

Finding the Way: Successfully Transitioning to Residential Care



Sean and June's Story

Shortly after Sean was diagnosed with behavioral variant FTD at 49, his wife, June, realized she could not care for him by herself. Sean was at home all day after retiring early due to his FTD, and the couple's only child, Sarah, was away at college. While Sean was strong and physically active, he lacked self-awareness of his illness. His impaired decision-making and judgment, combined with his newly impulsive behavior, required near constant supervision. One particularly challenging behavior was his penchant for going on unaccompanied walks – while Sean would usually return to his house after an hour or so, occasionally he would trek all the way to his old office, some five miles away.

June decided to hire a caregiver to come by and spend time with Sean in the mornings when he took his daily walks. After a protracted search for a home care aide who was familiar with FTD, June hit the jackpot with the third agency she tried. The aide sent by that agency, Marcella, seemed well versed in FTD symptoms and care and provided support for Sean in a person-centered way. She understood the importance of engaging with Sean during his walks, talking to him about things he found interesting, which distracted him from walking to his old office. Curious as to what the third home care company had done differently, June learned that it used resources from AFTD to train their caregivers and prepare them for aspects of dementia care that are unique to FTD.

Over the next year, Marcella patiently learned his needs and what triggered his challenging behaviors. Importantly, she discovered that Sean could be redirected to the types of physical activities he had enjoyed before his diagnosis, such as walking Rover, the family dog, shooting hoops, and exercising. She further noted that Sean talked a lot about cars and spent time looking at automobile magazines. In the market for a new car herself, Marcella engaged Sean in conversation by asking for his thoughts on specific makes and models. Her efforts to engage him were successful, and she reintroduced some pre-diagnosis activities back into his routine, such as washing and waxing the family car and regularly cleaning the garage and basement. When they played basketball they talked about their favorite team, the Celtics.

For families facing FTD, the decision to transition into a residential care facility is often a challenging one, fraught with emotional stress and logistical concerns. But steps can be taken by facility staff to ease that transition.

Employing a person-centered, individualized care plan, combined with creative problem-solving and careful collaboration, can achieve a care transition that honors the person diagnosed and maximizes their quality of life. In the following case study, Sean – diagnosed with behavioral variant FTD, the most common of the FTD disorders – successfully transitions from home- to facility-based care with help from his wife and daughter, a home care worker, FTD support groups, and facility staff and administrators. While other FTD subtypes present differing challenges, Sean's story can provide guidance to healthcare professionals looking to ensure effective care transitions for incoming residents with FTD.

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Finding a Facility

With Sean engaged and supervised every morning, June could finally attend to her own neglected medical care. At a routine doctor's appointment, a lump was found in her left breast. Shocked, she told her doctor that she had been so stressed caring for Sean and taking over all the household management, she had forgotten about herself. Sarah came home to help but was soon overwhelmed. She arranged for a short-term stay in a nearby care facility for Sean so she could better attend to June's care needs.

Sean's stay in the facility lasted less than a day. An administrator called Sarah, saying that he had hit another resident and had proven to be unmanageable. The administrator told Sarah to pick up Sean and take him home. Later, Sarah learned that her father had not, in fact, hit anyone; rather, he had pushed a resident out of his way while walking around the facility.

Even though they felt they were failing Sean by considering placement, June and Sarah knew they needed to find a safe home for him, especially given June's upcoming cancer treatment. But they struggled to find a place that would meet his needs. They began looking at memory care communities, hoping they would be a better fit. June reached out to the AFTD HelpLine, where the HelpLine advisor offered resources, questions to ask facility administrators, and suggestions on what to look for. The advisor also referred her to a local support group run by an AFTD-affiliated volunteer to see if they could recommend a nearby facility. June was not aware the group existed, and she started attending. AFTD also recommended an affiliated support group for Sarah, one specifically tailored to young adults caring for a loved one with FTD. Both Sarah and June found it refreshing to find others who understood FTD and their caregiving journey. They also learned a lot: Attendees from both support groups told them about nearby facilities that had successfully provided care to their family members.

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An AFTD HelpLine advisor suggested questions that June could ask administrators to help her find the right residential facility for Sean.

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 (or bvFTD, the focus of this issue's story of Sean and June), 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 the 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.

