

Case Studies in Frontotemporal Degeneration

Case 3: Behavioral variant FTD

History prior to placement

Cathryn Beech is a 63-year-old disabled CEO with a three year history of behavioral change. She was widowed at a young age, raised two children alone, and started her own corporation. She had always been assertive and outgoing. Three years ago she was asked to leave her position for inappropriate behavior with a younger married executive. In addition her business abilities were slipping; she made several large inappropriate purchases including a mansion and five sports cars, all the same make. She spent her entire fortune, several million dollars, spending frivolously and entering sweepstakes. Almost broke, her daughter made arrangements for Cathryn to rent an apartment near her home.

Two years ago, Cathryn became obsessed with sales and was stopped by the police for driving 75 mph and crossing the center line to pass slower traffic on the main city street. She explained that there was a sale at the mall and she wanted to get there by 5:00. The police confiscated her license and her daughter drove her home. Cathryn promised not to drive again. Two weeks later she was again arrested for unsafe driving. While Cathryn verbalizes she is no longer able to drive, she continues to try. She has no insight into her lapses. She continued to be obsessed with shopping. Cathryn's daughter has tried reasoning with her to no avail. Her daughter pursued guardianship and placed her mother into adult day programming. Cathryn did not want to be associated with "old people," and refused to attend.

Individualized Community-based Interventions

- Evaluation for diagnosis was accomplished at a large medical center by an interdisciplinary team that included behavioral neurologist, advanced practice nurse (APN), social worker, speech pathologist, occupational and physical therapies.
- Family followed up with social worker and APN for long term care management strategies, coordination of family and community resources, and ongoing specific FTD behavioral variant education. The family was referred to AFTD for additional resources and support.
- A guardianship and conservatorship were obtained empowering her daughter to make decisions on Cathryn's behalf and pay bills. Her daughter applied for SSDI; Cathryn's credit cards were cancelled and replaced with gift cards for a set amount.
- Internet connections were eliminated from the computer and replaced with games. Phone solicitors were blocked. Activities that would trigger old obsessions (clipping coupons and advertisements) were avoided.. Family/friends provided limited choices in other activities, such as supervised shopping, walking, and going to lunch after the lunch rush was over. They played cards and games that were well-preserved.
- The physician reported Cathryn to the Department of Motor Vehicles and her license was rescinded. Her car was sold and her daughter kept her own car keys away from her mother.
- In-home services, adult day programming, housekeeper, companion, and Meals on Wheels were all refused. Cathryn's daughter agreed to provide food and oversee eating habits.

Post-admission to long-term care setting

Her daughter sought an assisted living facility with an independent living apartment but Cathryn repeatedly picked arguments with residents and staff. She walked away from the facility repeatedly and hiked to her apartment, now rented by someone else. She broke and entered. The decision was then made to place Cathryn in a secured memory care unit within the assisted living complex.

In the memory care unit, Cathryn presents as a pleasant bright woman who appears younger than her stated age. She does not bathe or groom herself without considerable direction. She has a poor appetite and spends much of the day sitting in her apartment. When she does attend activities she often becomes disruptive. She has spontaneous bowel movements in the dining room after each meal, a stress response to the stimulus in the dining room. Dining companions frequently complain of her poor table manners and request to be seated with another resident. This does not bother Cathryn as she is totally self-absorbed.

She has typical obsessive behavior associated with behavioral FTD including insisting on watching “General Hospital” five to six times per day, watching reruns of her alma mater’s football games every day, and sorting loose change. Cathryn continuously argues with staff and tries to manipulate staff to bring her catalogues and a credit card. She has caused some splitting among staff as some feel she should not be in a memory care unit (“She’s just fine!”). Others feel she is rude and purposeful. She routinely violates other resident’s needs for privacy, having no understanding of the needs of others. The staff is demanding they discharge her or drug her...but there is nowhere else for Cathryn to go.

Post-admission Person-Centered Interventions

- Team meeting with family, staff, management, and physician to identify effective redirection approaches, personal care techniques, need for increased monitoring at certain times of day, and behavioral interventions.
- Staff education - care management team visit to the facility to orient staff on specific care needs, individual issues, preferences and potential challenges i.e. resistance to care and importance of unified, consistent approaches. Including family in this meeting as appropriate is encouraged.
- Behavioral approaches are central – provide individual, small group activities of interest; enable her to complete personal care as much as possible (follow routine and preferences); observe and positively intervene when arguing or violating privacy; provide snacks of choice with 1:1 attention; provide opportunities to make choices, i.e. clothing, timing of personal care, food.
- Structured but flexible routine with no activity lasting more than 60 minutes. Intersperse high intensity activities with quieter ones. Provide in-room activities such as her television with DVDs of “General Hospital” and football games. Have items for her to sort. Encourage attending activities but do not expect resident to resident relationships. Focus on brief physical activities, such as exercising, walking, music, dancing, or painting.
- Recognize that the dining room has too much stimulus and arrange for a small dining room or in her apartment. Monitor dietary intake for stuffing mouth with food, to avoid choking, and eating non-food items.
- Psychiatric assessment/treatment for disruptive social behaviors, manipulation, invasiveness, sexual gestures, and arguing. Work with staff to avoid splitting.

For more information on behavioral FTD see: www.theaftd.org: What is FTD/ The FTD Disorders