

Case Studies in Frontotemporal Degeneration

Case 2: Behavioral variant FTD presenting with apathy

History prior to placement

John Rider is a 49-year-old disabled father of three teenage sons and former state senator. John is 6'5," lean, athletic, and handsome. As a politician he has always been outgoing, intelligent, and socially charming. He resided with his wife, Mary, and youngest son in their own single story home. Three years ago John began to experience difficulty with his political career. He began to tell constituents exactly how he felt about their requests and took increasingly long lunches. One day he stopped at an automobile dealer and ordered a top of the line Mercedes Benz, which he could not afford. The car arrived but John couldn't figure out how. After that he voluntarily gave up driving.

John then decided to ride his bike which he did for long hours. He wrecked several bikes but never knew how the accidents occurred. Fearing for his safety, Mary removed the bike and replaced it with a stationary bike. John refused to use it and walked to the nearby junior high school and took students' bikes for the day that Mary then returned. Because of their ages Mary needed to continue to work but could not find respite workers for someone John's age. The adult day program accepted him but John refused to attend; the town librarian offered to let John "volunteer," however he did not show-up.

John began to spend increasing amounts of time sitting in his recliner, denying he was tired, depressed, or lonely. Sometimes he would turn the television on but never changed the channel. Mostly he just sat. John would forget to prepare lunch while Mary was at work and he began to lose weight. Mary prepared sandwiches for him and left them in the refrigerator but they were never eaten. She finally started to leave them by his recliner but these too remained uneaten. John stopped bathing, shaving, and doing oral care over the next few months. He had one outfit he wore every day, arguing if Mary tried to wash it. Desperate for help, Mary found the only option was to divorce John and place him in long term care.

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 education specific to apathetic presentations of FTD. The family was referred to AFTD for additional resources and support.
- Special counseling was provided to John's teenaged son.
- Family obtained durable power of attorney and applied for Social Security Disability. Alternative financial options for care were explored. Because of his age John qualified for



Partners in FTD Care

no services – although the day care center agreed to make an exception. Finally the couple sought legal advice and ended divorcing. They continued to live as man and wife.

- SSRI Antidepressants were prescribed to combat apathy for anxiety, apathy, and depression.
- Behavioral approaches included activities of interest with a companion, i.e. going bowling, playing basketball, discussing current events/sports, walks; and structured opportunities for socialization, i.e. lunch. Matching outfits were purchased and changed when bathing; involve in personal care as much as possible; provide opportunities for choices, i.e. TV programs, snacks, time of day for personal care.

Post-admission to long-term care setting

Admitted to the Alzheimer's wing of a long term care facility, John was not happy. Tall, dark, and brooding he spent days staring at other residents and staff with a look that was at once angry, filled with contempt, and empty. The staff decided it would take several of them to provide care. John became somewhat aggressive when bathed and medication was provided to calm him. He reacted to the medication with increased agitation and aggression. He was admitted to a geriatric behavioral health unit for two weeks and returned to the facility quiet and subdued. He could now be bathed and dressed; however, he still did not eat.

Post-admission Person-Centered Interventions

- Team meeting with family, staff, management, and physician to identify effective redirection approaches, personal care techniques (coordinate bathing with family re: routine and preference), 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 - limit 1-2 caregivers during care (follow routine and preferences); approach with calm, simple communication approaches and enable choices; provide individual, small group activities of interest, i.e. current events, sports, walking; provide low-stimulus environment for eating and personal care; approach calmly when "staring" – use positive communication techniques to redirect.
- John is unable to initiate activity so staff must begin him in ALL activities providing simple direction, one at a time. Engage in individual/small group activities based on past interests, i.e. politics, socialization, athletics, biking. If possible, hire companion for outings and physical sports. Family will take to basketball games.
- Meal times may require individual monitoring and encouragement to eat by staff and/or family. Additional recommendations from speech therapy.
- Attention to core strength and balance from physical therapy indicated; fall precautions.
- Psychiatric assessment and treatment for on-going monitoring of apathy and aggression, and reduction of mood-controlling medications.

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