

Everything Is Just Fine: Anosognosia in Frontotemporal Degeneration

Caring for people with FTD presents challenges no matter what. Anosognosia can make it even more difficult. Anosognosia is the inability to recognize or perceive one's illness and its associated limitations. Also referred to as "lack of insight," anosognosia is a hallmark symptom of FTD, especially in behavioral variant FTD. People who present with anosognosia display a profound lack of emotional concern about their disease and its impact on their family members.

Even those who acknowledge they have a brain disorder may deny they are upset or worried about their condition. Anosognosia is one of the main reasons people with FTD refuse medication and medical/personal care. People with anosognosia may be able to function normally in some areas of their lives, yet demonstrate risky behavior elsewhere because they do not recognize their limitations.



The Case of Roger A.

Early disease

Roger A. is a 60-year-old farmer from Ohio. He lived on his family's Century Farm his entire life, raising seed corn, wheat and cattle. After college, he spent several years in the Navy, then spent the rest of his adult years working the farm.

At 23, he married his high school sweetheart, Alma, and raised two sons and a daughter; all three work in the family business and are married with children. Roger was president of his local Rotary and was a deacon in his church. A strapping man with a booming voice, he was usually assertive about getting his way.

Roger began to change in his early 40s. He became irritable and stopped paying attention to farm prices. He stopped attending church regularly and began to collect muscle cars. A lifelong hunter, he began to add pistols and semi-automatic weapons to his gun collection. Believing the guns weren't loaded, Alma allowed this—until the day their oldest grandson picked up a gun and fired a bullet through the living room floor. Roger was outraged that the child had touched his gun but still refused to use his gun safe. For their own protection, the grandchildren were told not to be around Roger unless supervised by another adult.

On his 44th birthday, Roger quit his civic positions following rumors that he had made sexual advances toward women at church. Alma did not believe the rumors but threatened divorce if they proved true.

Shortly thereafter, Roger said he wanted to move to Sun City, Arizona. He and Alma purchased a second home there when he was 45—but a year later, he sold the house, saying he did not like his “female neighbors.” Instead, the couple bought an apartment in a posh golf community in Arizona and planned to spend their winters there.

Back in Ohio, Roger started openly spending time with Heather, a divorced beautician. Mortified, Alma tried to get him to give up the affair. He refused and began taking Heather to Arizona with him for the winter. Increasingly stressed by Roger's odd behavior, Alma was almost relieved to stay in Ohio and spend time with their grandchildren.

One day while driving to work, Roger's daughter got a call from her father. He demanded she pull over, remove her shirt, take a cell phone picture of her naked breasts and send it to him immediately. This shocking request prompted a full-blown family crisis. Alma knew she had to act: She insisted Roger see their primary care physician for help.

Roger went to the appointment alone and told the doctor the only thing wrong was Alma: She was “frigid,” he said. The doctor

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BEHAVIORAL ANOSOGNOSIA COMPLICATES DIAGNOSIS, CARE AND FAMILY RELATIONSHIPS

People with FTD will vary in their capacity for self-awareness or insight. Some people may experience cognitive unawareness reflected in difficulty with memory, language, spatial and temporal orientation, calculation, abstract reasoning, and putting abstract ideas into practice. People with behavioral unawareness, meanwhile, become impulsive, have little understanding of safety, and tend to be more narcissistic. Language and functional deficits are less prominent than in people with cognitive unawareness – in fact, people with behavioral unawareness often appear to be normal to all but close family and friends, who are attuned to their changing behavior.

People with behavioral unawareness are often misdiagnosed with bipolar disorder, narcissistic personality disorder, antisocial personality disorders and other psychiatric disorders until their FTD progresses beyond its early stages. They may exhibit reckless spending habits and spontaneous social outbursts, refuse treatment and diagnostic evaluations, and neglect their personal care. They may show a lack of empathy and increased self-centeredness, confounding family and social relationships, and can become hypersexual and manic. It is not uncommon for them to develop legal and financial problems, resulting in marital and/or family discord.

