Partners in FTD Care

BEHAVIORAL SYMPTOMS OF FTD

The FTD symptoms that family caregivers find most challenging are often the drivers to pursue facility-based care. To help facility staff provide person-centered FTD care, this article will focus on some of the most challenging behavioral symptoms. While the behaviors listed below are more common in those diagnosed with behavioral variant FTD (bvFTD), they can appear in those living with other FTD disorders. A comprehensive list of common symptoms for each FTD disorder can be found here: www.theaftd.org/for-health-professionals/clinical-features

Successfully integrating a person with FTD into a community care setting will depend on the caring, organized, and creative approach of a well-trained and skilled program. As with Alzheimer's disease and other neurodegenerative conditions, each person with FTD, regardless of the disorder type, is individual and unique. Not every behavioral symptom will occur for each person. Also, symptoms do not necessarily present in a particular order or at a specific stage of the disease. New symptoms can appear (or disappear) as the disease progresses. All professional staff, including non-care staff, must be aware of and understand these symptoms as part of the disease process. Staff benefit from learning supportive ways to respond to, accommodate, prevent, or minimize the disruption these behaviors can cause. It is also important to ensure staff do not blame or shame the person with FTD.

Many FTD symptoms can also occur with other dementias. But because of the often-younger age and greater physical health of those with FTD, and the fact that memory is generally preserved early in the disease, care providers may be more likely to believe that residents with FTD have the capacity to do or not do something. Staff may think these residents "know better," and that their disruptive behaviors are intentional. It is important to acknowledge that this incorrect thinking can happen, but also to reinforce that these behaviors are caused by the disease, and that that these behaviors are not willful actions by the resident.

This chart focuses on the behavioral symptoms that can pose the most challenges in a community- or facility-based setting. It is intended to be used as a training resource for discussion about specific symptoms, a handout for staff to use as a guide, and a jumping-off point for discussions of behavioral symptoms as observed by staff to brainstorm viable solutions.

BEHAVIORAL SYMPTOM	Practical Examples, Interventions, Additional Information
Apathy/Lack of Motivation	
Indifference, lack of interest, or inability to begin or initiate previously meaningful activities. May include: Loss of interest in hobbies, and personal relationships Neglect of personal hygiene	A person used to independently ride a bike in their community. They are no longer able to initiate this activity on their own. • If guided to a stationary bike, and supported to initiate riding, they may begin to ride A person can no longer initiate or follow the steps in a task, like putting on clothes in the correct order. • If the objects involved are laid out, and they are cued and encouraged, they can execute the steps involved
Disinhibition	
A loss or lack of restraint based on social norms, leading to inappropriate behavior and impulsivity. May include: Making uncharacteristically rude or offensive comments Ignoring other people's personal space Touching strangers or engaging in inappropriate sexual behavior	Calling another resident or staff fat (or using an ethnic slur, etc.) directly to that person, or close enough that they can hear it. Approaching other people as if they are acquainted, and possibly hugging or kissing them – even children. Talking to strangers about very personal issues. • As with other dementias, offensive comments or rude behavior are caused by FTD and not willful • The person with FTD should be calmly redirected or escorted away from another resident or visitor

Hyperorality or Other Eating/Diet-Related Behaviors	
Binge eating or compulsive eating Craving carbohydrates or sweets Eating only specific foods Increased or first-time use of tobacco products Excessive water or alcohol consumption Attempting to consume inedible objects	Taking food from someone else's plate. Gorging on food to the point of vomiting. Eating just certain things, like only eating the red M&M's or a certain type of candy. Continuously searching for and/or eating food. • Staff should monitor their meal intake when seated with others • When finished with their meal, staff should redirect or escort the person diagnosed to another location and activity so that they are engaged elsewhere (and not in proximity to others who are eating) • Choices about accessible or available food should take into consideration foods that can trigger compulsive behavior
Lack of Empathy/Emotional Blunting	
Loss of warmth, empathy, or concern for others. May include: Indifference to notable events (e.g., death of a family member or friend) Failure to recognize that others are upset or unhappy	Laughing when another resident falls, is upset or in distress. • Redirect them to another activity • Lack of empathy can be especially upsetting to family, but may be less problematic in a community setting when staff understand that it is associated with behavioral variant FTD
Compulsive, Ritualistic Behaviors or Perseverative Behaviors	
Single behaviors or simple or complex routines that are performed over and over and unrelated to the situation or circumstances in which they occur.	Repeatedly talking about the same topic or story over and over. Continuously whistling, drumming fingers in a certain way, or repeating another noise regularly or continuously. Repeating words or phrases. Hand rubbing and/or clapping. Watching the same television show or re-reading the same book repeatedly. Following a set schedule in an exacting way. Walking to the same place at the same time every day. • Redirect them to another activity. Learning which activities constitute a successful diversion is part of the trial-and-error nature of caregiving work • As in Sean and June's story, observing, tracking, and problem-solving a behavioral challenge (such as the need to walk in a certain pattern at a certain speed) and the accommodation that works in your environment is key • If a repeated activity is not dangerous to themselves or others, can it be accepted or accommodated, at certain times or in certain locations?

Aggression	
May include shouting, name-calling, or physically abusive actions (hitting, pushing, biting, pinching, scratching, grabbing) Can be caused by a change in routine May be abrupt	Things to do or avoid: • Move other residents out of the way to safety and/or redirect the person diagnosed to another activity in a safe place • Do redirect attention to something they enjoy • Do stay out of their way if they are combative • Do debrief with staff to identify triggers for the aggression • Don't try to reason with the person, correct them, or shame them for the behavior in an attempt to prevent future incidents Remember that aggressive behavior is not purposeful and almost always has a trigger.
Anosognosia	
The inability to recognize or perceive one's illness and/or changes in behavior, and their effects on others. Also referred to as "lack of self-awareness or insight"	They may say, "There is nothing wrong with me," and not understand the need for environmental interventions to protect their safety, decision-making, etc. They insist they are being unjustly required to live in a care facility and that nothing is wrong. They may not recognize or perceive they have FTD. • Educate staff on symptoms so they understand that, although persons with FTD may retain memory, they may lack insight into their disease or the ability to control their behavior Do not try to argue with the person or convince them that they have FTD. • Acknowledge that you see they are angry/frustrated/anxious • Attempt to align with them by asking them to tell you more about what is going on • Try to redirect them to a conversation or activity that is calming for them