

## Compulsive Behavior in Frontotemporal Degeneration

Compulsive behaviors are common among people with frontotemporal degeneration (FTD). These behaviors include *simple repetitive movements* (e.g., clapping, rubbing, picking at skin), *complex ritualistic actions* (counting, checking, repetitive trips to the bathroom, walking fixed routes, hoarding) and *stereotypical repetition of words or phrases*, such as “you bet” and “just so.” While most of these behaviors are more annoying than unsafe, some place individuals with FTD at risk of physical harm. Managing these behaviors can be particularly challenging in care facilities where the needs of other residents must also be considered.

### Meet David

David is a 57-year-old former economics professor and marathon runner. He was diagnosed with FTD after returning suddenly to live with his elderly mother when his second wife divorced him. David’s mother and brother noticed major changes in his personality and behavior. For example, he lost his retirement savings after making poor financial decisions, wore the same clothes every day without showering, and laughed when learning of his mother’s diagnosis of cancer. In addition, he ate 10 candy bars daily, stopped exercising, gained 80 pounds over two years and was diagnosed with adult onset diabetes.

David’s mother grew increasingly distressed by his compulsive behaviors. He watched pornography on television from 9 am to noon every day, hoarded food under his bed, and insisted on having meals at exactly the same time every day. When his brother removed his computer from the house, David paced from room to room and shouted “no, no, no” for four hours until the computer was returned. David’s family reluctantly decided to place him in an assisted living facility (ALF) due to a concern for his safety after he began running down the middle of the road and back each time he finished urinating in the bathroom.

During David’s first week in the ALF, staff “buddies” monitored David (in four-hour shifts), accompanying him to meals, activities and outings. David seemed not to miss his computer and watched the large television set in the community room; he particularly liked playing poker. He followed simple one-step instructions to shave, shower and get dressed. Staff observed that after each scheduled activity (meals, games and exercise class), David walked to the large bowl of snacks and fruit on the reception desk and ate 10 pieces of candy. He also returned to the dessert bar three times after dinner each evening. By the end of the first week, David gained 8 pounds.

The ALF called a community meeting with the other residents and explored their willingness to make some changes in the facility routine. The candy and fruit bowls were relocated under the desk and residents agreed to ask for snacks when desired. When David pounded on the desk, he was given 10 tokens to use for poker. In addition, desserts were served individually to residents rather than made freely available. David was given one sugar-free dessert and then a staff member immediately asked him to help set up the evening’s activities in the community room.

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.

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## JOIN THE PARTNERS COMMUNITY: ONLINE FORUM IS LAUNCHED

AFTD has launched a new online forum for people working in adult day services, assisted living, long-term care, home health, hospice or other settings serving people with FTD. Join discussions of best practices in assessment and placement, stages of care, communication techniques, managing behaviors and more.

[Register online now!](#)

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## SERVE PEOPLE WITH FTD WITH CONFIDENCE

People with FTD need access to quality facility care. Partners in FTD Care training materials are available to train and support your staff. Packet includes: AFTD’s film *It Is What It Is*, print material and case studies. Order online at [www.theaftd.org](http://www.theaftd.org) or email us at [ftdcare@theaftd.org](mailto:ftdcare@theaftd.org).



David eventually developed additional compulsive behaviors that offended residents and their visitors. After he finished a meal, he stood up and touched his genital area. Staff was assigned to escort him to the bathroom as soon as he finished eating. During group activities, David snapped his fingers and constantly shouted “bingo-bingo-bingo,” regardless of the game being played. He also began picking his fingers until they bled and developed an infection. His nails were trimmed and cleaned carefully after he used the bathroom. David’s physician prescribes sertraline, a selective-serotonin reuptake inhibitor, to help manage these behaviors.

Several residents asked that he be discharged from the facility. David’s mother and brother requested permission to speak to the other residents to ask for their suggestions. They tried playing music during activities, ignoring the behavior and allowing David to interact with a staff member in a different room. Unfortunately, David’s annoying behaviors continued and he was transferred to a more structured wing with more impaired residents. David seemed unaware of the change in environment and spent time watching the sports channel on the television in his room. Due to the more structured environment, he lost weight, but rarely participated in physical exercise. While disappointed, David’s family understood the reason for moving him. The staff permitted family to accompany David to some activities with the ALF residents, and at the first sign of annoying behaviors, they would leave. Staff members from the ALF frequently visited David, played games with him and escorted him to the outside garden.