Families and care staff often get angry at the person with bvFTD, mistakenly considering them to be compulsive liars who make up stories purposefully. But it is important for them to remember that such behaviors are not willful. Lack of self-awareness is due to physical damage to the brain, specifically the right parietal lobe and/or frontal lobe, the anterior cingulate and the orbitofrontal cortex. The degeneration of these regions impairs one's ability to evaluate how others respond to their behavior and adjust accordingly.

There are no medications approved to reverse or treat anosognosia. The best management and care alternatives are nonpharmacologic, including modifying communication techniques and supporting the person's immediate understanding of his or her world, without compromising safety.

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To limit problematic behaviors by people with behavioral unawareness, families and care staff can alter certain elements of their environment. This might include: disabling the internet to prevent financial losses, removing weapons, hiding food and/or car keys, and opening new limited-access bank accounts. Whenever possible, avoid trying to convince the person that they have a disease; this may escalate to agitation and aggression. If the person has a pattern of aggressive behavior, medications may be necessary to assure family safety and the person's emotional comfort. ■

suggested the couple was experiencing marital discord. Alma arranged for counseling, hoping it would ease the tension in the family. But counseling proved frustrating and unsuccessful, as Roger became more self-centered and inflexible. He continued seeing Heather, unable to comprehend Alma's unease with the situation. He insisted that there was nothing wrong with him, even telling the therapist that he wanted a divorce so that he could pursue younger women.

Roger's spending habits grew more reckless. He bought two antique tractors, as well as a new combine and tractor every spring for three years. He ordered hunting gear and began to haunt farm sales, collecting old equipment. The family continued running the business, but Alma was concerned that Roger's erratic behavior would put their livelihoods in jeopardy. Neither had named a durable power of attorney for financial or healthcare decision-making. On the advice of a doctor, Alma and her eldest son began to seek a diagnosis so they could apply for guardianship of Roger. But he kept insisting that nothing was wrong, that he was still running the business well and that his marriage was "better than ever."

Roger's family nevertheless convinced him to see a series of specialists. The fourth specialist diagnosed him with bipolar disorder. Treatment efforts failed, however, and Roger said he was done seeing doctors. After an essentially normal neuropsychological battery, a magistrate denied Alma's request for guardianship.

In the midst of this trying ordeal, Alma began researching a condition one of the specialists had mentioned in passing: FTD. Roger's symptoms—disinhibition, lack of awareness, changes in mood—seemed to match those common in behavioral variant FTD (bvFTD). Notably, memory loss was not listed as a primary symptom. Most standard cognitive evaluation tools focus largely on memory and do not adequately assess the frontal executive skills or behavioral changes caused by FTD. Alma recalled that Roger's evaluations had primarily assessed memory. Her research highlighted the importance of finding a doctor with experience diagnosing and treating FTD. At the recommendation of the elder law attorney helping with guardianship, Roger's family insisted he see a behavioral neurologist, who diagnosed him with bvFTD at age 47.

Despite a measure of relief that came with finally getting a diagnosis, Alma had reached her limit and told her children she would be pursuing a divorce. She was increasingly frightened of Roger and upset about his relationship with Heather—he had even tried to convince Alma to let her move in with them at the farmhouse. When Alma told her husband she wanted a divorce and would be moving into an apartment by herself, he did not understand, saying, "There's nothing wrong with me."

Roger became angrier and more aggressive. Both Alma and Roger's doctor agreed he had become a danger to himself and others. He spent two weeks in a geriatric psychiatric unit, the safest inpatient option due to his dementia, and started medications to address his agitation. Staff recommended a more structured supportive living situation, but he refused. After being discharged, Roger relocated to Arizona but could not keep his apartment clean or independently manage his daily needs. He refused to take his medications, and the stress of his rapidly changing life made him agitated and argumentative. His children quickly relocated him to an assisted living center in Ohio,

PSYCHIATRIC ADMISSIONS IN ANOSOGNOSIA

"There is nothing wrong with me." This is a common response by persons with FTD and anosognosia symptoms after being presented with the possibility of an evaluation or care intervention. They can further become angry and disinhibited – which, combined with impaired judgment, presents a potential safety risk to family members, health professionals and themselves. Admission to an in-patient psychiatric unit or geriatric psychiatric unit may follow.

