

I'm Only Trying to Help: Approaches to Resistant Behavior in the Home

Introduction

In FTD, resistant behaviors occur when the person diagnosed opposes the efforts of a caregiver to help them with activities of daily living, including bathing, toileting, dressing, eating, medication administration, and many others. Resistant behaviors may present in a subtle manner, or can be accompanied by displays of force and even violence against the caregiver. Most of the time, the resistant behaviors in FTD are not intentional, as persons diagnosed often cannot control their behaviors. In fact, because many persons with FTD also lack awareness of their own disease—a symptom known as anosognosia—they may reject their

care partners' attempts to maintain their safety; they may grow frustrated and react in ways that are upsetting. Effective non-pharmacological approaches, along with medication as needed, are key strategies to diminish escalating resistant behaviors.

The following case study demonstrates the challenges and best practices for assisting individuals with FTD who exhibit care resistance. Effective management requires close collaboration between the family and health professionals to develop and implement a highly individualized plan of care.



The Case of Kai G.

Kai G. is a 68-year-old tenured research professor at a local university. A 6'5" bear of a man, he is well mannered and even-tempered—the proverbial “gentle giant.” Three years ago, his long-term partner Jenny noticed he was changing. Usually an easy conversationalist, Kai began to have trouble coming up with the right words in the right situations. His behavior and personality changed—he became less empathetic and cooperative while becoming more disinhibited and impatient. Despite his type II diabetes and daily insulin regimen, he began eating candy several times a day. He also, unbeknownst to Jenny, was spending money frivolously and struggling to manage the household's finances. At work, his performance began to decline, while he continued to oversee various research activities at his university's lab.

In early summer of 2018, Kai—brushing aside Jenny's strongly voiced objections—joined a few close friends for a week-long fishing trip. His friends became concerned with his increasingly odd behavior: He refused to eat any of the fish they caught, instead eating only junk food and sugary soda. (What his friends did not know was that Kai had forgotten his insulin. He never bothered to tell them or even attempted to rectify the situation.) Kai seemed more curt, confused and disoriented than usual; he also complained of headaches and dizziness. But when his friends asked if he was OK, Kai said he was perhaps a bit seasick, but felt fine overall.

His headaches continued when he got home, prompting Jenny to make Kai an appointment with his diabetes specialist. She insisted on accompanying him. He admitted to his specialist that not only did he forget his insulin on his trip, but that he frequently skipped doses even when he had his insulin in hand. His HbA1C levels, which measure blood sugar, were extremely high, and almost certainly accounted for his headaches and dizziness. Nevertheless, Kai could not seem to understand why taking his insulin regularly was so important.

Back at home, Jenny tried to keep Kai's insulin regimen on track, but he resisted. The former “gentle giant” became crass, agitated, and paranoid: He said he thought Jenny was trying to hurt him. Occasionally he became aggressive and ended up physically harming Jenny, yet he seemed not to feel remorse for injuring the person he loved most. Jenny started to fall into a state of despair: disheartened by her failed attempts to care for her declining partner, embarrassed by her bruised and battered appearance. As difficult as this time was for her, she felt she could not share any of her concerns—she feared that bringing her struggles to light would paint a negative public picture of Kai, potentially harming his reputation and career.

COMBATting COVID-19 WHEN FTD CAUSES HAND-WASHING RESISTANCE

As the country continues to grapple with the COVID-19 pandemic, hand-washing and hygiene are more important than ever. But when persons with FTD exhibit resistant behaviors, ensuring appropriate hygiene measures can become a challenge for care partners. To ensure safety in the home for both persons diagnosed and their care partners, it is important to employ effective behavioral and communication strategies to help combat the difficulties created by this stressful and uncertain situation.

Resistance to good hygiene is not a willful act of defiance or negligence by persons diagnosed with FTD. It is a result of the cognitive and behavioral changes caused by the disease. Activities that may seem like second nature—washing one's hands, for instance—can pose great difficulty to someone with FTD, who may not be able to sequence actions without effort and concentration, and may even feel the sensation of soap and water differently because of changes in their brain.

