

## It's Complicated! Incontinence Management in FTD

### Introduction

Loss of bladder and bowel control occurs in most dementias; however, in most cases, it occurs in advanced disease. This is not the case with people with behavior variant FTD (bvFTD). Bowel and bladder incontinence can occur early in the disease, especially when the person is under stress or in a highly stimulating environment. People with FTD may experience incontinence due to apathy with disinhibition, compulsive behavior, distractibility and a lack of insight. As the disease progresses, they may not know what to do with urges to evacuate. Moreover, because of the cognitive and behavior symptoms in bvFTD, persons may respond to the presence of urine or bowel movement (BM) in a socially inappropriate manner. This can increase stress for family and the risk of others in the environment being exposed to infectious illness, particularly nausea and diarrhea.

As a general rule people with FTD do not benefit from bladder retraining programs or from feedback from people providing care. They may resist wearing protective garments and become irritable or resistant when caregivers try to clean them. They may give caregivers "the look," a generally benign but frightening stare that keeps helpers at bay.

While incontinence commonly occurs in FTD, there are varied patient responses to management strategies and thus knowledge of FTD linked to creative thinking among staff members enhances successful management. The following case study demonstrates some of the problems and management tips for people with FTD and incontinence:

### The Case of Bob Weak

#### Mild bvFTD

Bob Weak was a tall 63-year-old disabled salesman who first exhibited behavioral symptoms eight years ago. He resided with his wife, Mary, adult son and two grandchildren, ages 5 and 6. His family reported he became increasingly childlike, laughing and giggling at things that weren't funny; having difficulty organizing tasks to accomplish a goal such as assembling furniture – a prior hobby. He became apathetic and repetitive in activities. He misplaced items around the house, becoming angry about the lost items. He was diagnosed with bipolar affective disorder and was placed on an antidepressant that made him more lively.

Bob made poor financial decisions: sold their house without telling his wife, ruined the lawn mower by adding a liquid to the gas, bought an expensive new car they could not afford and shopped online impulsively. He totaled the new car and purchased another without telling Mary. The family subsequently lost their house and car due to his poor financial decisions. Mary was forced to return to work, leaving him alone during the day.

Five years ago, Bob began to have occasional spontaneous loose bowel movements while at the supermarket. Mary felt he must have had food poisoning. He did not ask to use the men's room nor seemed to care that he had soiled himself. He resisted his wife's attempts to take him to the rest room and clean up. He walked to the car and climbed in, soiling

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### Did You Know?

Damage to the brain's frontal and temporal lobes affect complex thinking and reasoning abilities, which can result in the cognitive and emotional symptoms commonly associated with FTD. Increasing impairment in "executive functions" affects a person's ability to plan, organize and execute activities, while emotional changes impact relationships. Symptoms may include:

- Apathy, reduced initiative
- Distractibility
- Emotional blunting
- Mental rigidity and difficulty adapting to new or changing circumstances
- Planning and problem solving impairments, abstract reasoning decreases
- Lack of insight into one's behavior develops early
- Abrupt/frequent mood changes
- Poor financial judgment, impulsive spending or financial risk-taking.

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the driver's seat. After that, whenever they left the house, Mary carried an "accident bag" with gloves, paper towels, wet wipes, sanitizer and a change of clothing.

### Moderate bvFTD

Four years ago, the soiling occurred regularly during social activities. Bob refused to wear a protective garment. Mary would return home from work to soiled carpet and furniture. When directed to the bathroom, he did not go there reliably. Mary found he would use the toilet if she colored the water blue and put Cheerios in the water for him to "sink." Bob became obsessed with toilet paper, unrolling the entire roll into the stool and flushing it, flooding the bathroom and adjacent hallway. He was consistently unable to use the paper to clean himself after evacuating.

At the same time his language skills began to deteriorate. His wife reported that Bob stared at her as if he did not comprehend what she was saying, interrupting with unrelated ideas from what she was asking. His sentences became one- and two-word replies that often did not make sense. He did not know his grandchildren. He developed a way of looking at people that seemed hostile and, because of his size, frightened people.

