

Why Does He Act Like That? Aggressive Behaviors in FTD

Introduction

Because many individuals with frontotemporal degeneration (FTD) are not aware of their illness, they may become frustrated at limitations or constraints they do not understand and consider to be unfair. Aggression may include shouting, name-calling or physical abuse actions such as hitting, pushing, biting, pinching, scratching or grabbing (O'Hara, et al., 2009 in AFTD Partners in FTD Care Changes Behavior chart). In a person with FTD these behaviors can result from a frustrating situation, start for no apparent reason or can occur suddenly.

When behavior becomes aggressive the immediate approach includes to stay out of the person's way if they are combative; and never point out the problem to the person, try to reason about the behavior, or argue about the 'logical' solution. Developing a management approach to ensure the well-being and safety of the person with FTD and safety of residents and staff requires understanding of the disease and careful planning. The following case study demonstrates the challenges and best practices for assisting individuals with FTD and aggressive behavior. Effective management requires close collaboration among the family, staff and primary care provider to develop and implement a highly individualized Plan of Care.

The case of Jake McKnight

A call comes into the nurse's center at the memory care community: "Jake just punched Mary (one of the caregivers) and is grabbing two of the residents. We can't settle him down. We need help right away." The nurses rush to the dining room. When they try redirecting Jake from the dining room, he starts to yell. He tries to hit one of the nurses with a chair. The other nurse is finally able to calm and escort him to the living room. The residents and nurse have a few bruises; Mary has a broken nose. Mary asks, "Why does he act like that?"

History and diagnosis

Jake McKnight is a 59-year-old retired engineer. He married Helen after graduate school, has two married daughters and one grandson. His family describes him as a kind, dedicated and loving husband and father. He was a well-respected vice president at a major aircraft manufacturer for 25 years. Jake played guitar with a local band on weekends and enjoyed playing and coaching soccer. His friends describe him as loyal, fun-loving and dependable.

His family, close friends and business associates noticed some changes in his personality about five years ago. If he had trouble being understood or had to wait at all, he became frustrated. These incidents were sporadic and most of the time he retained his usual personality. Around the same time he began missing meetings and project deadlines at work. Jake's response was always the same, "I'll get to it." Eventually, he was encouraged to take early retirement. His family thought his behaviors were the result of work-related stress. He was prescribed Ativan for his stress, which actually increased his anxiety. He continued to play in the band and watch soccer. Jake could no longer coach or play soccer due to his anxiety.

Partners in FTD Care

Do you have questions about how to serve individuals with FTD? **Partners in FTD Care** can help. Clinical experts and experienced caregivers collaborate to offer case-based studies and practical interventions you can use. Sign up today! PartnersinFTDCare@theaftd.org

Did You Know?

The Association for Frontotemporal Degeneration (AFTD) provides information and resources for FTD patients, their families and health professionals. Check out:

- [AFTD Kids and Teens](#)—a **NEW** website just for children and teens who have a parent with FTD.
- An extensive website (www.theaftd.org) chock full of information and archived training presentations.
- Free publications on important issues in FTD care.
- FTD-specific support for caregivers and diagnosed persons.
- Respite grants for family caregivers.
- *It Is What It Is*, a powerful short documentary introducing people to FTD.
- Archived training presentations on clinical trials, approaches to self-care, advocacy, and a series on primary progressive aphasia.
- An annual FTD education conference—April 24, 2015 in San Diego.

Partners Yahoo Group

The **Partners in FTD Care** YahooGroup is an on-line space to ask questions and share practical interventions that work. The group is moderated by the team that develops the Partners in FTD Care materials. Join the conversation and learn from the pros. Sign up at: <http://groups.yahoo.com/neo/groups/PartnersInFTDcare/>

For permission to reprint this material in whole or in part, contact partnersinfldcare@theaftd.org.