Psychiatric admissions are used to initiate or adjust medications and to determine the best residential care environment. (Specialized geriatric psychiatry units will have more experience with dementia, but are not common in many areas.) Psychiatric admissions may also be used to manage compulsive behaviors that are overly disruptive or potentially dangerous.

Admissions, however, are often denied for individuals who have a dementia diagnosis and do not exhibit problematic behaviors in the structure of the hospital setting, leaving family members with limited options. And those who are admitted and then discharged may once again refuse medications and continue disruptive behaviors.

Advocacy on behalf of the person with FTD is crucial. In a memory care community with access to a psychiatrist familiar with dementia, a best practice is to have a psychiatric consult before move-in, and periodically
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afterward, to monitor their adjustment. In the community, consultation with a nurse practitioner, geriatrician or geriatric psychiatrist is recommended. Because FTD is not well understood, even among some healthcare providers, be prepared to offer educational resources on FTD (see the **For Health Professionals** section of AFTD's website) in addition to a summary of the individual's history and medications. Care partners should communicate with their local emergency services to inform and educate them about the individual's diagnosis prior to any potential need for help. ■

but he required more supervision than the program could provide. He was discharged after repeatedly fondling women. He did better after moving into a more structured assisted living facility, although he regularly resisted directions from the predominantly female staff. He denied his illness the entire time, asserting that he was perfectly healthy.

Meanwhile, Alma put the divorce on hold while she got her family's affairs in order. To save the farm and plan for the costs of Roger's care, Alma sold it to her children. Knowing her husband would not understand why she agreed to the sale—after all, he still did not recognize he had FTD—Alma followed the advice of Roger's doctor and told a white lie. She told Roger the farm's property taxes were overdue and the farm was bankrupt. Believing Alma's story, Roger consented to the sale.

With the matter resolved, Alma reinitiated divorce proceedings. Afraid of what the community would think, she limited her social outings to church and meetings of her local FTD support group. Heather remained involved with Roger and assisted with his care.

Moderate disease

For several years, Roger would stay in assisted living for most of the year and spend winters in Arizona with Heather. Eventually, Alma and the children offered to pay Heather a modest salary to care for him full-time. Heather accepted and moved Roger into her home in Ohio for a trial run.

As his FTD progressed, Roger needed greater assistance with activities of daily living, particularly following a mild stroke at age

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POSITIVE APPROACHES IN RESIDENTIAL FACILITY CARE

Without adequate staff preparation, transitioning a person with FTD and anosognosia symptoms into a residential care community can be challenging. Persons with FTD are often young, physically healthy and active, and exhibit a range of cognitive abilities and limitations. Staff familiar with the symptoms of Alzheimer's disease will meet little success and increased frustration if they use the same care approaches on a person with FTD. Staff may also report being fearful of persons with FTD, who are younger and stronger than typical residents.

Facility placement is smoother when staff receive ongoing FTD education, helping them better understand that impaired judgment, not memory loss, shapes the needs of residents with FTD. Positive approaches during the initial and ongoing stages of care include the following:

Before move-in, work with family members to assess the specific needs of the person with FTD, outline appropriate care approaches, and identify helpful resources.

Educate staff on FTD prior to move-in—sharing the above-noted assessment can provide clinical and individualized care knowledge.

Identify specific staff who understand and are comfortable with FTD.

Develop and post a daily routine that the person diagnosed is comfortable with. Rewarding task completion with a favorite snack or activity may increase success in activities of daily living and medication compliance.

Communicate to all staff that elopement risk is greater among persons with FTD due to their younger age, inability to assess risk and preserved language and cognitive skills. Note times or situations when the person is most active, and have on hand a current photo, a list of favorite places and other identifying information in case of elopement.

Observe interactions between the person with FTD and others (residents, visitors, and staff). Intervene positively when necessary, especially after observing sexual advances and other potentially unsafe behaviors. Teach staff how to similarly observe and intervene.