Three years ago he was taken to a behavioral neurologist and after another year, was diagnosed with behavioral variant FTD (bvFTD). By that time, Bob was unable to participate in household tasks, except vacuuming. He ate voraciously and gained

weight rapidly. Mary obtained locks for the refrigerator and pantry. The soiling continued, but now urinary incontinence occurred occasionally. Efforts to toilet him every two hours and get him up once at night met with increased physical resistance. The incontinence did not follow a consistent pattern, and except when in highly stimulating places or after a meal, triggers could not be identified. Mary took him to both a urologist and a gastroenterologist, but both found nothing wrong.

Each day, Bob would demand repeatedly to go to a restaurant. If she could get him into a protective garment they would go, but he would gobble his food and demand to leave – only to demand to return to the restaurant once they were home.

Bob's constant eating increased the volume and frequency of his BMs, thus accidents. He weighed 285 pounds, an increase of 90 pounds. With his increased weight and illness, he began to walk slowly. He did not recognize urges to eliminate. Mary coped with this by replacing the underwear from his dresser with incontinence briefs. Initially he shredded them; however, with time and repetition, used the briefs. He became fully incontinent of urine.

### Severe bvFTD

Six months ago, Bob suffered a bout of constipation. After six days with no BM, Mary took him to the ER. They diagnosed obstipation, and the physician ordered two ounces of Milk

## Troubles & Tips

**Q: Incontinence management was always routine care, but now we have a gentleman with behavioral variant FTD (bvFTD) and our direct care providers are having a hard time. Is incontinence different in FTD or is he just being difficult?**

A: Yes, incontinence in bvFTD is very different; the location of damage in the brain and resulting symptoms are different from other dementias. The typically younger age and increased mobility of persons with FTD also contribute to management challenges. In Alzheimer's disease (AD) urinary incontinence may be caused by a medical condition, not reacting quickly enough to the urge to urinate, physical difficulty getting to the bathroom, trouble finding the bathroom and difficulty removing clothing once there.

In FTD, fecal incontinence in FTD typically starts before urinary incontinence and early in the disease progression. It is a reflexive response to an overly stressful situation or excessive sensory stimulation. Management is complicated because people with bvFTD often exhibit disinhibited behavior and impaired social judgment. They are less aware of social norms and may remove protective garments in public, handle or smear feces, not recognizing the inappropriateness of their behavior. A higher physical activity level can create a greater area for cleaning and disinfecting. It is important to remember that these behaviors result from core symptoms of FTD and are not willful.

In Alzheimer's disease (AD), people become slowly incontinent of urine first in the evening or at night and don't get up to use the bathroom. The spontaneous episodes of fecal incontinence common in bv FTD are more public, occurring for example at a store or in a group dining room. People with AD retain the ability to inhibit their responses and tend to leave the room. They generally react calmly to wetting and cooperate with usual care practices such as distraction during personal care. Distraction does not work as well in FTD where people become very focused in their attention and may have compulsive behaviors. Overeating is common in bvFTD and adds to incontinence issues. A reflexive grasp and flat or blank facial expression associated with frontal lobe damage are often misunderstood as aggressive responses by direct care providers. Understanding the symptoms of FTD greatly contributes to improved care management.

Constipation is common among people with dementia if their fluid intake and physical activity are reduced, or as a side effect of medication. Facilities have established approaches to manage constipation that include both stool softeners and laxatives. While the use of stool softeners increases bowel control, laxatives should be avoided if at all possible for people with FTD due to the potential for gastrocolic reflex.



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of Magnesia three times per day. Over the next three days, he suffered severe diarrhea, which he smeared in all three bathrooms, the living room and kitchen. Mary was overwhelmed and tried to keep both him and the house clean, resisting advice to contact a professional cleaning service. She finally resorted to a dose of Imodium, which stopped the diarrhea.

Bob was now mute but continued to resist Mary's efforts to clean him, grabbing her wrists and squeezing as hard as he could. Mary stated "the look in his eyes is murderous!" She decided it was time for placement. Despite recommendations for medication prior to placement, Mary admitted Bob to the "light care" unit of an assisted living facility.

Bob lasted two weeks in that facility. He was aggressive when approached for personal care. The staff had no dementia training, was frightened of him and refused to try to clean him. They felt his incontinence was a purposeful ploy for attention. Mary drove to the facility three to four times a day to clean him, fussing because the staff was afraid. She did not want him to be given medication for mood because she felt he would become "zombified."