Helen had to continue working which left Jake at home alone. Jake began to have outbursts of verbal agitation. He would yell at Helen if she did not come home at the exact time every day. Their children convinced Helen to schedule a complete diagnostic work-up for Jake. Based on his history of behavior changes, physical and neurological examinations, neuropsychological testing, and brain imaging results, a diagnosis of probable behavior variant FTD (bvFTD) was made. Jake's most prominent symptoms and the most disruptive symptoms for his family were related to his anxiety and agitation in interpersonal interactions.

His family also noted that Jake appeared emotionally withdrawn and ignored his grandson. He began getting up during the night, roamed the house, and constantly rearranged items in the cupboards, refrigerator, and closets. He, also, took appliances apart which caused safety issues. He had verbal outbursts when Helen tried to redirect him. Without warning, he shouted during soccer games or just left. Also, his personal hygiene decreased and he was resistant to help from Helen. He was prescribed a sleeping medication and restarted on Ativan which did not help. He was, then, prescribed Seroquel, an atypical antipsychotic medication, which decreased some of his anxiety and agitation.

Episodic aggressive behavior

On several occasions, Helen came home to find Jake had broken dining room chairs and other home furnishings. When she

asked him about it, he would become upset and yell. One day she asked the question and he chased her throughout the house. She locked herself in the bedroom. Jake punched a hole in the door, and continued to scream. Helen called the police, and Jake was admitted to the psychiatric unit. The psychiatrist at the hospital adjusted his medications. The incidence of outbursts decreased with medication and the structured setting. He recommended that Jake be placed in a specialized care facility.

After encouragement from their daughters, Helen moved Jake into a memory care community. Upon move in, his family and the attending physician at the facility met with the staff. Helen had completed and discussed AFTD's Daily Care Snapshot Tool, and together the team developed a Plan of Care, with specific behaviors that might be anticipated, possible triggers and approaches. The Plan of Care was reviewed with all staff.

Jake would occasionally grab residents and not easily release them. Staff observed that his behaviors increased when residents were in close proximity, when he had to wait for meals, or when there was a loud noise. He resisted attempts at personal care. Trying to shake his hand or touch his shoulder made Jake anxious. He appeared to understand the staff but he had trouble following through with tasks independently. He could not sit down on a chair, for example, without specific verbal instructions. While triggers were identified for many of Jake's behaviors, there were also random, spontaneous behaviors.

The staff worked closely with Helen and the facility

Troubles & Tips

Q. Our staff implemented behavioral strategies and the resident continues to be resistant to care. Many think medication is the only way to effectively address the resident's frequent agitation.

A. Resistance to personal care is common in persons with FTD and may contribute to increased agitated behavior. These behaviors are associated with decreased ability to function and increase the risk of falls. The behaviors may also result in harm to other residents, family members or care providers; therefore, they require effective interventions.

One of the barriers to using behavior management strategies effectively is that staff lack confidence that they work. Referral to the primary care provider often occurs before behavioral interventions have been maximized.

Studies demonstrate the effectiveness of these interventions in minimizing the need for medications. Behavioral treatment includes vital first-line strategies of 1) careful assessment, 2) creative problem solving, and 3) addressing underlying causes of the person's behavior. Specifically:

- Check for new medical conditions, recent change in medication, or unmet needs, such as hunger or the urge to urinate. Make sure that even "mild" pain associated with chronic conditions, such as arthritis or back pain is managed with physical therapy and/or pain medication.

