

### In FTD, Roaming is Not Wandering

In over 70% of cases, frontotemporal degeneration begins younger than age 65. People are often quite physically active which, together with cognitive and behavioral symptoms, poses unique care challenges.

#### Early disease - Roaming by bike

Jay Gould is a 56-year-old former businessman who resides with his wife. All his life, Jay enjoyed hiking and outdoor activities. At age 48, he was diagnosed with behavioral variant FTD and unable to work; his two sons continue to manage the business. After obtaining disability, Jay spent his days riding his bike to the office, about five miles from home. As his disease progressed his visits would be repeated about 10 times each day. He rode to the office, went inside, looked in his sons' offices at family pictures for about five minutes and bicycled home.

He never became lost or fell; however, as he became less verbal his wife, Joyce, placed a GPS tracker on his bike. She became concerned that his routinized activity coupled with changes in judgment may cause him to ignore stop signs, traffic and other "rules of the road" posing safety risks. She consulted with his doctor who started sertraline (Zoloft), which can help to control compulsive behavior. During this time, the couple went on multiple cruises. Jay spent most of the time walking throughout the ship in a consistent pattern. One day when taxiing to the shore in a tender, Jay indicated he had to use the toilet and jumped overboard. He was unharmed, but that was their last cruise.

Last summer, the couple retreated to their cabin in the mountains. Joyce hired a companion to bicycle with Jay, but a forest fire stopped that. Joyce had the bicycle "stolen" as a practical measure while at the cabin, leaving Jay on foot. The area was too steep for much walking so Jay's roaming changed. He left the cabin and went to neighbors' homes, going into unlocked cabins. Once there, he would go to the refrigerator, open a bottle of wine and sit in the living room. One day, he entered a home while the female neighbor was in the shower. The neighbors became irate and refused, despite Joyce's plea, to lock their doors. One threatened to call the police and sue the Goulds. Joyce closed the cabin and returned home.

While they were away, Jay's sons sold his bike. Whenever shopping, Jay would insist on going to look at new bikes. Joyce handled this by using a therapeutic fib, telling him their sons would help him buy his next bike. Jay then started walking in his gated community continuously from morning until after dusk. Exhausted, Joyce supported this as she did not know what else to do. He was dependent in bathing, grooming, and dressing.

#### Mid-disease – Pacing indoors

This past winter was cold and rainy. Fearing influenza and because Jay was now mute, Joyce confined him to their sizeable home where he paced back and forth through the house. He tried the doors to go outside, so Joyce applied safety locks to the doors and later, the windows to prevent eloping. Three months later, he had confined his walking to repeatedly

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.

### NEW TOOLS YOU CAN USE

Beginning with this issue, each Partners in FTD Care e-newsletter will include a one-page, companion sheet with specific interventions and tips related to the topic. Give this to direct care staff and family members to develop understanding and consistency in care plans.

### HAVE A QUESTION ABOUT CARE?

Contact AFTD's HelpLine for a direct response to your question. Or join experts and colleagues on the Partners in FTD Care Forum to share questions, interventions and successes about serving people with FTD and their families. This members-only bulletin board allows professionals to exchange questions and ideas to help develop best practices in the field.

HelpLine – [info@theaftd.org](mailto:info@theaftd.org) or 866-507-7222

[Partners in FTD Care Forum](#)  
Register and post to the forum.

walking around the kitchen island while awake. The combination of increased ADL needs, his restricted activity and her exhaustion from providing constant supervision led Joyce to place him in a secured memory care unit in an assisted living facility.

Jay did not seem to mind placement and immediately developed a route to roam. He was calm and pleasant unless his walk was interrupted. A problem arose that his route contained another resident's room at the end of the hall, which he would enter. The staff redirected his walk past an aviary and watching the birds distracted him for several minutes whenever he passed it. The staff also covered the door knob and disguised the door with a forest scene to reduce visual cues. Periodically they would open the door to the enclosed courtyard so Jay could go outside and pace on the circular walk.

On occasion, Jay would run into other residents, not to push them, but it was as if he didn't see them. There was no confrontation; however, several residents fell. The staff tracked what time of day he paced, increased location checks at those times and quickly learned to redirect him to areas where there were few frail residents walking—like the dining and activity rooms. Jay would not sit to eat so the staff gave him snacks and

beverages continually while he walked. His family walked with him in the courtyard during visits and sat with him to encourage him to eat finger sandwiches and similar foods.

