

## 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!