The facility administration discharged him and he was admitted to acute care psychiatry unit where he spent four weeks. The medications used for mood reduced the resistance to care and allowed staff to get close enough to provide personal care one to two times each day. The staff found they could use the normal urge to defecate after eating by changing his protective garment one hour after each meal. He would remain free of BM after that. Bob continued to compulsively urinate in the toilet with blue water and cereal for him to "sink." While not totally eliminating incontinence, the condition was now manageable.

Bob was discharged to a nursing home that specializes in caring for people with complicated behavioral disorders. He adapted well in the nursing home with the new schedule and medication regimen from the psych admission. His behaviors are carefully monitored by a psychiatric nurse practitioner who quickly diagnoses and treats behavioral alterations. The facility made sure they followed the same incontinence regimen as was developed in the acute psychiatric unit.

Bob continued to be incontinent of urine and BM; however, on medications, he could be cleaned using two staff. Recognizing the problem of his primitive grasp reflex the staff would give him a rolled towel to grasp whenever they were providing care. This eliminated fears of being injured while administering necessary care.

Bob's diet was carefully monitored for overeating thereby achieving weight loss and normal stool volumes. Several months later Bob stopped walking and was enrolled in a hospice. He

started to choke on solid food and thin liquids and was placed on a soft diet. Bob choked on canned peaches and aspirated his own saliva. A week later, he passed away from aspiration pneumonia.

#### **Questions about the case:**

##### **1. At what point in the disease progression did Bob first experience bladder or bowel control issues? Why?**

Bob had spontaneous loose bowel movement in the early stages of the disease, about three years after initial behavior changes, but still two years before he was diagnosed with bv FTD. The first episode happened while he was out with his wife at the supermarket. She thought he must have had food poisoning and began to plan ahead for possible "accidents." Fecal incontinence happens early in FTD when people are in stressful or high sensory stimulation settings that trigger a gastro-colic movement. Bob also began to have occasional urinary incontinence, and again, triggers were highly stimulating places or after a meal.

##### **2. What challenges do facilities face managing incontinence for people with FTD?**

The greatest challenge is understanding FTD symptoms and how they differ from other dementias. Care workers may have less empathy for a younger, stronger person than they do other residents with incontinence and more often misinterpret behavior as the person purposefully wetting or soiling. Toileting must be added into the routine plan of caregiving and must consider any compulsive behaviors the person may have. Access to food must be limited if impulsive eating behavior is present. Disinhibition can lead to smearing of feces. Bob's behaviors were effectively managed using the normal urge to defecate after eating and routinely changing his protective garment one hour after meals.

##### **3. How does understanding FTD symptoms and behavior help in managing incontinence?**

People with Alzheimer's disease typically become incontinent of urine slowly, later in the disease and have muted reaction to it. In FTD, incontinence is often in response to overstimulation and has potential for greater impact on others through public behaviors and increased risk of infection. Symptoms such as disinhibition and compulsive behaviors, lack of insight and apathy and a blank stare are often misunderstood as resistance to care. If anticipated and incorporated into management strategies, incontinence can be managed effectively promoting the person's dignity and quality of life. It's important to limit access to food, reduce stimulation/stress and toilet on a consistent schedule as preventative steps. Compulsive behaviors can be used in strategies, such as aiming for a Cheerio in the toilet. Grabbing another's wrists during care is a frontal lobe reflex and can be minimized by putting something else in the person's hands to make it easier to change protective garments.



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## Resources – Incontinence Products

It is especially important to tailor the approach to incontinence management for each individual with FTD. Specific symptoms and compulsive behaviors will vary considerably from person to person. A proactive strategy and use of the right products will preserve the person's dignity and ease the provision of care.

- Introduce the use of incontinence products when needed. Delaying their use or withholding the products will not increase control; the person is not soiling willfully. Never refer to protective garments as "diapers" because the word indicates the user is infantile. It is better to call them "incontinence products," "pull-ups," "pads," "briefs," "boxers," etc.
- The sizing and absorbency of pull-ups (mens/womens; daytime and night) varies. Tabbed-closure types may provide greatest protection for some. Try different styles and types for what works best with an individual.
- The cost of products is not included in facility care and is only covered by Medicare if the person is on hospice. Compare prices at large stores such as WalMart or Target, from pharmacies such as CVS or Walgreens, or big box stores such as Costco or Sams. They are also available online at sites such as [www.depend.com](http://www.depend.com).