Request that family members provide a private duty companion, and increase staff monitoring checks due to heightened elopement risk and other risky behaviors. Assess the individual's response to one-on-one attention, as it may increase their discomfort.

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Complete environmental rounds daily to ensure safety. For example, eliminate poisonous and other unsafe materials, and limit access to observable food.

Frequently remind staff that the behaviors of a person with FTD are not willful; they are due to physical changes in the brain. Let staff talk about how the more challenging behaviors affect them.

Providing modified one-on-one activities based on past interests is generally more successful than group activities. These can include exercise programs geared to a younger person, such as shooting hoops.

Communicating regularly with family and staff is essential as the individual's needs change. ■

57. Nevertheless, he continued to insist that he was completely normal, and actually grew more resistant to Heather's attempts to help. Exhausted from these constant conflicts, Heather began to burn out. She learned that contradicting or correcting Roger only made him angry; he began to threaten her physically during confrontations. His doctor prescribed quetiapine (50 mg at bedtime) for aggression.

Roger began to develop aphasia. He could no longer read or produce words, and began having difficulty eating. He would stuff his mouth until swallowing was physically impossible. Heather

Roger's family agreed to try medication to address his aggressive behavior.

took a caregiver training course and learned to feed him slowly; she eventually switched him to a milkshake diet to prevent choking.

At age 58, Roger refused to allow even Heather to provide personal care. He occasionally experienced incontinence and would hide his soiled clothing in the drawer with his clean underwear. Each time Heather corrected him for doing so, he became belligerent. Frustrated, Heather spoke to a dementia care manager who recommended incontinence garments. She also bought pet stain remover to clean rugs and furniture, and to prevent upholstery from rotting.

Roger's FTD kept worsening. He began to eat compulsively and gained weight, causing mobility problems; Heather resorted to hiding food in a locked fridge. He refused all bathing and grooming. Roger's doctor prescribed additional medication to manage his angry outbursts.

Realizing she could no longer manage Roger on her own, Heather tried to enroll him in an afternoon adult day respite program, but he refused to go. Then, with the help of Roger's children, she found a specialized memory care facility for him. On the second day, he escaped; on the third, he tried to fondle two women and was asked to leave. Roger was then accepted to a Veterans Affairs Nursing Home with mostly male residents and care staff. He was placed on a secured unit. The staff initiated a meeting with his family, who agreed to try medication to address his aggressive behavior. Roger's issues decreased due to medication, less contact with women and positive behavioral interventions.

Advanced disease and hospice

Now 60, Roger has seen a decline in his health over the last several months. He is dependent in all activities of daily living



except walking, although he falls approximately twice per week. Care staff redirects him to a chair without foot pedals for easier mobility. He has become nonverbal but will have periodic spontaneous vocalizations. His resistance to care and prior aggressive behaviors have faded. Doctors reduced his medication to only those necessary to manage his restlessness. He cannot eat without choking and is on a full thick-liquid diet.

After Roger went through two bouts of aspiration pneumonia and a urinary tract infection, the staff spoke with Alma and Heather about the benefits of hospice care. Both women recognized how fragile his health had become and agreed to focus fully on his comfort. He entered hospice and is now in a quiet room, spending time with occasional visitors. Staff read and sing to him. He no longer takes food or fluids. Alma and Heather spend time by his side daily. ■

FAMILY CAREGIVERS' UNIQUE SUPPORT NEEDS

An FTD diagnosis presents families with an overwhelming and ever-changing list of new priorities, limitations, and responsibilities. Research shows that caring for someone with FTD is more expensive and is associated with more health risks than other forms of dementia. (See *"The Social and Economic Burden of Frontotemporal Degeneration,"* James E. Galvin, et al., *Neurology*, Oct 2017.) FTD's relatively young age of onset also presents families with unique struggles and difficult decisions.

Family caregivers commonly have feelings of guilt, sadness, loss, disbelief and grief, among others. And because of their diminished self-awareness, persons with anosognosia often resist limitations that caregivers must place on them to keep them safe, resulting in caregivers additionally feeling angry, frustrated and resentful. This complex mix of emotions increases the need for caregiver support. Finding others who understand how anosognosia affects caregiving is essential.