In such cases, developing a simple, sustainable hygiene routine is key to handling the disruptions caused by the current environment. If hygiene and hand-washing is met with resistance from the person diagnosed, care partners can prompt them to engage in hand-washing and other hygiene behaviors by making a card with two or three easy-to-follow steps. For example, a simple guide to hand-washing could say: Run warm water, apply soap, wash for 20 seconds. These behaviors can be further enforced by creating a daily schedule, which will add structure to what may feel like an unusual and disruptive environment.

In addition, it is important to ensure communication surrounding hygiene behaviors is direct, but not confrontational, as anger and hostility can further escalate resistant behaviors in the person diagnosed. It is best to use simple instructions and to be straightforward when relaying directions. It is important to remain calm and exercise patience. Speak in a clear, calm, reassuring and positive voice, and avoid saying “no.”

Ensuring proper hygiene may require creativity and flexibility, as goalposts shift frequently in FTD. If one approach does not seem to work, it may be beneficial to try a different tactic and/or set new goals for care. For example, if the recommended 20 seconds of hand-washing with soap and water proves too difficult, try using antibacterial hand wipes or a hand sanitizer containing at least 60% alcohol. Similar methods can be employed to accommodate other hygiene routines. ■

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Dementia Diagnosis

At the end of the summer, Kai's primary care physician retired, forcing him to find a new doctor. With Kai's permission, Jenny accompanied him to his first appointment. Kai's medical records did not mention any of his cognitive difficulties, so Jenny discreetly slipped a note to the new doctor describing how Kai had changed over the last three years: his problems with word finding; his short-term memory issues; his penchant for misplacing common objects (glasses, keys); his impulsive behaviors, particularly around spending money; his habit of repeating himself during conversations and his trouble following along with lengthy ones; and his resistance when Jenny tried to offer help. The note was co-signed by Kai's assistant at work as well as the financial advisor for his research department, both of whom had told Jenny about their shared concerns.

The subject of Kai's behavioral changes came up during the appointment. Kai, however, was able to mount an eloquent self-defense, arguing that he had no impairments at all. His lucid performance made Jenny feel defeated. Fortunately, after the appointment, Kai's physician called Jenny for a private conversation, during which she clarified her concerns and worked with the doctor to develop a plan of care.

At a follow-up visit in October, Kai took a cognitive screening test and was diagnosed with moderate dementia. He dismissed the results, insisting he was fine (although he confessed to having some trouble remembering names). Nevertheless, the doctor recommended he stop driving and insisted he let Jenny help him manage his medications. He also recommended blood work, a brain MRI, and a consultation with Dr. Fiore, a cognitive neurologist who specialized in memory and neurodegenerative disorders. Kai agreed, saying that Dr. Fiore would confirm once and for all that he did not have cognitive impairments.

Defying his physician's clear recommendations, Kai continued to work, drive, and manage his own medications, including his insulin. Jenny became extremely troubled. Even though Kai was not yet officially a patient of Dr. Fiore—he wasn't scheduled to meet with her until January—Jenny called her office for help. A receptionist transferred her to the practice's dementia crisis intervention line, where she spoke with Dominique, the practice's clinical nurse practitioner.

Jenny described how Kai was sternly and forcefully resisting any of her attempts to address his changes, and how he would frighten her by issuing what Jenny called a "firm no," often accompanied by

OPTIMIZING MEDICATIONS FOR DIFFICULT BEHAVIORS IN FTD by Nansi Greger-Holt, RN, MPH, MSN

Care-resistant behavior, often caused by distress, is a common symptom of FTD. And since many with FTD are younger in age, they can be quite strong physically; as a result, resistant behaviors can put them and their care partners at a greater risk of harm.

A medical evaluation is important to rule out common causes of behavior disturbances, such as constipation; infection; vision, hearing or sleep problems; a medication reaction; or pain. After a complete evaluation, non-pharmacological approaches should be used first to better manage resistant behaviors. But if these methods are unsuccessful, families should consider a stepwise approach of managing behavior through medications.

