



## What to Do About... Medications for FTD Symptoms

While healthcare providers' understanding of FTD is increasing, persons diagnosed and their families still face significant barriers to accessing effective treatment. The participation of the person diagnosed (to the extent they are able) and their caregivers is essential to developing and implementing any care plan. Care must be individually tailored to address changing symptoms, care settings and family needs. Effective pharmacological management of FTD depends on careful, ongoing observation of problematic behaviors and frank discussions between caregivers and doctors. Non-pharmacological interventions should be considered first; families should receive assistance and support to maximize their effectiveness.

### Engaging families and setting expectations

- Listen to the family's experience. Each family member's story of getting the diagnosis, understanding the symptoms and prognosis, and accepting the disease is unique, and can influence interactions with providers.
- Recognize that the diagnosed person's involvement—whether cooperative or resistant—will impact their care.
- Teach the family **common FTD symptoms** (e.g. impulsive behaviors, disinhibition, changing moods) and ways to respond to them—for example, by modifying the environment or adapting communication techniques that can minimize their impact.
- Ask how the family has tried to manage their loved one's behaviors so far.
- Emphasize the value of non-pharmacological interventions first. Provide ongoing assistance and support to help families determine the most effective interventions and responses.
- Introduce evidence-based responses such as the **D.I.C.E. Approach** (Describe, Investigate, Create Plan and Evaluate) for behavioral and psychological symptoms.
- Explain to families the differences between medication use in palliative care and hospice. Palliative care can be particularly valuable in light of the familial and financial stress that accompanies FTD.

### Assessing the impact of behaviors

- Find out which behaviors trouble the person diagnosed and their family the most. Ask for specific examples of each behavior.
- Rate the severity of the behavior on a scale of 1-10 (1 indicates little bother, 10 a great deal of bother).
- Determine each behavior's frequency (several times a day, daily, weekly, etc.).
- Indicate if behaviors create safety concerns for the individual, family members or others.
- Identify possible triggers of challenging behaviors, including presence of other individuals, environmental factors (noisy location, unfamiliar place, visual triggers), and time of day.
- Remind families that symptoms and behaviors of FTD change over time. Continual reevaluation allows adjustments in the type of medication or dosage prescribed. As the disease progresses, specific medications may no longer be needed.

### Guidance for families

- Record changes in the severity and frequency of specific behaviors. While the targeted behavior may not disappear, reduced severity and frequency indicate whether medications have been prescribed appropriately. Conversely, increased behavioral problems could suggest the need for a different type of medication.
- Note any variations in activities of daily living, such as changes in appetite, weight, sleep patterns, walking, falls, swallowing, and thinking abilities.

## Guidance for families (cont.)

- Present your observations in writing to the physician or office staff before being called into the clinic room if your loved one becomes upset during discussions of behaviors.
- Record video of your loved one's challenging behaviors at home, allowing the physician to see behaviors that the person diagnosed may not display in an exam setting.
- Ask a pharmacist for information about a medication, its side effects and possible interactions.
- Ask for written copies of discharge instructions to help ease future transitions.
- Educate doctors and other care providers who are less familiar with FTD by sharing AFTD resources.
- Ask your physician the best way to reach them so that you may contact them with any concerns you have about medications.
- Ensure that a complete and accurate listing of medications follows the person with FTD across services and physicians.
- Identify the physician who is the lead for managing medications and who will consult with other medical providers or facility medical directors for consistency in medication approach.
- Advocate for affected family members. It is essential, and you are not alone!

## Considerations for physicians in prescribing

- Let families know it may take time to find the right medications, and that the types of medications used may change over time.
  - Set realistic goals with the family. Discuss which FTD symptoms may be alleviated, the possible side effects and expectations for treatment.
  - Explain strategies of medication management—specifically, starting with a low dose and increasing it over time. Some medications take several weeks before they show any effectiveness.
  - Encourage families to use proven behavioral management approaches in conjunction with medication trials. (Visit the [Managing FTD](#) section of AFTD's website for further information.)
  - Ask the family to keep a journal of behaviors to document behavioral changes since medications began.
  - Follow an individualized approach to medications.
  - Prescribe medications approved for use in psychiatry to address targeted behavioral and mood symptoms.
  - Begin treatment with medications that are appropriate while also easy to tolerate and low in possible side effects. The use of SSRI antidepressants is common.
- Consider atypical antipsychotic or anticonvulsant medication when more disruptive or disinhibited behaviors persist.
  - Consider medication for sleep. Disrupted sleep is a common issue that contributes to caregivers' challenges.
  - Avoid anticholinergic medication, which can worsen cognition. Consider potential side effects of other medications (such as benzodiazepines, which could contribute to confusion, drowsiness or falls).
  - Avoid cognitive-enhancing medications such as donepezil and memantine in FTD as they may increase agitation. They may be indicated if the underlying disease process is Alzheimer's pathology, despite a clinical presentation of FTD.
  - Attend to changes in eating. Appetite may increase, and the person diagnosed may become more aggressive around food, or have a metabolic reaction.
  - Frequently assess both helpful effects and side effects. As the illness progresses, medications that affect gait have more side effects, and may cause falls.
  - Adjust medications as needed because behaviors change as the disease progresses. Some work for a time, and then stop. A medication that was not helpful early in the disease may be useful later. Stopping a medication may be as helpful as adding a new one.
  - Leave adequate time for the person diagnosed and their family to ask questions.
  - Coordinate with residential providers or the ER/inpatient psychiatric unit prior to and soon after a transition to ensure continuity of care. Having a relationship with a behavioral health unit, etc., is helpful if the individual is admitted for behavior/medication management.