Partners in FTD Care

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

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 ■