Families understandably try to avoid medications that can cause sedation—they don't want to "drug" their loved one. Fortunately, with caution and a scientific approach, managing FTD symptoms such as distress is usually possible while also maintaining optimal alertness and the ability to enjoy life. Neurologists or geriatric psychiatrists who specialize in FTD

have expertise in this type of medication management.

The medications with the safest side-effect profile should be tried first, with the dosing approach of "start low and go slow, but go." As long as a medication is tolerated without side effects, gradually maximizing its dosage is a sensible approach. Steady, regular medication administration is preferable to as-needed dosing, unless the symptoms occur infrequently (i.e. not daily).

There are no medications specifically indicated for the management of challenging behaviors in FTD. However, there are some FDA-approved medications that have been shown to have some efficacy in addressing FTD's behavioral and psychiatric symptoms. Prescribers should take care to avoid any type of anticholinergic medication (meaning those that can worsen cognition), and to carefully consider potential side effects. (More information about medications and FTD can be found in the Fall 2019 issue of *Partners in FTD Care*.) ■

CLASSES OF PSYCHOTROPIC MEDICATIONS COMMONLY USED FOR PEOPLE WITH FTD

Cognitive Enhancers	Can be useful if the underlying disease process is Alzheimer's pathology, despite a clinical presentation of FTD.
Selective Serotonin Reuptake Inhibitors (SSRIs)/ Antidepressants	Often the first line of treatment, can address behaviors such as irritability, tearfulness, depression or anxiety early in the disease. They may also help with overeating and impulsive behavior. Nausea, headache and gastrointestinal side effects may occur.
Neuroleptics/Atypical Antipsychotics	Antipsychotics are not FDA approved to treat FTD or any dementia, but can be effective in treating hyper-emotionality, aggression, severe compulsive behaviors and agitation. These medications have a "black box warning," meaning they have on rare occurrences (less than five percent of the time) been shown to contribute to death from pneumonia or stroke in persons with dementia-related psychosis. Care partners should consult with the prescribing physician to determine if the risk of these medications outweighs their potential benefits.
Anticonvulsants	Can serve as "mood stabilizers." Some of these medications may be used alone or in conjunction with an antipsychotic medication to help manage agitation

More information about medications and FTD can be found in the Fall 2019 issue of Partners in FTD Care.

banging on a table with his fist, which was highly uncharacteristic for him. She tearfully blamed herself for not having intervened sooner. Dominique empathized with Jenny's feelings and concerns, and offered a few non-pharmacological approaches she could use when Kai's behavior was particularly challenging. (In dementia, non-pharmacological interventions are attempts to positively influence one's cognition, mood, and other behavioral and psychological symptoms without medication.) Dominique suggested hiding Kai's car keys or disconnecting the car battery to discourage driving. She also told Jenny that, whenever Kai displayed a resistant behavior, she should note the physical environment and social context in which the behavior took place; this could help identify specific triggers. Dominique also offered to mail Jenny resources outlining everything they had discussed, and encouraged her to call back as needed. After the conversation, Jenny felt a bit calmer knowing she had at least one source of help for dealing with Kai's behaviors.

Whenever Kai displayed a resistant behavior, Jenny would note the physical environment and social context in which the behavior took place.

Visiting a Specialist

Early in the new year, Kai had his first visit with Dr. Fiore. Based on her assessment—her review of clinical notes from his primary care physician, information she received from Dominique, data from Kai's lab work and brain MRI, and her analysis of Jenny's observations—Dr. Fiore diagnosed Kai with probable behavioral variant FTD (bvFTD). She concluded that Kai was no longer able to manage money, self-administer his insulin (his blood sugar levels were very high), or safely drive a car. She recommended that he stop driving, retire from the university, and let Jenny assist him with his finances and health care needs; she also told both to contact Dominique as needed for support.

