in fact, it can manifest as impulsive behaviors that may or may not be performed in a social context. These include reckless driving, new-onset gambling (as evidenced by José), buying or selling objects without regard for consequences, trying to consume items or poisonous liquids, irresponsibly using dangerous objects, and indiscriminate sharing of personal information.

Failing to recognize the link between an undiagnosed person's newly disinhibited behaviors and FTD could lead them to being incorrectly treated for psychiatric illness, or potentially caught in the criminal justice system (Rankin et al., 2008). Clinicians need to be aware that new onset disinhibited behavior may be an early symptom of a progressive neurodegenerative disease. ■

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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:

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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.