### Discussion Questions:

#### 1. What are David’s compulsive behaviors both at home and in the ALF? Which behaviors place David at risk of physical harm?

- At home David eats 10 daily candy bars, watches pornography at set time, hoards food, rigid about timing of his meals and runs down street after using the bathroom.
- In the ALF David eats 10 pieces of candy after every meal and activity, eats three desserts at dinner, touches genitalia after meals, snaps fingers, speaks repetitive phrase (“bingo”) and picks his fingers until they bleed.
- David’s potentially dangerous behaviors include: compulsive overeating of sweets can worsen his diabetes, risk of being hit by an automobile by running down the street and picking his fingers makes him vulnerable to infections.

#### 2. What strategies are used to manage David’s compulsive behaviors?

- The structure of the ALF is most likely comforting to David as meals and activities are scheduled.
- During his first week in the ALF, staff members observe David’s behavior and discuss strategies in a team meeting. This permits the staff to formulate a plan of care and respond consistently to David’s behavior.
- Staff does not argue with David about his behavior, instead they modify the environment as appropriate. For example, candy and desserts are removed from his view. Desired behavior is substituted for unwanted actions (giving tokens instead of candy at the reception desk).
- David is removed from community areas when touching his genitalia and escorted to the bathroom. Staff accepts both David’s non-dangerous behavior and the feelings of the other residents.

## TROUBLES & TIPS

### *New Compulsive Behaviors*

**Q:** *Just when you find a way to manage one compulsive behavior, the person develops another and you just have to start over. How can you stay one step ahead?*

**A:** It can be exhausting to keep up with the compulsive behaviors in FTD. Be careful that your reactions to the behaviors don’t affect your care for the person; discuss ways to manage frustration with colleagues and supervisors so you can return to resident care with a fresh perspective.

Effective interventions require creative thinking. In the case example, David exhibits new compulsive behaviors over time: he unrolls the toilet paper in bathrooms causing the toilets to become blocked; he grabs the remote control changing channels at a rapid rate; he walks continuously around the facility and develops blisters on his feet.

Consider previously successful interventions for strategies to manage new behaviors. Removing sweets from David’s view worked to limit his sugar intake. David might be escorted only to the bathroom in his room and be given a few pieces of toilet paper. Paper and cloth towels should be removed from this bathroom. (*Some interventions, such as limiting toilet paper, may require a waiver, depending on facility regulations.*) Write David’s name on a non-functioning remote control and substitute it for the actual one. While walking is a good exercise, blisters may cause infection. Use movement rather than words; walk beside David and slowly decrease your pace. David will also slow his pace and can be gently guided into a chair.

Your creativity can help people with FTD live safely and with dignity. While you will not be able to change compulsive behaviors, most can be managed through interventions that adjust the environment and incorporate supportive contact by staff.



- It is very difficult to prevent David from picking his nails as mittens are easily removed. The staff keeps his nails short and as clean as possible. They observe for signs of infection.
- David's physician prescribes a medication to help manage his behavior.

**3. In what ways does the ALF show respect for David, his family members, other residents and staff of the facility?**

- The staff understands and accepts his non-dangerous compulsive behaviors as part of his FTD. They monitor him for non-safe actions and take an appropriate course. They provide activities he enjoys after he is moved to a more restricted environment.
- The staff encourages David's mother and brother to participate in problem-solving meetings with ALF residents.
- They listen to other residents' concerns and remove David when his behavior makes them too uncomfortable.
- Supervisors recognize the potential burden of monitoring an individual with compulsive behavior. Staff members are assigned four-hour shifts to interact with David and then are relieved. This also allows all team members to offer creative suggestions for David's care.

**4. What resources and support are available for David's family and the facility staff?**

- AFTD ([www.theaftd.org](http://www.theaftd.org)) for disease-specific education and support.
- Caregiver support group; connect with other families for education and support.
- *Partners in FTD Care* Online Forum for health professionals.

## AFTD's COMMITTEE ON LONG-TERM CARE EDUCATION

*Partners in FTD Care* is directed by a committee of professionals and caregivers dedicated to improving care for people diagnosed with FTD and their families. The AFTD Committee on Long-Term Care Education includes:

**Sharon S. Denny, MA**, Program Director, AFTD

**Sandi Grow, RN**, caregiver  
**Geri Hall, PhD, ARNP**, Clinical Nurse Specialist, Banner Alzheimer Institute

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