Both Dr. Fiore and Dominique knew that Kai's case could be especially challenging: He is highly educated, resistant to medications and did not seem to accept either his bvFTD or diabetes symptoms. Indeed, Kai did not believe Dr. Fiore's diagnosis. Nevertheless, he continued to see her, determined to prove that he did not have any cognitive issues, let alone FTD, and that he did not need Jenny's supervision.

The next month, Jenny and Kai had an appointment with Dominique, who immediately asked about the sling Jenny was wearing on her arm. Jenny tearfully explained that, while she was trying to administer his insulin, Kai had pushed her to the floor, dislocating her shoulder. She defended Kai, saying she knew he was reacting out of fear; he only acted aggressively when forced to do something he did not understand. The rest of the time, he was pleasant and calm, Jenny said.

THE IMPORTANCE OF RECORDING RESISTANT BEHAVIORS

Caring for someone with FTD can be extremely challenging. Common FTD symptoms such as confusion, loss of control and lack of awareness can manifest as resistant behaviors that make caregiving even more difficult.

The first step to managing these behaviors is to record them as they happen. By using a calendar to note the day, time and nature of each act of resistance, care partners and family members can gain crucial insight. What are the potential triggers? What words best characterize the behaviors (impatience, anxiety, frustration, irritability, agitation, aggression)? Which strategies seem to help? Which ones don't?

This information should be shared with relevant care team members to ensure everyone is on the same page. Together, they can arrive at a deeper understanding of the specific resistant behaviors displayed by the person diagnosed, which can point toward non-pharmacological solutions (for example, adaptations to the home environment designed to reduce triggering situations and/or de-escalate resistant behaviors when they arise). ■



STRATEGIES TO MAINTAIN SAFETY WHEN RESISTANT BEHAVIORS ARISE

Resistant behaviors in FTD can seem unpredictable, but are usually the result of a person diagnosed responding to a trigger. Triggers can range from a confusing instruction or request, an unfamiliar environment or location, an encroachment on their personal space, pain or discomfort, and many more.

To prevent stressful and potentially dangerous situations, both in the home and in community settings, it is essential to employ best practices for individualized, person-centered FTD care while ensuring the safety of all parties. Following are several best-practice strategies to help ensure that the individual with FTD, their caregiver(s) and others are safe when encountering resistant behaviors:

Behavioral strategies

Assess the situation for possible triggers. Ask yourself, "What did I do to contribute to this reaction?"

Redirect behavior away from potential triggers.

Determine what the immediate need is, and work to satisfy it. If something has been proven to calm resistant behaviors, have that readily available.

Communication strategies

Do not argue, or be confrontational.

Speak in a clear, calm, reassuring, positive voice.

Do not try to use logic.

Avoid saying "no." Instead, frame responses in a "yes" format.

Engage in respectful adult-to-peer communication.

Environmental strategies

Remove firearms and car keys, and lock away sharp objects, dangerous appliances and other potential weapons.

Reduce noise, glare and background distractions.

Identify a safe space for all parties that is free of triggers.

Install monitoring devices in the home.

Remember to revise and adapt any non-pharmacological FTD care approaches and strategies as needed, and to communicate the plan to all care parties involved. If necessary, seek private duty staff to assist with activities that prompt resistant behaviors. Develop a care team—including a primary physician, FTD specialist, and social worker—to assist with behavioral management and to review necessary medical interventions. Prepare for emergency situations and develop a plan. Always remember to follow your gut; if you feel you are in any immediate danger and your loved one is a threat to themselves or anyone else, contact local authorities immediately. Be sure to explain to emergency personnel the individual's diagnosis, potential behaviors, and needs. ■

Dominique knew that, without an intervention of some kind, Kai's resistant behavior would likely only get worse. She started by educating Jenny and Kai about FTD, medications that could help, and care partnering around relationship dynamics. Together, they developed an individualized, person-centered plan of care that focused on safety and encouraged the continued use of non-pharmacological techniques, although Dominique did prescribe a low dose of quetiapine (Seroquel) for Kai. All three agreed to hold biweekly phone check-ins, and Dominique strongly encouraged Jenny to attend FTD and caregiver education and support groups. She also told her to consider hiring paid caregivers for when Kai eventually retired.