No one should walk this difficult road alone. FTD caregivers can **find support** through face-to-face, online or telephone support groups; on online message boards; or from individual counseling. Professionals can offer guidance around physical and financial safety, while healthcare professionals—occupational therapists, physical therapists, speech therapists, social workers, psychiatrists, nurse practitioners, etc.—can offer valuable insights into providing FTD care and maintaining caregiver health.

Persons with anosognosia are likely to resist a transition to residential care, even when they are absolutely necessary

to keep them and others safe. Trying to wear down their resistance through reasoning will not be effective. Instead, encourage family caregivers to help the person with FTD to adjust to the changes involved in transitions.

Family caregivers need to feel supported when they are helping a loved one make a care transition. [For more information, see "Positive Approaches in Residential Facility Care," p. tktk.] Other family members, however, may disagree that the person with FTD displays symptoms severe enough to necessitate additional care. For primary family caregivers, feeling judged and questioned in this way complicates their already devastating loss. A family meeting facilitated by a professional may allow for the family to come together to focus on the needs of both the person with FTD and their primary caregivers.

Family caregivers need emotional support, practical help and frequent breaks. Encourage caregivers to ask for help as precisely as possible. Are there specific chores that need to be taken care of, or appointments to be met? Simply asking others to spend time with the person with FTD can have a salutary effect on a caregiver's health and wellbeing. Having friends and family check in regularly with caregivers reduces feelings of isolation and abandonment.

Encourage family caregivers to tell stories about the person with FTD before the onset of the disease. It is important for families to connect with those memories, and also helpful for hired care staff to know who the person was, how they lived and what they valued. ■

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Questions for discussion

Was Roger in denial of his illness?

No. There is an important difference between “denial” and “anosognosia.” Denial is a psychological defense mechanism or way of coping with an unpleasant or painful situation. When that situation is resolved, the denial response is no longer needed. Anosognosia is the result of damage to the brain’s right parietal lobe and/or frontal lobe, the anterior cingulate, and the orbitofrontal cortex, which is irreversible. Whereas denial is generally temporary, anosognosia will only worsen as the disease process continues.

Did the consequences of Roger’s behavior—including Alma’s response to that behavior—help him to recognize his disease and adjust to his limitations? Did medication help?

Nothing Alma, Heather or professionals said or did changed Roger’s lack of insight into his difficulties, nor his lack of concern about how his FTD impacted himself and his family. Attempting to reason with someone with anosognosia is generally ineffective, as are activities designed to help them understand they have an illness. Although you might get the person to verbally acknowledge their disease, the accompanying emotional indifference prevents them from caring about, or changing, their aberrant behaviors. Despite efforts from Alma and Heather, Roger kept saying he felt fine; he resisted efforts to help with activities of daily living and became aggressive when questioned about his actions.

There are no medications that can reverse or treat anosognosia. Carefully prescribed medications may help to lessen agitation or aggressive behavior, but they will not change the lack of self-awareness.

How could Roger develop reckless and inappropriate behavior and still be able to function independently in other areas?

The location of disease in the brain determines the earliest symptoms and functional impairment. Research has suggested that anosognosia in bvFTD is associated with atrophy in parts of the right temporal lobe that have been linked to a person’s ability to evaluate how others respond to their behavior. For a time, Roger retained the complex cognitive skills involved in driving a car, but was so behaviorally impaired that he demanded nude photos of his daughter. This disparity is a source of great confusion for many family members and loved ones, but it can be

explained by the fact that FTD is a progressive disease, gradually impairing different parts of the brain—and therefore different brain functions—as it worsens.

How could Roger’s behavior and relationships change so much, yet he continued to think nothing was wrong?

Due to damage in his frontal lobe, Roger was not able to recognize how much his personality had changed and how different his actions and decisions were from before. For many people, behavioral variant FTD (bvFTD) irreversibly damages the brain circuits involved in recognizing and maintaining our own self-image. Roger therefore could not understand how his new behaviors conflicted with the self-image he maintained: Essentially, he thought he was the same person he had always been. Despite the obvious changes in his personality, judgment and behavior, as well as the changes in his relationships, Roger believed that he was still running his business well and that his marriage was better than ever.