After two months, Jay lost weight due to disease progression and caloric expenditure. He became increasingly frail. His balance and gait were affected. One day, he tripped while going out to the court yard and fractured his hip. He was taken to the hospital and underwent a surgical repair. At the hospital, he was restrained to avoid weight bearing and began to yell spontaneously. He was treated for pain but continued to yell.

He was discharged back to the facility where he now receives physical therapy twice a day. He still yells, but the frequency and intensity are diminishing. The goal is to get him back walking if at all possible to minimize the spontaneous utterances. If this fails he will have a wheelchair without foot pedals, and staff will try to help him use his feet to push the chair.

*What is different about Jay's roaming versus the wandering of someone with Alzheimer's disease?*

Jay's behavior is an example of roaming due to restlessness and stress in the environment (too much noise, people, etc.) or

## TROUBLES & TIPS

**Q: A younger, robust person who is constantly in motion is very different from an older person with memory impairment. Our staff can't keep up and we need to curb this behavior. What do we do?**

A: It is important to recognize how roaming is distinct from wandering in order to develop effective interventions.

Roaming is more routinized, repetitive and purposeful activity. There seems to be a need for the pacing in FTD. Trying to stop or prevent a person with FTD from pacing or walking (i.e., restrain them to eat) often results in spontaneous vocalization or other disruptive behaviors. For someone who has had a physically active lifestyle, pacing can be a release of tension and stress. If it is taken away, the tension and restlessness increase. Effective interventions will focus on finding ways to shape the behavior in adaptive ways over time that allow the person to remain active and safe.

Arrange for the person with FTD to walk outside and to go where they want to go as much as possible. Ensure that he has proper



walking shoes that fit well and monitor feet for blisters. Incorporate daily walks into the care plan and enlist volunteers and family to help. One assisted living found a new resident's disruptive pounding on the exit door was greatly reduced by walking with him in the community for two hours each day. Staff hesitated at first, but found it was a good way to engage him and get exercise themselves!

Within the facility, decreased social judgment and disinhibited behavior can contribute to unintended issues with other residents, such as "running into them" or walking into rooms at the end of a hallway. Facilitate routine patterns for walking that minimize disruption to other residents who may be older or physically frail. Track the time of day the person is most active, where they naturally pace and their intake of food and beverages and use of the bathroom. Alter visual cues for areas you don't want the person to enter, such as Velcro signs saying "Turn Around" on doors, wallpaper on doors so they do not look like doors, or cover door knobs with cloth or a picture.

Roaming is a form of compulsive behavior in FTD. Redirect the person's route or activity to maintain structure, reduce stress and ensure safety. If roaming stops unexpectedly, assess for pain.



compulsive behavior common in FTD. Jay did not become lost. He knew where he was going and repeated the same route (home to office). His roaming was purposeful; Jay went to the office to view family pictures, entered homes and found wine to drink. He adapted his roaming behavior to new environments (biking to office, on the cruise ship, walking at the cabin and in the neighborhood, in the facility), and completed a specific, circular pattern (around the kitchen island).

In Alzheimer's disease (AD) individuals may become disoriented. They may forget why they are walking and where they are going and then become lost (e.g., walk to the bathroom and forget why they started, or forget how to get home after going to church or the store). Another type of wandering in AD may be based on a memory of responsibility from long ago. Rather than going to the office to view family pictures, the individual may believe they are still working. Finally, they may have difficulty adapting to a new environment and wander more – looking for the “familiar.”

*What purpose do you see in Jay's biking and walking early in his disease?*  
Jay was still able to enjoy past activities. Biking allowed him to retain a connection to employment, his business and his sons. It provided structure to the day, and the exercise helped to manage stress and maintain physical health. These activities enabled him

to remain safe at home with his wife throughout the early and into the middle stage of the disease.

*What adjustments were made over time to ensure his safety and that of others?*

Adjustments to the environment and behavioral interventions were needed as the disease progressed. When Jay became less verbal in the early stage, his wife placed a GPS tracker on his bike. A companion was hired to accompany him on bike rides. When biking was no longer safe, the bike was “stolen.” When Jay entered neighbor's homes, his wife asked them to lock their doors. When they refused, Jay and Joyce returned home to a gated community. To prevent elopement, locks were installed on the doors and then windows. In the facility, visual cues were assessed and staff guided him to areas with fewer residents.

*What role does communication impairment in play in roaming behavior?*  
As Jay's communication skills decreased, his wife implemented “safe roaming” interventions. In the early disease when his verbal skills became less, she placed a GPS tracker on his bike. In mid-disease when he became mute, she had to confine him to the house, unless accompanied. After surgery, when roaming was not possible, he began yelling to communicate. Pain medication was administered and alternate activities explored to decrease yelling.

