

### Hyperoral Behavior in FTD

## Changes in Eating and Managing Related Compulsive Behaviors

Changes in dietary preferences or oral behavior are among the criteria for the diagnosis of behavioral variant frontotemporal degeneration (bvFTD). Changes in eating may include: the development of unusual food preferences; food seeking or opportunistic behavior; binge eating; or eating non-food items. Such behavior – coupled with the ritualistic or repetitive behaviors and diminished social awareness that accompany FTD – contribute to care challenges and health and safety concerns.

### The Case of James McKnight

James McKnight, age 45, played basketball throughout college, and went on to play professionally. At age 30, he retired from professional basketball due to a leg injury, and became a local sportscaster. James still enjoyed playing basketball on community teams. He was well-known for his outgoing personality and community service, and he maintained a rigorous workout schedule and fastidious appearance. He has been married to his childhood sweetheart, Liz, for 25 years.

James interviewed for a national sports anchor position three years ago; he was not selected for the position. The reason James gave for not attaining the position was that he was asked “ridiculous questions.” During the same period, he began missing basketball games and community fundraisers, and he stopped going to the gym. Liz had to remind him to shave and he outgrew most of his clothes. There were complaints about his work, such as mixing up scores and not showing up for events. When asked about those issues, James shrugged and walked away.

Liz persuaded James to see their family doctor. He was prescribed an anti-depressant and a diet (James had gained 40 pounds). Four months later there was no improvement. Formerly meticulous about his weight and one who never ate snacks, he began binge eating. He ate and drank anything and everything in the refrigerator and pantry. When he went to grocery and convenience stores, he grabbed bags of candy and sodas, often eating and drinking them in the store. James refused to go to work and played basketball alone for hours at a time. He became belligerent or walked away when Liz tried discussing these changes. She finally convinced him to see a neurologist, who diagnosed James with bvFTD. Sertraline (Zoloft) was prescribed.

There was some improvement in his binge eating and obsessive basketball playing. However, when James was fired and spent his days at home, these behaviors increased again. He began walking to the local convenience store, and would take candy and soda without paying. Liz had an agreement with the store to pay for whichever items he took. When he became combative with another customer over a candy bar, he was prohibited from returning to the store. Liz and James stopped going out with friends because he would impulsively take food off of other people’s plates, or from a tray a waiter was bringing for another table. On one occasion his binge eating led to an episode of fecal incontinence for which Liz was unprepared. [Read more on incontinence in FTD in the [Winter 2014 Issue](#)]

### Brain Mechanisms in Eating Behaviors

The diagnostic criteria for a clinical diagnosis of behavioral variant FTD (bvFTD) include hyperorality and dietary changes.<sup>1</sup> Changes in several types of eating behavior are possible: altered food preferences; binge eating, increased consumption of alcohol or cigarettes; and oral exploration or consumption of inedible objects (known as Klüver-Bucy syndrome).

There are several mechanisms in the brain that control eating behavior and may be impaired in FTD. Believed to be of particular significance are the satiety and pleasure centers within the orbital frontal region. The amount of pleasure we get from food gradually decreases the more we eat to the point of satiety. This gauge doesn’t work in FTD. Rather than an internal message of satiety, the individual will respond to the visual images of food; cognitive assessment of value of food; high or low calorie content; and the smells, tastes and flavor of food.

Many people with hyperoral behavior exhibit other obsessive-compulsive behaviors and the orbital frontal circuitry has a relationship to these. Orbital frontal circuitry tends to be more injured on the right than the left side of the brain, and people with bvFTD tend to have more right than left side involvement.

1. Rascovsky K et al. Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. *Brain*. 2011 Sep, 134(pt9): 2456-77. Epub 2011 Aug 2.

### Neurology Grand Rounds

Bradford Dickerson, M.D. and Bruce Miller, M.D. presented a Clinicopathological Conference at Massachusetts General Hospital that demonstrates differential diagnostic process in neurodegenerative disease. Case 9-2015: A 31 Year-Old Man with Personality Changes and Progressive Neurologic Decline was published in the *New England Journal of Medicine* on March 19, 2015.



