

Case Studies in Frontotemporal Degeneration

Case 1: Primary Progressive Aphasia

History prior to placement

Rinda Stout was a 58-year-old woman who had a three-to four-year history of difficulty speaking; later diagnosed as primary progressive aphasia (PPA) agrammatic/non-fluent type.* Rinda resided in a small rural community where she worked at a windshield fabrication plant for over 20 years. She was married to a veteran and has an adult daughter. When Rinda began to have difficulties with language, her husband filed for divorce. At first she had trouble finding certain words; then speaking in sentences became impaired. She continued to work and live alone with support from her daughter, sister, and mother, all of whom reside in a nearby city.

As the disease progressed, Rinda lived on disability insurance and functioned due to special equipment, community support services, and supportive health professionals. Local police and firefighters became part of the care team. Two years ago Rinda became mute and her family noted a change in her ability to concentrate. Her yes/no responses were no longer accurate. She neglected her home, stopped grooming herself, and lost weight. A decision was made to place Rinda in a nursing facility with a memory care unit.

Individualized Community-based Interventions

- Evaluation for diagnosis was a lengthy process, ultimately 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 and Rinda followed up with social worker and APN for long term care management and strategies, coordination of family and community resources, and PPA specific education.
- Family obtained durable power of attorney and applied for Social Security Disability (SSDI); Rinda qualified for Medicaid to pay for limited community-based in-home services.
- Because of her anxiety due to inability to communicate, Rinda chose not to participate in adult day programming. Home health was provided with companions for preparing meals, personal care, assisting with shopping, companionship, and transportation. The family was provided with educational materials and referred to the AFTD for additional resources.
- Rinda was prescribed an SSRI-type antidepressant for anxiety and depression.
- Speech therapy consults prior to Rinda becoming mute provided techniques to help with communication, such as communication boards and simplifying communication. Once mute, she needed swallowing studies every six months to check for incomplete swallowing.
- Safety in the community was monitored. Driving was evaluated periodically and a GPS device placed in her car. The family obtained a Medic Alert/Safe Return bracelet. Rinda was provided with a letter from her physician to carry in her wallet explaining that she had a neurodegenerative language disorder and was not driving under the influence. Driving

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cessation plans were developed and discussed at each clinical visit.

- Family provided calorie dense foods and supervised both eating and medications. The physician minimized medications to the very essential and one dose per day. Family obtained an electronic medication dispenser that dispensed and had an alarm to let her know when to take the medications.
- Activities: continued with religious participation, friends took her for walks, and she enjoyed exercising at the senior center.

Post-admission to long-term care setting

Once placed, Rinda was unhappy and let everyone know by wailing loudly day and night. Her behavior became very disinhibited with inappropriate sexual comments and advances toward male residents. When staff tried to redirect her, she became aggressive and remained agitated. She resisted personal care. She began to eat everything she saw, including food from other resident's plates and non-food items, such as paper products and cosmetics. Six months later she became completely incontinent and had increasing difficulty coordinating chewing and swallowing. The staff worked tirelessly to try and meet her special needs. As the last months passed, Rinda's risk of choking increased and she died choking when she put too much food in her mouth at lunch one day.

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.
- 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, safety concerns. Staff must know that resident can neither produce nor understand language. Include family in this meeting as appropriate.
- Speech therapy consult for altered diet for chewing/swallowing issues and feeding techniques; non-verbal communication, i.e. gestures, pictures. Considerations for meal-time: seating location (individual setting with cloth versus paper products); individual monitoring by family/staff to watch for pica (eating non-food items) and stealing food from other resident's plates.
- Behavioral approaches include redirecting to interest of choice/snack when wailing, wandering, aggressive, etc.; approach with calm, simple communication techniques (focus on non-verbal cues, picture board); provide individual, success-oriented programs, i.e. massages, make-up, music; incorporate past routine into daily schedule, i.e. towel-type, preferred time of day for bed and bath. Offer doll or stuffed animal to cuddle for comfort.
- Engage in activities built around past and present interests (position at the plant, hobbies). Encourage physical activities such as music, dance, and daily exercise; prioritize 1:1 engagement.
- Physician assessment for weight loss, behaviors, and swallowing issues; psychiatric assessment/treatment for wailing, hyper-sexuality, aggressiveness, compulsive eating behaviors, and possible depression (post-admission).
- Supervise and minimize interaction with male residents.
- Hospice referral once she started choking, stopped walking, or developed failure to thrive.

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