

Welcome to the first quarterly newsletter for healthcare professionals interested in frontotemporal degeneration. Partners in FTD Care is your resource for case-based learning to build knowledge and confidence in serving people with FTD. Each issue presents an actual care scenario that can be used easily in staff training.

Meet Margie Eline

Margie Eline is a 51-year-old well-known local artist. Her husband, Larry, and she have custody of their five-year-old grandson, Luke. Margie had spent her days caring for Luke, painting, attending exercise classes, and volunteering for local organizations. All describe her as sociable, easy-going, generous and intelligent.

Family and friends noticed changes in her behavior and mood about two years ago. She spent her days in bed watching television. She was obsessed with eating bags of chocolate chip cookies and gained forty pounds. When Larry tried to stop her from buying cookies, she screamed and even punched the wall one time. Her personal hygiene became neglected. After being misdiagnosed and treated for anxiety disorder, depression, and obsessive-compulsive disorder without improvement, she was seen at a dementia clinic. She was diagnosed with behavioral variant FTD (bvFTD). As her need for care and constant supervision increased, Larry recognized that placement in a dementia-specific personal care facility was necessary.

Margie has been at the secured facility for four months. She constantly takes food from other residents' rooms, and often from their plates. She has broken the safety latches on the community refrigerator and cabinets to find food. This has resulted in several verbal altercations between Margie and the other residents. Families complain to the management and want her monitored at all times or discharged. She refuses to take a shower or change her clothing. She yells and interrupts the leader during group activities. She enjoys going to the facility hair dresser for manicures. She responds well to individual staff visits, and remains quite knowledgeable about art. She, however, no longer self-initiates painting.

Margie attends the dementia clinic on an outpatient basis. Her medications continue to be monitored and changed. Some are effective for a period of time; others worsen her behaviors. She is now a borderline diabetic. Larry visits weekly for a short period of time. He no longer brings Luke to visit because it is too upsetting for everyone. Margie holds onto Larry when he tries to leave, and accuses him of having an affair. During a care conference, Larry shared, "I don't know how much longer I can do this."

Discussion Questions:

- 1) What signs and symptoms of behavioral variant FTD (bvFTD) are exhibited by Margie?
- 2) What approaches could the team try?
- 3) How has bvFTD affected Larry and Luke?
- 4) What resources and support are available for Margie's family?

Partners in FTD Care is an education initiative of the Association for Frontotemporal Degeneration that brings together health professionals, experts and families to promote understanding of FTD and to develop best practices in community care.

PURCHASE YOUR PARTNERS IN FTD CARE TRAINING PACKET TODAY!

Order **Partners in FTD Care** training materials to introduce your staff to frontotemporal degeneration. Packet includes: AFTD's film - *It Is What It Is* on DVD, new print materials for facility staff, and instructions on how to connect with AFTD for continuing education opportunities. Visit AFTD's website to order online: www.theaftd.org.

SIGN UP FOR OUR NEWSLETTER!

If you found this newsletter on AFTD's website or if a friend sent it to you, feel free to sign up to automatically receive it in your email box! Simply send an email to ftdcare@theaftd.org with "Sign Me Up!" in the subject line.



Discussion Questions:

1) What signs and symptoms of bvFTD are exhibited by Margie?

- **Obsessed with food (hyperoral/impulsive acts)** – chocolate chip cookies; takes food off resident's plates, from their rooms and from the community refrigerator
- **Behavioral and emotional symptoms (lack of insight & empathy/change in personality/hyperactive behavior)** – no awareness or concern of how her behaviors affect Larry, Luke or others; yells and interrupts during group activities; verbal altercations with residents; holds onto and accuses Larry when he leaves
- **Personal hygiene (apathy/change)** – refuses to shower and change clothing
- **Stopped activities of interest (apathy/lack of motivation)** – stayed in bed watching television; stopped exercising; golfing; and volunteering; does not initiate painting

2) What approaches could the team try?

- **Food issues** - monitor for time of day when Margie's focus on food is increased; distract with individual activities and consider private duty companion during those times; provide supervision while eating; dine in private area, if needed; store food in secured containers in the community storage and offer for resident rooms; monitor blood sugars; meet individually with other residents' families to discuss concerns
- **Behavioral and emotional symptoms** – speak in a calm, reassuring manner; approach with a positive facial expression – smile; do not argue; limit stimulation, e.g., not too many people or loud noise; request Larry contact a staff member when he is leaving to redirect Margie; distract with conversation; monitor and report effectiveness and side-effects of medications
- **Personal hygiene** – ask about preferences for shower or bath and best time of day; purchase similar outfits, and change during bathing; simplify tasks and encourage to assist; compliment her appearance
- **Activities** – offer/initiate individual activities with staff e.g., social visits painting, manicures with the hair dresser; offer small group or individual exercises and golfing; observe for signs of frustration or being overwhelmed in group activities; discretely redirect from activity; limit and offer specific choices; if Margie refuses, do not force her

3) How has bvFTD affected Larry and Luke?

- Luke no longer visits; Larry is the sole caregiver for Luke
- Larry visits less frequently and is upset when he leaves; feels frustrated/hurt that Margie is indifferent to Luke's and his feelings
- Loss of spouse and grandmother

4) What resources and support are available for Margie's family?

- AFTD (www.theaftd.org) for disease-specific education and support
- Facility and dementia clinic staff – “partnership” with Larry is essential. Include him in care planning meetings to discuss status and care approaches, and provide education/support
- Caregiver support group; connect with other families for education and support

TROUBLES & TIPS

Q: “Some staff members are intimidated by residents who are young, physically fit and do not seem to have dementia. What can we do to serve people with FTD better?”

A: People with FTD have needs that are quite different from those with memory impairment, but share a need for compassionate care.

Behavioral FTD is often marked by a lack of empathy and is sometimes accompanied by a blank stare. These may contribute to staff feeling the person is ignoring them or even angry.

It is important for staff to understand that the person is not aware of the impact of their words or actions on others. They are symptoms of the disease.

Try not to take behaviors personally. Approach the person in a calm, non-threatening manner. Smile. Do not argue or use try to use logic to persuade. Engage the person in individual activities based on current or past interests; avoid overstimulation. Maintain the person's schedule and daily structure.

TELL US WHAT YOU THINK!

Partners in FTD Care seeks to build a community of professionals working together for high quality services. Send us your questions, suggestions for care scenarios and/or needs by email to ftdcare@theaftd.org or call 267.514.7221.