## Memory Care Placement

Liz could no longer safely care for James at home because he needed constant supervision. He would roam the neighborhood looking for food and would eat excessively, stuffing food into his mouth to the point of choking. His neurologist recommended placement in an assisted living or memory care community. Liz toured multiple communities; many were unfamiliar with FTD and/or James's behaviors and needs. Liz selected a memory care community where several other residents with FTD resided, one that was committed to work with her and James.

Upon move-in, Liz met with the staff and shared [AFTD's Daily Care Snapshot resource](#), which she completed describing James's interests and needs. They discussed his obsessive behaviors, such as eating all of the food in the refrigerator and cupboards, taking other people's food and compulsive eating of candy, poor personal hygiene and verbal belligerence. She also shared his basketball achievements, community service and work history. James was placed on 15-minute observations for the first 72 hours in order to monitor his behavior and location.

He walked constantly and would attempt to take food from refrigerators, cupboards and other residents' plates. When staff assisted him with personal care such as showering, he stiffened and yelled "No!" With limited success, staff continually tried to re-direct him from food and engage him in group activities or conversation. Snacks were placed in kitchen

cabinets with child-proof locks. Other residents and family members complained as snacks and beverages were normally available to residents at all times. Staff liked James but were increasingly frustrated and apprehensive of him, particularly after he broke locks. The director encouraged staff to discuss these feelings with her and provided education and support.

The staff met with Liz one month after move-in. James's physician joined the meeting. New approaches were agreed upon, including: escorting James to the dining room when the other residents were almost finished eating; seating him at a table alone or with a resident who needed assistance with feeding to ensure that he was supervised by a staff member; and purchasing indoor and outdoor basketball hoops to provide a positive redirection activity (including prior to joining others in the dining room). Staff began providing non-verbal cues, such as hand gestures and visual props (including a small basketball used during personal care and when James was pacing). A daily schedule of activities was posted in James's room, including personal hygiene and activities of interest.

Non-clear plastic shelves were installed in refrigerators and cabinets so that food and beverages were not easily seen. The physician increased James's dosage of Zoloft. The doctor also prescribed acetaminophen to treat observed signs of pain, e.g. resistance to personal care (read more about assessing pain in the [Summer 2013](#) issue). Liz tried to schedule her visits during the evening meal to assist with his care.

## Troubles & Tips

***Q. A woman in our adult day program has behavioral variant FTD. She roams the facility looking for sweets and can be disruptive of planned activities. Her husband knows she likes rum raisin ice cream, and brings 2 gallons every week for us to give her to redirect her behavior; she also has more at home. She has gained 50 pounds in the last 4 months, but her husband does not want to take away what seems like her only pleasure. What should we do?***

A. Because the person diagnosed is unable to control disruptive and potentially unsafe behaviors, the responsibility shifts to others to create a safe environment and provide adequate supervision. However, with multiple care issues to address, caregivers often feel reluctant to take away a "simple pleasure" such as a favorite food. Left unchecked, excessive over-eating or drinking and binging can lead to significant weight gain that can make care harder and may contribute to other medical issues. Food

and clothing budgets at home may need to increase. Incontinence and risk of diabetes or dental issues may occur. There is more chance of injury with falls and people can be harder to lift if they do fall, or are unable to walk. Personal hygiene and care of skin folds may become difficult.

Help the caregiver to evaluate the impact of unrestricted access to food on the person diagnosed, as well as the impact of related behaviors on others in the environment. If the family and care team choose to restrict access to food, implement this through gentle shaping and redirection of the person's behavior. Caregivers feel guilty and need support to know that it's OK to limit favorite foods, even if these foods may provide comfort for the person with FTD.

The transition to a day or residential facility requires attention to communal issues and involves a change in routine from home that can be challenging for both the caregiver and the resident. It is important that all involved are aware of the plan and that all

understand the reasoning behind it so there is consistency.