A Successful Care Transition

Based on this new information, Sarah and June decided on Eagleview, a local memory care community. Its administrator and director of nursing were eager to learn more about both Sean and FTD and contacted AFTD for resources to help train their staff prior to admission. Before Sean was admitted, June met with the facility's dementia specialist to create a care plan. They discussed his preferred schedule, compulsive behaviors, triggers for agitation (noisy, crowded places; being rushed or physically pulled or

pushed), and other information necessary to provide the best care for Sean. They even talked about things Sean had enjoyed in the past that could be helpful in devising meaningful activities for him.

Sean moved into the facility on a Monday when management was on site to help with the transition. June hired Marcella to assist with his transition during the first two weeks. It took a month or so for the staff to learn Sean's routines and needs, but eventually, he became successfully established in his new home.

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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.

(see TIPS, next page)



“Sean’s Way”

One of the reasons June had selected Eagleview was its “walking circle,” a path in an enclosed courtyard that residents were encouraged to follow. Sean enjoyed walking, and it became part of his daily routine: He would wake up and eat breakfast, then walk the circle until lunch. After lunch, he went back to the circle and walked until dinner.

One day after lunch, staff heard a resident screaming. They found Sean pushing the resident in her wheelchair around the circle. They were able to intervene but told the director of nursing that they were concerned about other residents’ safety when Sean was in the walking circle.

During a care discussion after the incident, staff suggested several ways to try to solve the problem. Eventually they agreed to put tape on the floor to establish a path just for Sean – which they named “Sean’s Way” – so that other residents could safely walk on the walking circle. Sarah and June recruited friends and family to accompany Sean on the new path to help him get accustomed to it. The staff continued to monitor his walking and reported that “Sean’s Way” was a success.

Sean also got to spend time with Goldie, the community’s yellow lab. Like Rover, Goldie was a very relaxed and sweet dog and quietly visited residents during the day. At the end of each day, when Sean liked to relax in the community room, Goldie would jump onto the loveseat with him and put her head in his lap. Although Sean didn’t smile or show any emotion, he did allow Goldie to sit with him sometimes for hours at a time. Eventually, staff worked to engage Sean in a men’s activity group where they talked about cars and basketball and watched car races and Celtics games.

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- 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.

Addressing a Troubling Symptom with Creativity

Over time, Sean's enthusiasm for walking developed into a compulsive behavior. He started the moment he woke up and didn't stop until he went to sleep; he no longer even stopped to eat. Sarah and the staff noticed his clothes were getting looser and he was losing weight, but no matter what the staff tried, they could not get him to pause for meals.

One day one of the caregivers decided to see what would happen if they handed Sean a peanut butter and jelly sandwich while he was walking. Surprisingly, Sean ate the whole sandwich. The aide informed one of the facility's nurses, who worked to adjust Sean's care plan to allow him to eat finger foods while walking. Sarah brought in a cup with a lid and straw so that Sean could drink smoothies and milkshakes while walking, to increase calories.

As part of a public-education series about the various types of dementias (which was open to family members of residents), Eagleview invited an AFTD volunteer to present a session called "Frontotemporal Degeneration: The Most Common Dementia Under 60." Many of the people in the audience had never heard of FTD. The session helped to dispel some of the confusion and misunderstanding about younger people, like Sean, who lived in the community. Staff agreed that the session led to greater understanding and acceptance among residents and family members toward Sean.

June, Sarah, and the community staff had to work together flexibly and creatively to adjust Sean's activities and care as his FTD progressed, but he was able to live comfortably at the facility until his death two years later. Sean passed away at the facility with Sarah, June, and staff at his side. After Sean's death, community staff hung a sign near the walking circle path in honor of "Sean's Way." ■

Staff FTD education: Finding the Way can be used to train staff at your organization. Go to page 8, for Finding the Way: Discussion Questions.

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No matter what the staff tried, they could not get Sean to stop walking long enough to eat meals.

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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.

(see SYMPTOMS, next page)

(SYMPTOMS, continued)