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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AFTD extends special thanks to this issue’s special guest contributor, **Geri Hall**, PhD, ARNP, an advance practice nurse who has specialized in the care and management of people with dementia for the past 40 years. She developed the first theoretical framework for planning and evaluating care of people with dementia, published and spoken extensively, and served on policymaking committees. Over the last 20 years Dr. Hall has become increasingly active in the care of people with FTD. She currently conducts research, counsels families and runs two monthly support groups.

To join the Partners in FTD Care mailing list, or for permission to reprint this material in whole or in part, contact partnersinfldcare@theaftd.org.

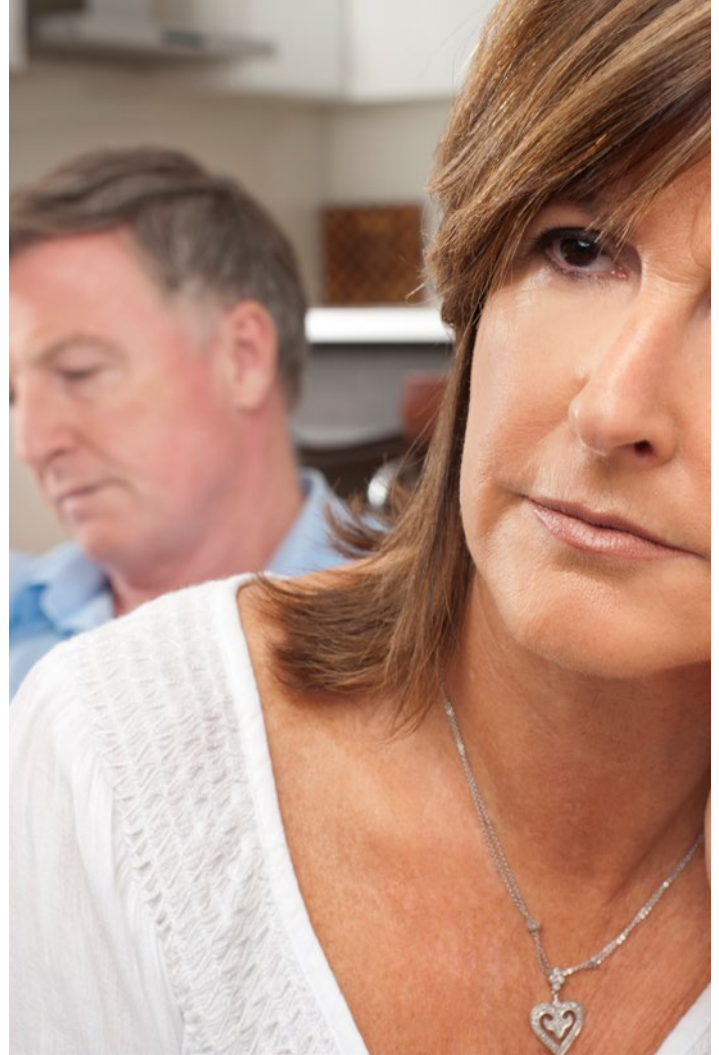
FINANCIAL SAFETY AND ANOSOGNOSIA

Financial supervision early in FTD care is extremely important, particularly when anosognosia is a factor. Mary is a registered nurse and single mother to two sons in high school. After her 50th birthday, she began showing personality changes – formerly helpful and attentive on the job, she became critical and difficult to work with; once known for her punctuality, she began showing up late. A behavioral neurologist diagnosed her with behavioral variant FTD (bvFTD).

Although she had to stop working, Mary continued to live independently (with some supervision) and seemed to be doing well. As far as her family knew, she was paying her bills, maintaining her home, and taking her daily medication. But when her oldest son started applying to college, he discovered that the money she had saved for his tuition had been transferred overseas to a “new boyfriend” she met online. Confronted, Mary was completely unbothered; no amount of explaining could convince her of the seriousness of her error. Not a penny was recovered. In fact, while her family took steps to limit her internet access, she still found a way to send her “boyfriend” even more money. Guided by advice from an eldercare attorney familiar with FTD, a family member was granted guardianship, a legal tool that limits an individual’s rights based on the determination that they cannot care for themselves.