Include the caregiver and, to the extent possible, the person diagnosed, in care planning to collaborate in designing limits and steps to curb the most challenging food-related behaviors at home and in the day program. The person with FTD often functions well with a consistent routine. Try offering snacks at the same time of day and in a set amount. Try specifying a day of the week for a specific snack – for example: Ice Cream day is Wednesday.

Substitute more acceptable alternatives (e.g. pretzels instead of M&Ms) or consider chewing gum as an option. Reduce visual cues and triggers by storing food out of sight and in a secure area. Identify preferred activities to redirect the person's attention. Over time, consistency will help to curb the behavior. The goal is not to stop the behavior entirely or withhold comfort, rather to improve overall quality of life and protect against reasonably-anticipated risk.



## On-Going Plan of Care

James continued to wander and seek food six months after his move-in, returning repeatedly to those places where he had found food previously. His verbal communication decreased to phrases and he presented a “stare” that some staff found to be angry or threatening. Staff approached him slowly with a smile, gave him ample time to respond and to complete tasks and provided primarily visual cues. He was now served his meal at a separate table. Community snacks and beverages were stored in non-clear plastic containers with twist lids. If James could not see the food or could not easily pour beverages, he walked away.

He was provided a comfortable chair at the back of the activity room. James attended activities such as music and exercise in the late morning and then could exit freely. When he was not easily redirected, the staff played basketball with him. He continued on Zoloft and acetaminophen. The director met individually with family members of other residents when they had concerns about James not belonging there due to his odd behaviors, blank stare and young age. Most gained an understanding of and tolerance for his behaviors. Staff continued to intervene between James and a few other residents when he reached for their food or walked too close to them, redirecting him and moving him to another area or activity. Liz continued to visit frequently to assist with his nightly meals and personal care.

One year post move-in, James now paces excessively, and he is now grinding his teeth. Staff monitor for dental issues and a speech therapy consult has been requested. Showing impulsivity to push too much food into his mouth, and having an increasing potential for choking, he is provided smaller portions of food throughout the day. Food is cut into bite-size pieces, and beverages are served in a covered cup with a straw. James takes food that is in full view and has occasionally tried to eat inedible objects such as napkins, plastic silverware and Styrofoam cups. He is no longer interested in playing basketball but will watch short segments on TV or on the computer. Staff have learned to approach him slowly and always from the front.

James enjoys short musical and exercise programs. Liz has created a scrapbook showcasing his basketball and sports-casting careers, which he likes to view. The director continues to meet with staff, family members and other residents to discuss concerns. As James’s needs continue to change, Liz, the physician, and staff will continue to meet to revise his plan of care.

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### Questions for Discussion

*(Use for staff in-service training or in resident-specific situations.)*

**What changes in James’s behavior contributed to the recognition that physician and neurological evaluation was needed?** Changes and behavior that were atypical for

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James included not going to the gym, poor personal hygiene, missing basketball games and community fund raisers, binge eating, grabbing food and soda at stores, refusing to go to work, shooting hoops for hours at a time, work performance issues and belligerent or apathetic responses to concerns.

### **What additional issues related to James’s eating behavior contributed to the need for memory care placement?**

James began walking to the local convenience store and taking items. An altercation with another customer resulted in his prohibition from the store. Liz and James could no longer dine out because he took food from others’ plates and from waiters’ trays. James was binge eating, which resulted in weight gain, the possibility of choking and an instance of fecal incontinence. Due to these safety issues and an increasing need for supervision and care, the neurologist recommended placement.

**How did other residents and their families respond to James’s behavior and presence in the program?** Residents and family members complained when food and beverages were not accessible. They shared concerns when James took food from other resident’s plates. Several families questioned his appropriateness as a resident in the community due to his blank stare, different behaviors and young age. Individual meetings with the director offered education and support that helped to assuage these concerns.