## RESOURCES TO CHECK OUT

### GPS and Tracking Devices

There are different types of GPS tracking devices and services available. No single device will work for every person with FTD who roams; it must fit the individual's patterns, habits and needs. Some devices can be worn as a watch, belt or shoe, and some cell phones services offer tracking. Think about how it works, (Must it be turned on each time? Will it be easily lost or forgotten?) and how to present it so the person will accept it.

Finding a device or system that works for your situation, may require creativity. What is most important is to get one because it can be a lifesaver. Contact your cell phone carrier for options and to discuss needs. View options via a Google search on “GPS trackers/tracking devices & Child locators.” The Alzheimer's Association offers a service called “[Comfort Zone](#).”

### It Is What It Is on YouTube

AFTD's powerful 18-minute documentary about the impact of FTD on families is now available in HiDef on YouTube. Educate others by sharing the link or order the DVD and the [Partners in FTD Care](#) materials for staff training.

[Click here to watch the video.](#)

## SAVE THE DATE!



Watch for these upcoming FTD education conferences and continue to learn how to serve people with primary progressive aphasia, frontotemporal dementia and related movement disorders.

### Friday, June 7, 2013 - University of Pennsylvania FTD Caregiver Education Conference

AFTD's founder, Helen-Ann Comstock, will give the keynote address. For more information contact Christine Ray, MSW, 215-349-5863 or [rayc@mail.med.upenn.edu](mailto:rayc@mail.med.upenn.edu)

### Tuesday, August 27, 2013 – Alzheimer's North Carolina FTD Education Conference, Raleigh, NC

Details to come!



The Association for  
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### Roaming Behavior

People with FTD are often physically active and may roam—bike, walk or pace—the same route over and over. Roaming behavior serves a purpose. The person knows where they want to go and can usually get there and back. Roaming provides structure and helps to reduce restlessness and stress.

They generally do not become disoriented or lost, but may not pay attention to how long they walk, may ignore “rules of the road” or street safety, and may say or do things that are seen as rude or odd by other people.

The caregiver must keep the person safe but still allow as much freedom as possible. Do not try to stop the roaming behavior entirely. Instead adjust the activity, the level of supervision and the setting as the disease progresses.

Tips for managing roaming include:

- Make the roaming and physical activity part of a daily care routine.
- Walk with the person or watch when and where they walk to see the pattern. Most often, a person goes to the same place and back. Look for trouble spots and take steps to prevent problems (i.e., if he goes to a previous work place or local store, ask their help to redirect the person. If an assisted living resident walks to the end of the hall and sees a resident room, he will enter. Block the room, and he will turn and keep walking).
- Check that shoes are in good condition and fit well. Excessive walking can cause shoes to wear out rapidly. Make sure shoes have any aerobic-type sole rather than heavy tread to minimize potential for falls and trips. Check feet often for blisters.
- Help the person walk outside as much as possible in the community while it’s safe, or in a protected area with a walking path. Inside ensure that there are sufficient options in areas free of clutter and obstacles.
- Use a GPS-type tracking device on the person’s bike, shoe or watch.
- Monitor food and beverage intake because they physical activity will burn calories and could lead to dehydration. Give finger foods as they walk if trying to stop for meals causes more problems.
- Use Velcro signs saying “Stop” or “Turn Around” on doors to areas you don’t want the person to enter; use wallpaper over doors so it looks like book shelves, bricks, murals, etc., rather than a door; cover door knobs with cloth or a picture.
- Place a bird aviary at end of hall with a comfortable chair near it. The person may be distracted for a time and rest. A birdfeeder outside a window or an inside bird aviary or is more effective than a fish tank. A box of items to rummage through (pieces of wood, jewelry, etc.) next to a chair also works.
- Walk beside person, gradually slowing your pace and they may slow theirs. When they come to a chair, a gentle prompt to sit may sit down may help them to rest.
- Use soft music, soothing lighting and decreased clutter to reduce level of stimulation and help the person relax and reduce roaming for meals and sleep.
- Use acetaminophen to ward off pain in the back, foot, muscles or joints. Someone who unexpectedly stops routine roaming may be experiencing pain.
- As needs change, find alternate, repetitive physical activities that the person can do in a safe, non-disruptive way (i.e., basketball hoops with an electronic return, etc., stationary bikes are of limited success).