- Many caregivers remove underwear from the person's bureau and replace it with briefs or pull-ups. This helps to gain acceptance.
- Incontinence products should be changed several times during a 24-hour period to prevent skin breakdown and urinary tract infections.

*How do you turn toilet water blue?* Grocery stores carry toilet bowl cleaners that can be placed in the toilet tank to dissolve slowly over a period of a month. Many of these cleaners turn the toilet water blue. If using one, make sure pets do not drink from the toilet.

*Addressing constipation* - Any time a stool softener is used, special care is needed to ensure the person has adequate fluid intake and exercise to prevent constipation.

- Stool Softener – Helps to prevent hard dry stools by causing water retention in the fecal material. Examples include Colace, Pericolace and fiber products such as Metamucil, Benefiber, Fiber-Con and Fiber One Cereal.
- Laxative – Irritates and stimulates the gastric track with the goal of producing a bowel movement. Laxatives can be given by mouth or as a suppository. Examples include Milk of Magnesia, Dulcolax suppositories or tablets, glycerin suppositories and Sennakot. Sodium phosphate (Fleet) enemas also produce a laxative effect.



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### Incontinence

Unlike Alzheimer's disease, reasons for bowel incontinence in FTD are complicated. These are not people who forget to use the toilet in advanced disease. People with FTD can defecate impulsively during periods of high stress or stimulus. Any strategy to manage it must consider the particular cognitive, behavioral and communication impairments in FTD, and address as many of the potential causes as possible.

- Recognize that bowel and urine incontinence is common in early and moderate FTD.
- Do not take the incontinence personally or think the person is doing this on purpose to spite you. While incontinence is a very frustrating problem, this is simply another example of disinhibited symptoms in FTD.
- Do not try to punish the person or retrain them. It will only frustrate you.
- Carry a "Please excuse my companion" card whenever in public. These cards can be handed to individuals witnessing the behavior.
- At the first sign of urinary or fecal incontinence, have the person evaluated by a physician to rule out other pathology such as an infection.
- Carry a bag with gloves, paper towels, wet wipes, sanitizer and a change of clothing in the car or with you whenever out.

#### Fecal (bowel) Incontinence

- Be aware that certain medications, such as the cholinesterase inhibitors, SSRI-type antidepressants, antibiotics, and benzodiazapines (Ativan), as they may increase the potential for diarrhea for a variety of reasons. If a particular medication increases diarrhea, ask the doctor to substitute another in the same class.
- Encourage use of incontinence products as early as possible – using "pull-ups" instead of underwear, especially when going out where there will be crowds, noise, or high stimulus. Encourage the person to wear them by replacing the underwear in the bureau with protective garments. One caregiver reported ordering the products online so the package seemed like a gift.
- Recognize that fecal incontinence can be dangerous due to the potential for infections, especially gastroenteritis. Wash your and your person's hands frequently. Use hand sanitizer routinely before handling food. Make sure you disinfect surfaces your person has touched.
- Untreated carpet and upholstery will rot if exposed to BM. Routine carpet cleaners and stain removers do not treat this. Purchase products specifically designed to clean BM. These are available at pet stores.
- Watch your person's intake. If overeating occurs, try eliminating meals and focus on continual provision of small snacks.
- Limit use of prepared canned nutritional shakes, which can cause diarrhea.
- Try to get the person to use the toilet 20 minutes after eating.
- Avoid using oral laxatives as they may cause a loss of control. Instead check with the physician/provider about products such as fiber or stool softeners. If constipation occurs, try using suppositories.
- Give the person something to hold during care provision. Rolled towels or washable toys work nicely. This eliminates the person's need to grasp the caregiver. Grasping is a primitive reflex where they grasp anything nearby but are unable to release it.
- Caregiving staff should wear two sets of long sleeves so they can twist out of the grasp if needed.

#### Urinary Incontinence

- For urinary incontinence with a male, try coloring the toilet water and adding cereal for him to sink.
- Try to get the person to urinate in a routine every 2-3 hours. Limit caffeine as it is a bladder irritant.
- Try to achieve fluid goals of about 1 ½ quarts per day before 6 p.m. and sips after 6 p.m.
- Try to get the person up at least once a night to urinate. Keep a light on in the bathroom.