One rainy March afternoon, Kai found spare car keys that Jenny had hid and left without telling her. After realizing what had happened, Jenny tried several times to call Kai's cell phone, but he did not pick up, nor did he return home that evening. Jenny then contacted everyone she thought might know Kai's whereabouts, but no one had seen or spoken to him that day. She called Dominique, who recommended she call 911; eventually local authorities issued a Silver Alert, an urgent search for missing persons who are elderly and/or have cognitive or developmental impairments.

A Disturbing Incident

Finally, just after midnight, law enforcement officials found Kai in the university parking garage, calm and unharmed, unaware of the widespread hysteria his disappearance had caused. He denied any substance abuse or suicidal thoughts, and insisted he was not confused. Rather, he said he was monitoring a fraternity party across the street; he had thought it needed adult supervision, so he planned to spend the rest of the night watching it from the parking lot. In actuality, Kai had lost his car in the parking lot and

A CARE PARTNER'S PERSPECTIVE: THE IMPORTANCE OF SUPPORT IN ADDRESSING RESISTANT BEHAVIORS **By Sandra Grow**

My husband was diagnosed with FTD at the age of 54. As his caregiver, I sought out a support network to help deal with the progression of the disease, and along the way, became a support group volunteer to help the families of persons diagnosed with FTD.

During monthly support group meetings, we discuss any questions, issues or feelings related to life with FTD. Some of the challenges that arise in our discussions are the result of resistant behaviors, such as not wanting to bathe, rejecting medications, or refusing to change clothing. Sometimes, group members describe behaviors that are aggressive, verging onto threatening. Such behaviors differ from resistant behavior, creating safety concerns for the caregiver and person diagnosed.

It is important to note that not all persons with FTD exhibit aggression. But if these behaviors occur, caregivers should know that there are ways to address and even prevent them while keeping themselves and their loved ones safe.

For example, if a person with FTD is exhibiting resistant behaviors, it is important for the caregiver or family to be honest with their physicians and other health care providers. It is difficult for health care providers to detect these behaviors in a 20-minute office visit. Caregivers and family members should not be embarrassed to discuss what is happening.

When dealing with resistant behaviors in FTD, logic is not your friend. Rational discussion and debate are not always effective

communication tools as the disease progresses. It may help caregivers to understand why resistant behaviors occur; I often express to my support group members that their loved one may be experiencing some combination of fading inhibitions, lack of insight into their behavior, distortion of reality, difficulty speaking, and the inability to understand words. I also offer reassurance that these behaviors are often a result of the degeneration of the part of the brain affected by the disease.

I often encourage caregivers to watch for the triggers or warning signs that lead to resistant behaviors. They may present as sudden or abrupt changes in facial expression, unusual or compulsive pacing, sudden changes in voice tone, and/or uncharacteristic actions (i.e. shouting, grunting, or making a fist or another threatening motion).

As a support group leader I have to be diligent in knowing when to refer the caregiver to seek additional help, especially when resistant behaviors escalate to the point where they pose a safety risk. Most of all, I let my group members know that they are not weak or incapable if they need to ask for help and guidance. I tell them, "Do not feel like you have to do this alone." Working with a care team—one that includes physicians, social workers, spiritual leaders, counselors, and support groups—can be an important part of this journey. ■

Partners in FTD Care Advisors

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts and family caregivers. Advisors include:

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AFTD extends special thanks to change to this issue's special guest contributor, **Nansi Greger-Holt**, RN, MPH, MSN, a geriatric nurse practitioner at the University of North Carolina.

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ADDITIONAL IN-HOME AND COMMUNITY-BASED CARE OPTIONS

Having to manage the resistant behaviors of a person with FTD can directly impact the health and well-being of both the person diagnosed and their caregiver. Caregivers must feel as safe and healthy—both physically and mentally—as possible in order to properly tend to the well-being of the person with FTD. Having additional in-home care and regular respite opportunities can help families to better manage, both emotionally and logistically.