Mary’s story reflects the crucial need for financial supervision when anosognosia is present. Simply recognizing the need for outside supervision is important: People with FTD often score well in standard dementia testing, leading to the false belief that they can manage their finances independently. To avoid problems, start by offering support to the person with FTD, including by organizing and simplifying their finances. Limit access to junk mail, especially “too good to be true” opportunities, and monitor their internet activity. If overspending becomes a problem, make sure they only have access to credit and debit cards with relatively low limits. Identify a trusted advisor who can keep an eye on their spending.

Loss of judgment plus the impulsive and impaired decision-making that accompany FTD are not often well understood by those who do not understand the disease, making obtaining guardianship difficult and stressful for FTD caregivers. Decisions to grant guardianship are based not on behavior or emotional control, but on the ability to perform daily tasks. A person with FTD may remain relatively high-functioning in the disease’s early stages, able to cogently answer questions such as, “How do you pay household bills?”



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Guardianship is therefore often denied in FTD cases. In those instances, spouses may consider divorce as necessary to protecting their personal finances. Sometimes, however, divorce could cause the spouse to lose income on which they depend. Acknowledging the particular financial risks inherent to FTD and taking steps to protect one’s finances early can help mitigate the disease’s long-term financial impact. ■

What to Do About... **Anosognosia**

Anosognosia is a lack of awareness of one's own condition and can be a symptom of FTD because of the specific region of the brain that is affected. The person with FTD may not recognize they are ill, and they may not monitor and adjust behavior or its impact on others. They are not being manipulative or deceitful. They are simply not aware of their changing behavior, which complicates evaluation and diagnosis. Although the person with behavioral variant FTD (bvFTD) may be unconcerned about their behavior or risky choices, anosognosia adds to the family's challenges and frustration. Effective management requires acceptance that the losses are due to disease rather than psychological "denial." You cannot convince a person with FTD who lacks insight that they have a problem. Strategies must seek to change the environment rather than the person.

Evaluation and diagnosis

- Expect that others may not see the symptoms those closest to the person see. They may seem perfectly normal to others, including healthcare professionals.
- Maintain a log of behavior changes, unusual actions or risks taken.
- Go with the person to all medical appointments. Take information on **signs and symptoms of bvFTD** to community physicians.
- Find an expert in FTD or a behavioral neurologist for diagnosis and care.
- Consider creative, indirect ways to have the patient seen by a healthcare provider if they resist. For example, some persons with FTD will agree to see a provider if you tell them that it is necessary to keep their insurance benefits, or to refill medications they take for a different condition. Keep the explanation as simple as possible.
- Arrange to talk with the provider apart from the person diagnosed, or present your concerns in writing. Focus on the person's ability to perform daily activities, noting any changes from prior functioning.
- Providers may initially resist a family's efforts to speak to them alone, as insurance reimbursement dictates the person with FTD must be present for billing. Be creative and persistent.
- Stand or sit behind the person affected in the exam room to mime disagreement with the person's self-reported history.
- Hospitalization may become necessary if other evaluation efforts fail.

Importance of support

- The person with anosognosia often sees the care partner as the problem. Thus it is important to ensure that the family care partner receives FTD education and support.
- Encourage family care partners to consider which type of **support** is best for them: in-person support groups, telephone support groups, online message boards or individual counseling.
- Acknowledge the complex mix of emotions that care partners may be experiencing: anger, frustration and resentment; guilt, sadness, loss, disbelief and grief.
- Recognize that families are forced to bend and adapt in unfamiliar ways, and it is normal that they may struggle in making difficult decisions.
- Help families establish a team of professionals they can call upon for help. Occupational therapists, speech therapists, social workers, psychiatrists, nurse practitioners and physical therapists can offer valuable insights into the needs of the person with FTD, as well as the health and support of the family care partner.
- Assist care partners in their decision to limit, take away or prevent access to activities that pose financial or safety risks. Because anosognosia diminishes the person's ability to understand how significantly they are changing, they are often at odds with their family care partner's decision.
- Support family care partners who decide that residential facility placement is necessary. Feeling judged and questioned complicates their already devastating loss.