BEHAVIORAL SYMPTOM	Practical Examples, Interventions, Additional Information
Apathy/Lack of Motivation	
<p>Indifference, lack of interest, or inability to begin or initiate previously meaningful activities. May include:</p> <p>Loss of interest in hobbies, and personal relationships</p> <p>Neglect of personal hygiene</p>	<p>A person used to independently ride a bike in their community. They are no longer able to initiate this activity on their own.</p> <ul style="list-style-type: none"> • If guided to a stationary bike, and supported to initiate riding, they may begin to ride <p>A person can no longer initiate or follow the steps in a task, like putting on clothes in the correct order.</p> <ul style="list-style-type: none"> • If the objects involved are laid out, and they are cued and encouraged, they can execute the steps involved
Disinhibition	
<p>A loss or lack of restraint based on social norms, leading to inappropriate behavior and impulsivity. May include:</p> <p>Making uncharacteristically rude or offensive comments</p> <p>Ignoring other people's personal space</p> <p>Touching strangers or engaging in inappropriate sexual behavior</p>	<p>Calling another resident or staff fat (or using an ethnic slur, etc.) directly to that person, or close enough that they can hear it.</p> <p>Approaching other people as if they are acquainted, and possibly hugging or kissing them – even children.</p> <p>Talking to strangers about very personal issues.</p> <ul style="list-style-type: none"> • 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	
<p>Binge eating or compulsive eating</p> <p>Craving carbohydrates or sweets</p> <p>Eating only specific foods</p> <p>Increased or first-time use of tobacco products</p> <p>Excessive water or alcohol consumption</p> <p>Attempting to consume inedible objects</p>	<p>Taking food from someone else's plate.</p> <p>Gorging on food to the point of vomiting.</p> <p>Eating just certain things, like only eating the red M&M's or a certain type of candy.</p> <p>Continuously searching for and/or eating food.</p> <ul style="list-style-type: none"> • 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	
<p>Loss of warmth, empathy, or concern for others. May include:</p> <p>Indifference to notable events (e.g., death of a family member or friend)</p> <p>Failure to recognize that others are upset or unhappy</p>	<p>Laughing when another resident falls, is upset or in distress.</p> <ul style="list-style-type: none"> • 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

(see SYMPTOMS, next page)

(SYMPTOMS, continued)

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.	<p>Repeatedly talking about the same topic or story over and over.</p> <p>Continuously whistling, drumming fingers in a certain way, or repeating another noise regularly or continuously.</p> <p>Repeating words or phrases.</p> <p>Hand rubbing and/or clapping.</p> <p>Watching the same television show or re-reading the same book repeatedly.</p> <p>Following a set schedule in an exacting way.</p> <p>Walking to the same place at the same time every day.</p> <ul style="list-style-type: none"> • 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	
<p>May include shouting, name-calling, or physically abusive actions (hitting, pushing, biting, pinching, scratching, grabbing)</p> <p>Can be caused by a change in routine</p> <p>May be abrupt</p>	<p>Things to do or avoid:</p> <ul style="list-style-type: none"> • 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 <p>Remember that aggressive behavior is not purposeful and almost always has a trigger.</p>
Anosognosia	
<p>The inability to recognize or perceive one's illness and/or changes in behavior, and their effects on others.</p> <p>Also referred to as "lack of self-awareness or insight"</p>	<p>They may say, "There is nothing wrong with me," and not understand the need for environmental interventions to protect their safety, decision-making, etc.</p> <p>They insist they are being unjustly required to live in a care facility and that nothing is wrong.</p> <p>They may not recognize or perceive they have FTD.</p> <ul style="list-style-type: none"> • 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 <p>Do not try to argue with the person or convince them that they have FTD.</p> <ul style="list-style-type: none"> • 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

Adapted from family caregiver "Changes in Behavior" chart originally created by Northwestern University. M. O'Hara, S. Weintraub, D. Morhardt, J. Rao, and A. Duhlig. Copyright 2009 Northwestern University Cognitive Neurology and Alzheimer's Disease Center.

Finding the Way: Discussion Questions

A Successful Care Transition

Q: How did the memory care community staff and June work together to help Sean transition to living there?

Prior to Sean's admission, June and the care staff discussed:

- Sean's interests: Cars; basketball; exercises like running, walking, shooting hoops.
- Calming influences: Activities such as walking, calisthenics, dancing, and spending time with dogs or other quiet, relaxed pets.
- Sean's behavioral triggers: Noisy, crowded events and being physically pushed or pulled both triggered anxiety and agitation.

During the initial phase of Sean's transition:

- June hired a home care worker temporarily to work part-time with him at the memory care community to help him adjust to his unfamiliar environment.
- The director of nursing and supervisors accessed educational resources on FTD.
- Care staff spent the first few weeks paying special attention to Sean's needs and preferred activity schedule.
- Staff looked for things that triggered anxiety or agitation in Sean, employing a number of strategies to de-escalate the situation as needed, including redirecting Sean to another location, asking him to help move things, or simply talking about cars, the Celtics, or another of his interests.
- Staff encouraged him to use the facility's walking circle both in the morning and afternoon, enabling him to establish a daily routine that involved physical activity.