There are several ways to look for in-home care. For families who lack the financial resources to pay privately for such care, the agencies listed below may be of help. Through the Aging and Disability Resource Center initiative's "No Wrong Door" system model, family caregivers should be able to better access care in their area.

1. Local Area Agency on Aging Office (over age 60)

Area Agencies on Aging (AAAs) were established to respond to the needs of adults (typically 60 and over) in every local community. AAAs maintain resources that allow adults to find necessary and affordable care in their communities. To find your local AAA and learn what specific in-home care and respite services are offered locally, use the Eldercare Locator tool at eldercare.acl.gov.

2. National Aging and Disability Resource Centers (under age 60)

Aging and Disability Resource Centers are an important part of the No Wrong Door system model. A collaboration between the Administration for Community Living, the Centers for Medicare & Medicaid Services, and the Veterans Health Administration, the No Wrong Door model streamlines access to services and supports for people with disabilities and their families. In communities where AAA services are limited to people age 60 and older, the local ADRC should offer similar services for those under 60. Find your local ADRC by using the Eldercare Locator tool at eldercare.acl.gov.

3. Veterans Health Administration (VA)

For those eligible, the VA offers a number of in-home dementia supports and resources. These services include: adult day health care centers, home-based primary care, home hospice care, homemaker and home health aide care, telehealth services, up to 30 days of respite care per year, and skilled home care. To learn more about any of these services, contact the VA's Caregiver Support Line at 1-855-260-3274, or find your local Caregiver Support Coordinator by visiting www.caregiver.va.gov/care_veterans.asp. (Services may differ by geographic area. Find your local VA office below to learn more: www.va.gov/statedva.htm.)

4. Medicaid Home and Community-Based Waivers

Medicaid is a program in every state that pays for medical assistance for certain individuals and families with low incomes and resources. While Medicaid services vary from state to state, in-home services provided can include: case management (i.e. supports and service coordination), homemaker and home health aide care, personal care, adult day health services, and respite care. One must qualify for Medicaid to receive these benefits. Contact your local Medicaid office for more information.

5. AFTD Respite and Quality of Life Grants

AFTD offers direct financial assistance to care partners and persons diagnosed in the form of Respite and Quality of Life Grants, both part of AFTD's Comstock Grants program. Respite Grants offer full-time, unpaid caregivers funds to arrange short-term daytime or overnight care for a loved one diagnosed with FTD. The Quality of Life Grant, on the other hand, helps persons diagnosed with an FTD disorder access services or supports that will improve their quality of life. For more information about AFTD's Comstock Grants, visit www.theaftd.org/living-with-ftd/resources/comstock-grants.

Palliative Care

The Center to Advance Palliative Care (CAPC) is a nonprofit organization affiliated with the Icahn School of Medicine at Mount Sinai, located in New York City. It provides a variety of resources designed to promote the use of palliative care, so that people facing serious illnesses can receive quality, person-centered care. Visit GetPalliativeCare.org for more information. ■

spent four hours looking for it, and when he finally found it, he accidentally locked the keys inside. When a police officer shone a flashlight into Kai's car, he could see his cell phone lying on the passenger seat, with more than 30 missed calls.

Overwhelmed by the flashing lights and the police interrogation, Kai grew confused and frustrated. He could not answer the officers' questions coherently, or provide Jenny's contact information; he also refused a ride home. The officers tried to coax him into their vehicle, but in doing so encroached into his personal space. Kai reacted with loud objections and by aggressively waving his arms. The police slowly backed away, giving Kai more space and greatly reducing the potential of a dangerous incident. They calmly told him they had called an ambulance to take him to the emergency room. Once Kai reached the ER, hospital personnel contacted Jenny, who explained that Kai had FTD.

University security reported the incident. His department considered the incident in light of his increasingly disruptive behavior and unsatisfactory work performance and pressed him to retire. During a farewell party the university threw for him, Kai seemed perplexed, but remained cordial.