**How did the staff and care planning team respond to James’s behavior? What contributed to the effectiveness of the placement?** The care team met initially with Liz and together they developed a comprehensive, individualized plan of care for James. During the first month staff got to know him but became frustrated by the need to adjust set routines around him (i.e. not leaving food out, continual redirection). Staff became apprehensive, particularly after he broke locks. The director encouraged staff to discuss these feelings with her and provided education and support. A month after placement, Liz and the team met with James’s physician and updated his plan of care with new approaches based on observation and assessment of his current behaviors and needs. Liz, James’s physician, the director and staff continued to meet pro-actively to review his needs and update his plan of care. The team approach, open discussion of feelings between the staff and the director, and continual revisions based on James’s changing needs ensured effective placement and a unified plan of care.





## Spotlight on Success: Arden Courts and Ms. D

Ms. D was a 49-year-old woman living with FTD. She resided in the dementia unit of a reputable, expensive, assisted living facility that was geographically close to one of her legal advocates.

One of the biggest challenges – as perceived by the assisted living staff – related to Ms. D’s hyperoral behaviors. Ms. D would eat anything within her sight including food on other residents’ plates, any snacks placed at “nourishment stations,” even sugar packets left on dining tables. Rather than provide the facility staff with education, support and tips for redirection and management, the assisted living facility requested that her family hire 24-hour home care aides for one-on-one care to manage her behaviors. According to the family, this meant that Ms. D spent most of her time in her room, behind closed doors.

After approximately one year with this care arrangement, Ms. D’s advocates decided to explore alternative living options. One of the options included [Arden Courts](#), a memory care community dedicated solely to serving the residential needs of individuals living with cognitive changes. Ms. D’s advocate contacted the local Arden Courts and decided this community was a better option for her care.

Arden Courts had prior experience working with individuals with FTD and utilized individualized care plans to work with each resident’s needs.

Ms. D moved into Arden Courts, with 24-hour home care

aides engaged to assist through the transition. Prior to her move-in, the leadership at Arden Courts provided education and training on FTD for all caregivers, maintenance, housekeeping, nursing, program and dietary staff. While snacks were available for residents in this community, staff used artful distraction techniques and provided appropriate food options for Ms. D. They provided small, healthy snacks throughout the day when requested, and they seated her at a dining table with residents who needed assistance eating so that the staff could also help monitor her during meals. Additionally, Arden Courts activities provided the physical and emotional stimulation that she needed. Ms. D especially enjoyed programs that included music, dancing and outdoor activities. She appreciated the large courtyard and the freedom to exit to the outdoors in the secured backyard.

The right environment with the right care decreased the hyperoral behaviors. Because of this, the care team determined that the additional home care aides were no longer needed and, in fact, believed the aides had made Ms. D feel that her independence and autonomy were being threatened. At Arden Courts, Ms. D was able to thrive while living with FTD. She no longer spent her days isolated in her room. She engaged in the programs offered and developed special relationships with fellow residents as well as staff. This not only impacted Ms. D, it also provided peace of mind for her advocates. Kudos to Arden Courts – their leadership and staff – for rising to the occasion to meet the needs of Ms. D and others living with FTD across the country.

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**Partners in Care Advisors** The Partners in FTD Care initiative is the result of collaboration between AFTD, content experts and family caregivers. Advisors include: Sandi Grow, RN, caregiver • Geri Hall, Ph.D., ARNP, Banner Alzheimer Institute • Lisa Gwyther, LCSW, Bryan Alzheimer’s Disease Research Center at Duke • Barbara Harty, GNP, UNT Health Science Center • Susan Hirsch, M.A., HCR ManorCare • Jill Shapira, Ph.D., ANP-BC • Rebekah Wilson, MSW, Choices in Senior Care

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## Hyperoral Behavior

Changes in eating behavior are symptoms of FTD that the individual cannot control. Talking and logic will not stop compulsive eating behavior. The caregiver must take different actions to interrupt or manage the behavior. The following techniques can be used in home, adult day program and residential settings.