"Sean's Way"

Q: At first, the community walking circle was a success. But it became a problem when Sean pushed another resident's wheelchair with her in it, creating a safety risk and causing fear for the resident. How did the community creatively resolve this issue?

At the time of the incident, staff:

- Intervened and redirected Sean to another activity.
- Calmed the other resident and attempted to minimize any bad feelings.
- Reported the incident to the facility's director of nursing.

After the incident, facility administrators engaged staff in a problem-solving and brainstorming activity, asking: How could they support Sean's need to walk while ensuring the safety of other residents?

Some ideas suggested by staff included:

- Reserving the walking circle for Sean's use at certain times.
- Requiring a staff member, volunteer, or an outside aide to accompany Sean on all his walks.

Both were rejected, however – the former for being too limiting to others and too difficult logistically, the latter for being impractical due to staffing limitations and the potential cost to Sean and June.

Further brainstorming led to a potential solution. Using tape, staff created a separate path on the floor that Sean could follow without disturbing other residents. They then helped Sean adjust to this change by taking the following steps:

- June and Sarah recruited friends and family to accompany him on his first walks on the new path, which staff called "Sean's Way."
- After that, friends and volunteers walked alongside Sean two or three times a week.

Staff monitored Sean throughout and were pleased to report to administrators that "Sean's Way" was a success.

FAMILIES AND COMMUNITY CARE STAFF: WORKING TOGETHER TO ACHIEVE PERSON-CENTERED FTD CARE By Sandra Grow, RN

During a loved one's transition to a residential facility or care community, most family caregivers will want and expect that the care they receive is as individualized and person-centered as the care they provided for years at home. In FTD this can be particularly challenging. To achieve this goal, family caregivers will need to be strong advocates for their loved ones, teaching healthcare professionals ways to manage FTD's unique symptoms and explaining that their behaviors are not willful, but byproducts of their dementia (which, given the younger age of onset in FTD, can be difficult for providers to understand). The following is a personal account of how one FTD family caregiver learned to successfully partner with facility staff to talk about challenges, try creative solutions, and achieve person-centered care.

At the age of 54, Karl, my physically fit, active husband of 35 years was diagnosed with behavioral variant FTD. His symptoms included poor judgment, impulsivity, and an inability to recognize that anything was wrong with his actions. For these reasons – combined with newfound time on his hands due to the loss of his job – Karl presented safety concerns while he was home alone and I had to work. An adult day program provided supervision and activity for Karl for a few years. When his care needs progressed, I was faced with the difficult task of seeking a facility for 24-hour care. Some of the staff at the facility I chose had never heard of FTD, and although Karl was in a secure unit with other residents living with dementia, staff were not accustomed to some of his behaviors. I worked to learn the names and roles of the staff members, collaborated with them on his care plan, and put up photos and information about Karl so they could know the person he was.

Caring for the person he had become was the next step in the journey, one that required me to partner with the facility to respond to the day-to-day challenges. First, I learned that the plan of care was often several pages long, and that the direct care staff primarily relied on the Kardex tool, or assignment sheets, for guidance on his care.

Karl had a very strong grasping reflex. Once he grabbed an object, he was often unable to release it. This caused problems. For example, while Karl was willing to shower, he would often grab the showerhead's hose and refuse to let go, spraying staff members in the ensuing struggle. I knew I needed to educate the staff that his grasping reflex was not done out of aggression but

was rather a symptom of his FTD. I also brought in rubber toys to put in his hands before he got in the shower, making sure that this intervention was noted on his care Kardex for bathing and dressing.

This became my two-stage approach to any of Karl's behavioral issues – first, educating staff to help them understand his behaviors, and second, collaboratively brainstorming until we agreed on a successful, easily repeatable care strategy. While this may sound simple, it often took a good deal of trial and error to find the right person-centered solutions, to think of the best way to communicate them, and to ensure that they are used consistently. When I became frustrated, I worked on recognizing and acknowledging my feelings of grief and loss as the disease progressed. Patience was also important in helping with teamwork and collaboration.

As Karl's disease progressed, we continued learning how to adjust his changing care needs from all the facility disciplines. Dietary helped with eating issues and provided adaptive options. Speech therapy had tools to help with communication as Karl lost the ability to speak. Physical therapy helped keep Karl safe as mobility issues arose. Options for palliative care and, eventually, hospice in the facility setting came from the social worker.