The day after the party, Kai and Jenny visited Dr. Fiore and talked about Kai's most recent medical and behavioral issues. Jenny told the doctor that while administering Kai's insulin was easier than before, he still occasionally resisted. Dr. Fiore recommended an increase of his quetiapine to reduce his paranoia and resistance to care. She reinforced the use of non-pharmacological interventions and again suggested hiring in-home caregivers.

A few months after that visit, things started to get a little better for Kai and Jenny. Dominique helped Jenny hire a home health aide to help with Kai's morning and nighttime care routines, and assist in administering his insulin. The increased dose of quetiapine helped to reduce his most challenging behavioral symptoms. Eventually, Kai began to attend an adult day program, which he enjoyed. Jenny appreciated the respite, as well as the chance to go to meetings of her local FTD support group.

While not every person living with FTD will resist care, it is nevertheless a fairly common symptom of certain types of FTD. Like Kai, many will resist care because they simply do not think anything is wrong with them, and may act out with a level of aggression that they never used to display. Resistant behavior can make the job of being a care partner significantly more difficult. But it is important to know, as the case of Kai and Jenny demonstrates, that there are options available to reduce resistance—through the use of medicine, caregiver education and non-pharmacological interventions.

Discussion Questions

1. What are three examples of Kai's resistant behaviors seen in the case, and how were they addressed?

Three examples of resistant behaviors seen in the case were:

- Jenny's descriptions of Kai's "firm no," often followed by banging his fist on a table
- Kai refusing to accept a ride from local police, aggressively waving his arms while doing so
- Physically fighting off Jenny's attempts to administer his insulin, hurting Jenny in the process

Some best practices for resistant behaviors used in this case are: non-pharmacological care approaches, care partner education, and the use of paid caregivers. Additionally, Kai was prescribed medicine—quetiapine, in this instance—targeting his resistant behaviors and other symptoms.

2. What challenges arose in obtaining a bvFTD diagnosis? How did Jenny communicate her concerns to clinicians?

A care partner's own observations, carefully documented, are often the most important part of the diagnosing process. Care partners should record any changes in behaviors and personality that they see. Jenny was able to slip a note to Kai's primary care physician explaining the changes she had seen in him. When Kai was lucid and eloquent during the appointment, she was anxious that her concerns would be ignored. But the doctor recognized that Jenny's list of concerns, combined with the cognitive assessment performed on Kai, warranted a follow-up visit with a dementia specialist who had experience in FTD.

3. How did the dementia nurse practitioner address Kai's resistant behaviors while improving his and Jenny's quality of life?

The dementia nurse practitioner introduced Jenny to non-pharmacological care approaches to address Kai's resistant behaviors. She also made herself available by phone, offering support and suggesting ways to best minimize Kai's distress while working to maintain his health and quality of life. Based on those suggestions, Jenny started attending caregiver education classes and a local FTD support group; she also hired a home care worker and enrolled Kai into an adult day program.

What to Do About... Managing Resistant Behaviors

Persons diagnosed with frontotemporal degeneration (FTD) may resist family members or healthcare professionals who attempt to provide care or take steps to ensure their safety (for example, by hiding their car keys or removing weapons from the house). Care-resistant behaviors are fairly common in FTD, a result of numerous symptoms that characterize the disease, including anosognosia (a lack of self-awareness of the impairments caused by their disease), decreased inhibition, and increased impulsivity. While resistant behaviors by persons with FTD are not intentional, they can prove to be upsetting to everyone involved. Managing resistant behaviors effectively requires close collaboration between family members and healthcare professionals to develop and implement a highly individualized plan of care.

Strategies for family caregivers

- Convey your concerns to clinicians. If talking about their behavior makes your loved one upset, write your concerns down and give them to the physician or office staff before being called into the exam room.
- Consult with your clinician to rule out common causes of behavior disturbances, such as constipation; infection; problems with seeing, hearing or sleeping; a medication reaction; or pain.
- If possible, record, whether by writing or using a camera, your loved one's behaviors at home to show the clinician behaviors that the person diagnosed may not display in an exam setting.
- Use communication and environmental strategies to create a low-stress, positive environment and reduce the risk of escalation.