Importance of support (cont.)

- Encourage care partners to ask for specific help. “Can anyone mow the lawn this week?” “My wife needs some new clothes. Can someone help me shop with her?”
- Ask family members to tell stories about who the person was before disease onset. It is important for families to connect with those memories and also helpful for hired care staff to know who the person was, how they lived and what they valued.
- Encourage the use of in-home or day program respite for care partner well-being. For financial assistance, tell care partners to apply for AFTD’s **Comstock Respite Grant**.
- Focus energy on helping them adjust to the change.
- Adjust your expectations. If you find yourself frustrated when the person diagnosed refuses to do certain tasks, ask yourself “Is this really that important?”
- Avoid potentially stressful social engagements. Carry cards explaining FTD for when the person begins to act out publicly.
- Discuss sexual issues with a primary care provider for possible medication (e.g., selective serotonin reuptake inhibitors).
- Practice self-care. Use formal and informal respite to enable patience in caregiving.

Strategies for family caregivers

- Avoid power struggles and angry escalations. What may be experienced as the person “lying” or not “admitting” to the disease could be anosognosia and a symptom of bvFTD.
- Use the AFTD website (theaftd.org), AFTD HelpLine, and other resources to learn more about FTD.
- Share AFTD resources with healthcare providers to ensure understanding of FTD symptoms.
- Complete legal forms, including durable power of attorney, healthcare power of attorney and advanced directives. These may be difficult to obtain when the person feels nothing is wrong. Consult an attorney who specializes in elder law.
- Some family members may disagree about the severity of the behaviors or the need for additional care. It may be helpful to hold a family meeting facilitated by a professional to refocus on the needs of the person with FTD and their primary care partners.
- Secure family financial safety by limiting access to credit cards, money and the internet. Use rechargeable gift cards to monitor and limit spending.
- Continually assess the safety of the person with FTD, their family and community members. Special care is needed when children are in the home.
- Write down concerns and give them to healthcare providers or program staff without telling the person with FTD.
- Don’t try to reason with the person or contradict their own assessment of their health or abilities.
- Discuss issues and plans only at the last minute. When you need your loved one to do something, you may need to “sell” it rather than present the request forthrightly.
- Tell little white lies if necessary to protect the person.
- Pursue driving cessation, starting with a driving evaluation. People with impaired awareness and judgment should no longer be driving, operating machinery or have access to firearms.

Moderate and later stages

- If a person diagnosed must complete a task, break it down into small components and help them get started. Don’t verbally correct the person. Suggest that the proposed task is simply something you need help with, or tell a little fib: “You agreed to this earlier, remember?”
- Consider residential care early to identify appropriate placement. A person with behavioral unawareness may do well if placed early, as there is less pressure to consider the needs of others.
- Ensure initial training and regular in-service boosters for residential care staff. Include an overview of FTD and bvFTD, communication techniques, managing obsessive behaviors, recommended activities, safety precautions, and modifying care protocols to lessen potential for violence. Use psychiatric acute care when necessary.
- Elopement may be a problem, even in a secured unit. Ensure that care staff monitor the person diagnosed closely.
- Avoid the use of television to prevent illusions and delusions. Instead, give them objects they can examine, sort and tinker with.
- Pacing and movement help the person cope with stress. However, do not make them stop walking without a substitute activity in place, or spontaneous vocalizations may occur. Establish a quiet area near a window where they can sit when they need to stop pacing.
- Use bathing and dressing as a preliminary step to going out for lunch or another valued activity.
- Avoid showers and use **alternative bathing techniques**.
- Use scheduled mild analgesics in the morning and evening to prevent or treat discomfort from pacing.
- Provide small frequent snacks to avoid weight loss.
- Assume the person with dementia is trying their best.