My training and work as a nurse did not prepare me for this diagnosis. A physician referred me to the AFTD website to get information specific to this disease. I continued to use AFTD resources to help educate the staff about Karl's disease and to gain ideas about dealing with different behaviors. ■

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DEVELOPING A PERSON-CENTERED FTD CARE TEAM AND PLAN OF CARE

by Susan Hirsch, MA

Successful care for persons living with frontotemporal degeneration (FTD) in a facility setting begins with staff education. This includes training on a broad range of FTD topics, starting from “what is it?” and then covering FTD subtypes, causes, and symptoms; the needs of persons diagnosed; approaches to care; and successful interventions.

Ongoing staff and family participation in the individual’s plan of care is crucial. After the initial phase of transition into the community, staff should continue to rely on the individual’s history (including, but not limited to, their medical, social, and psychological background, their primary symptoms, and which care approaches have worked in the past), as well as their current status and needs. This will best position the team to develop and then implement positive care approaches that are individualized, creative, and adaptable as the needs of the person with FTD change.

Creating and updating plans of care that address the individual’s changing needs can be challenging. Being open to investigating, testing, and evaluating different approaches, and then clearly communicating the plan with everyone is critical to success.

Following are some recommended approaches to guide person-centered FTD care:

Communication Approaches

- Use basic communication techniques including: speaking slowly and clearly; using simple, shorter sentences rather than open-ended questions; waiting for responses
- Do not argue with the resident or try to get them to think “logically”
- Smile! Persons with FTD often continue to understand facial expressions. Although the resident may present with no affect, that does not mean they will not respond positively to yours
- Residents with FTD may connect more with staff (based on age, interests, music) than other residents, who will likely be older
- For those with communication challenges, create a communication notebook (an album of photos with names of people and objects)
- Use nonverbal communication, including gestures or drawings
- Use lists of words or phrases that are generally understood and/or often used by them
- Work with the family or doctor to obtain speech and occupational therapies for assessment and interventions as needed

Behavioral Approaches

- Do your best to create a low-stimulus environment
- Avoid overstimulation: limit noise, bright light, number of people, distractions
- The resident may not think they have FTD. Teach staff that this lack of awareness – known as “anosognosia” – is a hallmark FTD symptom

- The resident’s facial expressions may be blank or appear threatening – do not take this personally
- Pay attention to nonverbal cues that the person diagnosed is anxious and/or agitated. People with FTD may not show frustration via facial expressions

Programming Approaches

- Create and maintain the resident’s daily routine; post their schedule for accountability with staff. This may support the resident to engage with activities.
- Individual programs may be more effective than group programs – post their daily schedule in their room
- If the resident attends group programs, let them sit near the exit so they can easily leave if they become overwhelmed
- Since persons with FTD may not self-initiate program activity, help them to initiate active involvement when possible
- Provide a safe outdoor space for the individual to walk or sit
- Encourage or help to create a personal music playlist for individual activity
- Note that reminiscence therapy may not be effective, even though memory is typically less impaired in FTD than in other types of dementia
- Repetitive activities may be effective. Examples include sorting objects (papers, coins, cards, pegs), folding, doing puzzles
- Invite and include the resident’s family in programming as much as possible

(see *DEVELOPING*, next page)

*(DEVELOPING, continued)***Caregiving Approaches**

- Follow individual's usual routine. For example, if they bathe or shower first thing in the morning, try not to deviate from that
- Be aware of the resident's abilities, and encourage independence when possible
- Provide verbal, visual, and physical cues to encourage initiation of a care activity or task
- Tell the individual what you are going to do before proceeding. Then go slowly and explain each step
- Be aware of their personal space. Allow at least an arm's length to provide care from a safe distance when providing care
- Give the resident something to hold while providing care
- Know that bowel incontinence may occur in early stages of FTD, even before bladder incontinence
- Adjust your approach to care as the disease progresses. The person diagnosed may not realize they can no longer complete tasks like they used to – you may need to provide encouragement, persuasion, or distraction
- Consider providing praise or rewards for completed care tasks, whether a favorite activity, food, or beverage, or simply words of encouragement ■

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 guest contributor, Jennifer Pilcher, PhD, the founder of Clear Guidance LLC, a care management practice that specializes in working with clients and families challenged with atypical dementias, including FTD.

For permission to reprint this material in whole or in part, contact Esther Kane, AFTD Director of Support & Education, at ekane@theaftd.org.

To join the Partners in FTD Care mailing list, or to view the full archive of back issues, visit www.theaftd.org/for-health-professionals/partners-in-ftd-care