- Carefully assess unsafe behavior by identifying what triggered the event. Describe the actual behavior and the effect of the behavior on the resident and others. Write a note that tracks the timing and frequency of events to identify clues for possible interventions. For example, a resident pushed anyone in his way when walking to the dining room. Staff reported this aggressive behavior and when they looked closer at the behavior in the context of his history, it became evident that he was anxious there would be no food left. When he was allowed to go to the dining room before everyone else, the behavior stopped.
- Use proven behavior management approaches including: follow set routines, speak in a soft/pleasant voice, give the resident enough room to respect their personal space, redirect to another activity if possible, reduce stimulation, involve family members, and assign consistent care providers. Avoid arguing with the person, as it will worsen agitation.
- Assign enough staff to carefully observe behaviors and evaluate results of interventions. Clearly communicate what does and does not work with all facility staff.
- Recognize increased distress among staff working with agitated individuals. Provide opportunities for staff to talk about their concerns and feelings when confronted with unsafe situations.



psychiatrist concerning approaches and medication adjustments. While Ativan and Haldol increased Jake's negative behaviors, Depakote and Seroquel decreased them. Behavioral approaches included establishing a predictable daily routine, encouraging him to walk in the secured courtyard and providing a soccer ball to kick; permitting him to nap wherever he felt comfortable; and providing immediate assistance for meals and the bathroom. Challenges included keeping residents away from him when his anxiety or aggression increased and the inability to provide Jake immediate attention when other residents needed help. Several staff remarked that Jake was different from the other residents. He was younger, stronger, and gave that "blank, scary look" at times. Staff expressed concern and some fear that they did not know what he was going to do next. Due to incidents of physical aggression and safety concerns, Jake was re-admitted to the Geriatric Behavioral Unit several times for observation and medication adjustment.

Helen was conflicted about some of Jake's behaviors; she saw them differently from staff. Since they were inconsistent, she remarked that she thought Jake was "acting like that just so he could come home." She also thought the medications caused some of his problems. Helen took Jake to a different psychiatrist who wrote an order to decrease his Seroquel and Depakote. This was presented to his attending physician at the facility who did not want to decrease the medications. However, he eventually did decrease the dosages based on the psychiatrist's recommendation and Helen's insistence.

"Why does he act like that?" Reviewing the incident

On the morning the caregivers called the nurses for assistance, Jake appeared more anxious. Nighttime staff reported that he had not slept well. Breakfast was served a few minutes late. Jake was pacing in the dining room, approaching residents, and demanding food. He grabbed one resident who yelled at him and another who did not respond. When Mary, the caregiver, took his hand to redirect from one of the residents, he turned around and punched her.

Upon review of the preceding incident, the staff identified behavioral triggers that included Jake not sleeping well and increased anxiety. A reason for his sleeplessness could have been that a new caregiver encouraged him to sleep in his room versus the chair in the living room. Breakfast was slightly late as well, and the caregivers did not have a chance to serve him cereal and juice until the full breakfast arrived (not his usual routine). Also, Jake recently had a decrease in several medications.

Mary was concerned for the safety of other residents, so she took his hand to redirect him. Since touching triggered Jake's aggressive behaviors, he turned around and reflexively punched her. One nurse rushed into the dining room to assist, and this could have overwhelmed Jake; he then tried to hit her with a chair. The other nurse took over, using a calm, directing voice, and provided single phrases to escort Jake from the dining room to the living

room, where the cook had set up his breakfast.

Jake was re-admitted to the Geriatric Behavioral Unit for medication adjustment. He was also evaluated and treated for pain, secondary to prior soccer injuries. The staff met with Helen and Jake's physician, and all agreed upon increased dosages of Depakote and Seroquel. Two approaches were added to his Plan of Care: serving Jake's meals in the living room if he is anxious and administering a pain medication prior to personal care. Jake was, also, seen by Physical Therapy for pain management. The revised Plan of Care was reviewed with all staff and a process was implemented to review the Plan with new staff. With these changes and ongoing review, Jake's anxiety has decreased and he has not had any physically aggressive behaviors this quarter.

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

1) What are examples of Jake's aggression? He screamed at Helen; broke the dining room chairs and other home furnishings; punched a hole in the door; caused physical injuries by grabbing and bruising other residents and punched Mary; physically threatened Helen by chasing her around the house; tried to hit the nurse with a chair; and resisted care with verbal and physical outbursts.

