

## 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.