### FTD Medical Approaches

- Assess changes in eating to distinguish possible medical issues from disease progression.
- Arrange a dental consult to assess teeth grinding as a possible sign of mouth discomfort or pain. Watch for: sensitivity to hot/cold when eating; refusing to eat; mouth odor; or infection.
- Check lab work for nutritional deficiencies that might contribute to food cravings. Monitor sugar levels if the individual eats excessive sweets, as sweets may increase risk of diabetes.
- Consult with a physician about a trial of medication. While behavioral interventions are often most effective, SSRI antidepressants (e.g.: sertraline, citalopram) or epileptic agents (e.g.: Topamax®, Depakote®, lamotrigine) may be helpful.
- Monitor urgent bowel issues and fecal incontinence as triggered by eating behavior (e.g.: binge eating, sugar-free candy). [Read more on incontinence in FTD in the [Winter 2014 Issue](#)].

### Behavior Responses

- Keep a behavior log to track information about behavior and correlate with medication changes.
- Enlist input from all professional disciplines for possible intervention strategies: speech therapy; occupational therapy; or see a physician for a medication trial.
- Arrange for the person to eat in an atmosphere with less stimulation and potential anxiety; provide an opportunity for an individual pursuit while others are eating.
- Draw the person away from the table and into a different activity when she or he is finished eating.
- Use fiblets or lies with a positive purpose, e.g. , if chocolate cake is more likely to promote binge eating, say, “We are out of chocolate cake, but we have Jell-O for dessert.”
- Provide smaller amounts of healthy foods throughout the day.
- Monitor chewing behavior closely, i.e.: 15 minute safety checks and encouraging use of Chew Stixx® (available online) to reduce risk of choking on non-food items.

### Modifications in the Environment

- Store food out of sight and out of context, i.e.: put food in the linen closet and put linens in the pantry. Do not put non-food items that might be ingested in places where food is typically stored; particularly avoid colorful objects that would attract attention.
- Avoid attending buffet-style social events or all-you-can-eat restaurants.

*(continued on reverse side)*

## Hyperoral Behavior

### Modifications in the Environment, *continued*

- Serve food in a single portion or put food in a squat food bowl to limit quantity; remove the rest.
- Lock cabinets and the refrigerator to limit access.
- Remove inedible objects from eating area or tray, including straws, paper products, Styrofoam cups and plastic silverware.
- Provide a safe alternative for chewing that can occupy the person's attention. Gum may work for some people for a time.
- Purchase clothing with no buttons and a sport collar that cannot be easily put in the mouth.
- Purchase Chew Stixx and attach to the person's shirt via a retractable badge holder to avoid loss.
- Open a package of food and remove most of the contents, leaving only a few items or pieces of food rather than allowing the person to eat all that was inside.
- Disguise "trigger foods" (e.g.: put ice cream bars in emptied frozen vegetable bags or the box of waffles). Put the linens in the pantry and put food in a linen closet with a locking door handle to create a "safe closet."
- Lock items that state "Seek medical attention if swallowed. Contact Poison Control Center if swallowed." Cleansers, soap, etc. may be mistaken for food.
- In a healthcare community, escort the individual to the dining room when most of the residents are finished eating. Seat individually or with a resident who requires assistance with eating to provide monitoring.
- Place food and beverages in non-clear plastic and top-lidded containers. This will limit visibility and accessibility.
- Limit visual pictures of food, such as magazines and cooking books.
- Do not display artificial fruit or vegetable arrangements.
- Schedule one day per week for preferred food, such as chocolate cake on Wednesday.

### Support for Family Members

- Educate caregivers and, to the extent possible, the person diagnosed about possible complications of over-eating. These may include: the increased cost of bigger clothes and a larger food budget; more chance of injury with falls; the person being harder to lift if they do fall; difficulty walking; incontinence issues; skin issues if folds develop; and dental and medical issues.
- Consider an [FTD support group](#) or individual counseling. Family members may feel reluctant to limit food if it is seen as all the person has to enjoy, and often experience guilt for restricting preferred foods and setting limits.
- Create a partnership between FTD family members and the care team; enlist active support and assistance from all parties with the care plan. Creating a partnership is critical to consistent implementation and success.
- Integrate FTD family into facility culture. Changing access to food in assisted living facilities is a change from the culture expected by other residents and staff and can add to the isolation of FTD caregivers.
- Encourage family caregivers to attend social functions even if they are not able to take the person with FTD.