2) Were there any triggers to Jake's aggressive behaviors? Jake became visibly frustrated when he had to wait for meals or receive attention/responses from staff or residents; when he could not complete a verbal request, such as sitting on a chair; loud noises, such as residents talking or yelling; too much stimulation from meal time and group activities; and people getting too close to him, or touching him was overwhelming. He was resistant to personal care. He did not want to move from the living room to his room if he was sleeping.

3) What approaches were the most beneficial to Jake's family and the staff? Jake responded best in a quiet setting with little stimulation; calm and single verbal instructions; no/minimal touching; an established routine; an opportunity to walk and kick the soccer ball in the courtyard; pain medication prior to personal care; Physical Therapy, and sleeping in the living room, or his room, with music.

4) What were the keys to the success of Jake's Plan of Care? Jake's family, physician, and staff discussed his history, diagnosis, symptoms, medication regimen, and approaches, and agreed upon a Plan of Care that addressed Jake's need for supervised care, Helen's desire to have him in the program, and the concerns of the facility. This occurred upon move-in, quarterly, and whenever there was a change in his condition. Developing interventions that were person and family centered was critical to address all concerns. The Plan of Care was reviewed and discussed with all staff.



Medications for Agitated Behaviors

Medications may be necessary when behavioral strategies are not effective in managing unsafe behaviors in FTD. The same careful observation and creative thinking used for behavioral interventions should be applied for effective use of medications. The following are general approaches for medication use. *This information should not be considered medical advice. Medications should be prescribed only through careful consultation with the family caregiver, the care team and the primary care provider.*

- Be specific about the behavior to be targeted with medication (for example, unprovoked confrontation to other residents and visitors). Careful observation by staff is critical to evaluate both the effectiveness and potential side effects of pharmacological management.
- Start with a low dose of one medication and wait sufficient time before increasing it. Some medications take several weeks before their effectiveness can be measured.
- Medicines for mood and behaviors work slowly. It often takes several weeks to see the true effect of the medication. For that reason, giving single doses on an “as needed (PRN)” basis is discouraged.
- Reevaluate periodically as the type of medication or dosage may need adjustment.
- Set realistic goals: reduced frequencies of the targeted behavior indicate the appropriateness of the prescribed class of medication.
- Discuss possible side effects with the prescribing physician.
- Family members may hesitate to medicate their loved ones. Communicate concerns about the safety of all residents and staff in the facility while respecting the needs of individuals with agitated behaviors. Listen to families’ suggestions about management strategies and encourage their active participation in care.

Categories of Medications

There are currently no FDA-approved medications for treating FTD. Best practice guidelines for agitation come primarily from studies in older individuals with Alzheimer’s disease rather than the younger FTD population. There are several categories of medications used for agitation associated with FTD. It is important to carefully review potential side effects by referring to patient education materials available from the pharmacy.

The following medications are listed by generic name/trade name:

- The selective serotonin reuptake inhibitors (SSRIs) can reduce disinhibition, repetitive/compulsive behaviors, sexually inappropriate behaviors, and carbohydrate craving/overeating. Examples of these medications include: fluoxetine/Prozac, sertraline/Zoloft, paroxetine/Paxil, fluvoxamine/Luvox, and citalopram/Celexa. It will take several weeks to fully evaluate the effectiveness of these medications.
- Trazodone/Desyrel also increases the availability of serotonin in the brain and may improve agitation, depression and eating behaviors. Trazodone can cause sedation and may help sleep.
- Mirtazapine/Remeron stimulates appetite and may cause sedation and help with sleep.
- Atypical antipsychotics (including risperidone/Risperdal, aripiprazole/Abilify, olanzapine/Zyprexa, and quetiapine/Seroquel) are prescribed for severe uninhibited behavior and verbal and physical outbursts in FTD. These medications carry an FDA ‘black box’ warning for use with elderly dementia patients due to increased risk of stroke, heart attack, and death. While the risk to younger FTD individuals is unknown, discussion of these possibilities with their families and them is required. In addition, some persons with FTD have increased sensitivity to these medications and may be more likely to develop body rigidity, neck stiffness, swallowing difficulty, and falls. Careful monitoring is essential.
- Mood stabilizers include the anticonvulsants carbamazepine/Tegretol, valproate/Depakote, gabapentin/Neurontin, topiramate/Topamax, lamotrigine/Lamictal, oxcarbazepine/Trileptal and lithium/Lithobid or Eskalith. These medications may help manage compulsive and agitated behaviors.
- Medications in the benzodiazepine family tend to decrease inhibitions and may cause rebound agitation once they wear off. These medications are generally not recommended for agitation: lorazepam/Ativan, alprazolam/Xanax, and diazepam/Valium.
- Medications for Alzheimer’s disease are generally avoided, as they may worsen cognition and behavior in FTD. These include the anticholinesterase inhibitors (donepezil/Aricept, galantamine/Razadyne, and rivastigmine/Exelon and memantine/Namenda).
- Avoid stopping any of these medications suddenly. Taper each medication slowly.
- Notify the prescribing physician if there is no sign of the specific agitated behavior for 3-6 months. A trial off the medication may be considered.



Aggressive Behavior

Because many individuals with FTD are not aware of their illness, they may become frustrated at limitations and constraints that they do not understand and consider to be unfair and punitive. As a result, the person may occasionally strike out at the caregiver or resist assistance. Aggression may include: shouting, name-calling, cursing, or lewd comments; or physical abuse actions such as hitting, pushing, biting, pinching, scratching or grabbing or disinhibited sexual behavior.

Anticipate and prevent wherever possible

- Reduce overstimulation such as too much noise, people or activity.
- Always avoid confrontation. This can be done by not arguing or trying to point out the truth.
- Assess and treat pain or other illness.
- Maintain routine, when possible. If necessary, make changes gradually. Disruptions to sleep, structure etc. may add to behavioral issues.
- Do not rush, argue, or touch without permission.
- Acknowledge the individual's feelings.
- Provide activities that are individualized and success-oriented. Promote individual versus group activities which may overwhelm the individual.
- Offer constant encouragement; maintain a calm voice and smile as individuals with FTD understand positive emotional expressions better than negative ones.
- Evaluate benefits and side effects of medications (mood and behavioral) closely and continuously .
- Note: Re-direction is not usually effective with individuals with FTD, as cognitive and memory abilities are often retained.
- Be aware that physical agitation without aggression (such as increased pacing or yelling) predicts a greater risk of aggression towards another person.

Intervene with confidence and respect

- Remain calm, lower your voice (this may not be recognized by the individual with FTD but may assist in calming you). Do not attempt reason or logic. Validate the individual's emotions.
- Maintain safety. Give the individual space (about five feet). Make sure there is an exit route. Keep yourself standing on the individual's least dominant side. Observe the location of the individual's arms and legs. There may be physical aggression without warning, such as change in facial expression and body stance.
- If there is an aggressive behavior, use a calm, directing voice and single phrases to escort the person to a nearby area and engage in a positive activity.
- Call 911 if aggression or risk to the resident or others escalates.

Address staff concerns, review incidents and revise Plan of Care

- Address staff concerns (e.g., "He is younger and stronger, and he gives that blank, scary look.") openly.
- Education concerning the disease is essential. Help staff understand that the behavior is a result of the disease process.
- Communicate that personality changes may occur with the disease. Remind staff that the individual does not identify that there has been a change in his behavior.
- An individual's facial expression may be blank or appear threatening; do not take it personally.
- Encourage staff to share their observations, concerns and needs.
- Reinforce that there is no intent to hurt; someone with FTD is unable to have normal reactions and feelings.
- Review possible triggers and implement positive approaches.
- Develop a Plan of Care with the family, staff, and primary care provider. Review the Plan on an ongoing basis, and communicate to review and discuss with all staff.