Partners in FTD
Care

TIPS FOR RESIDENTIAL CARE STAFF TO CREATE A SMOOTH TRANSITION

By Jennifer Pilcher, PhD

The successful transition for any resident with dementia into a new living environment can be challenging, necessitating thorough assessment, planning, attention, and communication. This is particularly true in FTD, a disease whose symptoms are less well understood by most community healthcare providers. The younger age of onset compared with other dementias adds to the challenge. Understanding the family's experience is especially important to develop an effective care partnership.

Each person with FTD is unique and individual. Their abilities, needs, and symptoms may differ depending on their specific FTD subtype: behavioral variant FTD, primary progressive aphasia, corticobasal degeneration, progressive supranuclear palsy, or ALS with FTD. The individual progression of their neurodegenerative process will also play a role in their care needs and changes over time.

Before admission:

- Identify potential triggers for problematic behaviors, particularly those associated with agitation and aggression. Working with the family to identify and document when and how such behaviors begin is essential in developing a plan to avoid, prevent, and respond to them in the residential setting. Know that persons with FTD can have very sensitive fight-or-flight reactions; even a small trigger can cause a big reaction. Repetitive or compulsive behaviors, meanwhile, are often triggered by visual cues. Do your best to eliminate or mitigate those triggers in your environment or approach.
- Create an initial behavior plan around any existing behaviors observed or reported by family in the home. Some people with FTD have significant apathy and lack initiation to address personal needs. Develop a script or guide outlining ways to respond to those behaviors based on what the resident's family reports was effective at home and distribute to staff for their use.
- Create a crisis plan with family to prepare them for the potential for hospitalization, what would necessitate it, and its ramifications. Developing a plan for this worst-case scenario not only prepares the resident's family, but it can also make other concerns about adjusting to a residential facility seem less daunting.
- If the facility does not already have a connection to a neuropsychiatrist, geriatric psychiatrist, or behavioral neurologist with dementia and/or FTD experience, evaluate and confirm one. This type of specialist may also be someone the family has already worked with. If possible, determine that they will be available to make medication changes, if needed, in the first few weeks after move in. The current neurologist may consider starting a temporary medication for the added stress prior to the move.

During the initial period after admission:

- People with FTD may be more likely to perceive threats than persons with other dementias. Staff should pay special attention to any signs of agitation, especially in the first few weeks. These signs of agitation may be individual to them. It is key to know these signs in advance from family members, or monitor for them when the residents first move in. When providing care, if you notice that the resident is getting agitated or upset, immediately back off and reapproach later. If you see them getting agitated in large crowds or in noisy environments, staff should engage with them and escort or redirect away from the cause of agitation.
- People with bvFTD may have a flat facial expression or blank stare when approached with a request or direction. This blank stare reflects slower information processing but especially in a younger, healthy-looking person may be misinterpreted as resistance by staff not familiar with it and lead to escalation of a situation into a crisis.
- If their general health permits and the individual is interested or restless, plan for vigorous physical activity. As many residents with FTD are younger, they can benefit from exercise to help with sleep or to manage the anxiety that may accompany this diagnosis. Build daily exercise into the resident's care plan.
- Behaviors are often expressions of an unmet need. When you witness a behavior you were not expecting or do not understand, investigate by collecting data using an ABC Chart or the DICE approach. This will give you objective data about what was happening when the behavior was occurring, and give you clues as to what need the person with FTD was trying to fulfill.

- Plan for and provide opportunities for relaxation and downtime. Deep-breathing techniques or meditative exercises are good tools to employ when a resident becomes agitated.
- Especially in the first few weeks, focus less on tasks like showering and more on building rapport and trust with the resident. Younger residents often interact more naturally with staff of similar age than older residents.
- When a resident becomes upset, acknowledge and validate their feelings. By trying to soothe them or change their mind about being upset before acknowledging their feelings, we are telling them that their feelings are not valid or important. Acknowledging their feelings confirms that you see and understand. Using language like "I can see you are upset/angry/frustrated/sad" can go a long way to defusing a situation before it escalates.
- For residents with FTD language variants, communication difficulties can be frustrating and lead to expressions of anger when they cannot make themselves understood. Create personalized communication boards with pictures of people, places, and items that they commonly discuss. And as always, practice patience.
- Persons with FTD may not be able to understand or follow verbal cues or direction, particularly if they have been diagnosed with a language variant. Teach staff nonverbal communication techniques, and practice with them regularly. It helps when giving a direction, to move slowly and demonstrate what you are going to do before you do it.
- Redefine success for these residents. Expect at least 12 weeks of transition. Acknowledge and celebrate small improvements over time.

Now and ongoing:

- Seek out FTD-specific training for your staff. AFTD may be able to point you to resources in your area, provide training materials, or even arrange a virtual training. Knowing the differences between FTD and other dementias is critical for staff to have informed responses to the specific behaviors that, while common in FTD, may be unfamiliar to them. ■

NOTE: Never assume that all people with FTD disorders will have behavioral symptoms.
Use customized approaches based on each individual resident.