Communication strategies

- Acknowledge and name the emotions that the person diagnosed is expressing: For example, if they are showing anger, say, "I see you are angry." Do not attempt to reason, argue, or try to change their feeling. Instead, redirect them to a preferred activity.
- Remember to keep your composure and remain calm; do not overreact. Do not ask questions about the behavior, and avoid statements that may be misinterpreted (e.g. "It's time to go to bed").
- Use a calm, reassuring voice. Take a positive tone; avoid saying "no." People with FTD respond better to upbeat interactions.
- Employ respectful communication. Do not speak down to a person with FTD: Show respect to them, their accomplishments and their place in the community.
- Identify which specific positive statements are most helpful in diffusing resistant behaviors. These may change based on the situation.
- Recognize that changing communication strategies is a difficult adjustment for family, caregivers and other healthcare staff. It takes time, practice and patience.

Environmental strategies

- Avoid overstimulating environments. However, if taking your loved one into potentially triggering public environments is unavoidable (doctor's visits, for example), consider making accommodations such as using side-door entrances, scheduling early-morning appointments, and asking about quiet areas for breaks.
- Identify things that calm the person with FTD (some examples may be playing soothing music, taking walks, or tending to the garden).
- Act with foresight. Remove firearms and lock away sharp objects, dangerous appliances and other potential weapons. Hide vehicle keys.
- Create a safe space for all parties that is free of triggers and unintentional distractions.
- Identify possible triggers of resistant behaviors, including certain activities of daily living, the presence of other individuals, certain times of day, and specific environmental factors (noisy and/or unfamiliar places, other visual triggers).
- Note when behaviors create safety concerns for the person diagnosed, family members or others.
- Initiate frank discussions with clinicians about person-centered care strategies. Ask them how to use non-pharmacological interventions, and whether they should be used alone or in combination with medications.
- Note that non-pharmacological interventions should be used first, and can be behavioral, communicative or environmental in nature. Revise and adapt interventions as needed.
- Understand that medication may not cause the resistant behavior to disappear completely, but may reduce severity and frequency, which indicates whether they have been prescribed appropriately. Conversely, increased resistant behaviors could suggest the need for different medications.
- Ask a pharmacist for information about a medication, its side effects and possible interactions.
- Educate doctors and other care providers who are less familiar with FTD and its symptoms by sharing AFTD resources.
- Advocate for affected family members.
- Call 911 if resistant behaviors put the person with FTD and/or their caregiver in immediate danger.

Guidance for medical health care teams

- Hold regular meetings with the caregiver and other family members to maximize care efforts and keep everyone informed about care challenges and behaviors. Review and adjust the care plan on an ongoing basis.
- Listen to what the caregiver thinks and feels about the situation. This can present opportunities to educate and offer person-centered care strategies for the person diagnosed.
- Ask how the family has tried to manage their loved one's behaviors so far.
- Reinforce that the person with FTD does not intend to cause harm when they exhibit resistant behaviors. Rather, they are often simply unable to react in "normal," socially accepted ways.
- Help the caregiver facilitate the use of support by helping them to tell appropriate parties about the FTD diagnosis and seek needed assistance.
- Inform caregivers about the FTD diagnosis and how to seek needed assistance; AFTD's HelpLine and support groups can be valuable resources.
- Emphasize the value of non-pharmacological interventions first. Provide ongoing assistance and support to help families determine the most effective interventions and responses tailored to the individual with FTD.
- Encourage caregivers to use proven behavioral management approaches in conjunction with medication trials.
- Set realistic goals with the family. Discuss which FTD symptoms may be alleviated with medication management and what side effects could occur.
- Assess the family's situation for safety concerns. If there is no immediate threat, work with caregiver to develop an in-home safety plan. If an immediate threat is present, refer the individual to the nearest emergency room.
- Reassure families and caregivers they are not alone in their journey!