

## Only Part of the Answer: Medications and FTD

**F**rontotemporal degeneration is clinically and biologically complex. There are currently no medications to slow or stop its progression, nor are there any FDA-approved treatments. Medications approved for other conditions, however, can be used as part of an individualized care plan to address some FTD symptoms. Effective pharmacological treatment requires correctly diagnosing the FTD subtype, a

careful and patient approach to prescribing, and adjusting medications based on ongoing observation of problematic behaviors. Educating and engaging care partners as full members of the care team is essential. The case of Jane L. shows how patient and ongoing engagement with knowledgeable professionals can help a family navigate the complex emotions and heart-breaking decisions faced in FTD.



## The Case of Jane L.

### Early symptoms and diagnosis

Jane was a successful real estate agent living in a Boston suburb, where she was known as a loving wife and caring mother of her two children, Maddie and Eli. But beginning in her mid-50s, Jane began displaying changes in her behavior, personality and judgment, raising concerns among her family. She began posting inappropriate comments on Facebook, and spent hundreds of dollars on lottery tickets. She lost interest in old hobbies such as gardening, walking and doing the daily crossword. Most troublingly, she was bilked by scammers, who convinced her to give them nearly \$150,000 in her family's savings.

Once a warm, friendly and social person, she became agitated, paranoid and secretive. At work she was quick to anger, snapping at colleagues. Due to Jane's increasingly antisocial behavior and declining performance, her employer put her on medical leave until she underwent a psychiatric evaluation.

Jane's psychiatrist recognized that her symptoms were both unusual and seemingly increasing in severity. She immediately referred her for neurological and neuropsychological testing at a local interdisciplinary clinic. An MRI revealed bi-temporal atrophy, greater on the left than the right. While the family had not expressed concerns about her language or comprehension, the neurologist identified impairments in her ability to name objects.

Based upon the findings, Jane was diagnosed with behavioral variant frontotemporal degeneration (bvFTD) with features of semantic variant primary progressive aphasia (PPA), meaning she often struggled to understand the meaning of words. Clinic staff gave her family information about bvFTD and encouraged them to meet with both the clinic's geriatric psychiatrist and its social worker for further disease education, supports and resources.

Jane's husband, Charles, was overwhelmed—he was in denial about his wife's dementia, and how drastically it would change their lives. He began to disengage, spending more time at his office rather than confront the problems at home. Despite his children's insistence, he refused to talk to them about making a care plan, and declined to meet with clinical staff. For her part, Jane did not appear concerned about her diagnosis, but rather angry that she had to undergo testing. She believed nothing was wrong, and that she would soon return to work—but her employer would not re-hire her due to her diagnosis.

Jane's husband was in denial about her dementia, and how drastically it would change their lives.

## AN OVERVIEW OF MEDICATIONS USED IN FTD

### By Deborah Reed, MD, Guest Contributor

Currently there are no FDA-approved medications specifically for the treatment of FTD. However, other medications can address FTD's behavioral and psychiatric symptoms.

Cognitive enhancing medications such as donepezil and memantine can be useful if the underlying disease process is Alzheimer's pathology, despite a clinical presentation of FTD. But for persons diagnosed with FTD, other categories of medications are more useful: selective serotonin reuptake inhibitors (SSRIs), atypical antipsychotic medications and anticonvulsants/mood stabilizers. Prescribers should take care to avoid any type of anticholinergic medication that can worsen cognition, and to carefully consider potential side effects. Benzodiazepines, for example, can contribute to confusion, drowsiness and poor coordination, leading to a fall risk.

Often, SSRIs—such as sertraline, fluoxetine and escitalopram—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. Sedating medications such as trazodone, meanwhile, can be helpful for sleep disturbances.

Antipsychotic medications such as quetiapine can treat significant aggression, agitation or severe compulsive behaviors. 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. Sedation, dry mouth, decreased blood pressure and weight gain are common side effects of antipsychotics.

(see *OVERVIEW*, next page)



### Family grapples with planning care

At home all day with no structure and little social interaction, Jane became more susceptible to financial scams. She spent significant portions of each day in contact with scammers; and despite her children's attempts to convince her otherwise, she could not understand that they were deceiving her. Eventually they tried to take control of her banking accounts, disable her cell phone and cut off her internet access, but these attempts were successful only in infuriating their mother and creating even greater tension.

Eli met with the neurology clinic's social worker, who informed him that the family would have to take steps to protect the family's finances, and that his mother would need additional supervision during the day. Convinced that Jane's anger, mistrust and aggression precluded such measures, Eli asked if any medications could be prescribed to "stop" or "control" her more dangerous behaviors, and possibly to address her language and memory changes. The social worker encouraged him to see the clinic's geriatric psychiatrist, who had expertise in FTD. She would explain that medications can be helpful in conjunction with behavioral and safety interventions, and that the family would still need to find additional supervision for Jane at home. The next available appointment with the psychiatrist, however, was three months away.

Seeing that the family was struggling, the social worker tried convening a family meeting to discuss a plan for care, engagement and safety. But Charles declined to participate, saying he was too busy with work and that his children could fill him in on the details. The social worker said his presence was important and encouraged him to reconsider joining the meeting.

### (OVERVIEW, continued)

Anticonvulsant medications (divalproex or oxcarbazepine) that are often used in seizure disorders and bipolar disorder can help with disinhibited behaviors. Dizziness, headache, sedation and nausea can occur with these medications.

Persons diagnosed and/or their care partners should identify each problematic symptom or behavior, along with contributing medical conditions and environmental issues (temperature, noise level and social factors) before any medications are prescribed. Non-drug interventions such as redirection, music therapy, and structured activities can also help to reduce problematic behaviors, and should be considered first. ■

Jane's son asked if any medications could be prescribed to "stop" or "control" her more dangerous behaviors.

### Incorporating medication and non-medication interventions

During the family's three-month wait for the psychiatrist's appointment, the social worker regularly met with Jane's children to identify triggers of her agitation. Based on those triggers, the social worker suggested ways to anticipate and respond to her behaviors, as well as techniques that could alleviate her distress. For example, they discussed how to simplify her environment, minimizing overstimulation—and, therefore, her frustration. They learned the importance of adapting the way they spoke with her, creating structure and predictability in her days, and taking her outside the house for outings with friends, or by attending a day program for people with young-onset dementia.

The social worker suggested a speech therapy evaluation for communication strategies and an occupational therapy evaluation to identify home modifications to keep Jane safe. Her children were also receptive to attending an FTD support group and learning self-care methods. After implementing some of the modifications, they began seeing improvements at home. They began to understand that managing her more challenging behaviors took trial and error, and they felt more comfortable asking the social worker for advice when certain techniques proved ineffective. Knowing they could always ask the social worker for help empowered them to try out different approaches with their mother. One approach that worked surprisingly well was bringing friends over to spend time with Jane. Agitated at first, she eventually adjusted to these visits and began to look forward to them.

The family had high expectations for the psychiatrist appointment, hoping the doctor could prescribe medications to ease Jane's more difficult behaviors and improve her thinking. As the date approached, Eli told the social worker he was worried that Jane would refuse to go, or would go but angrily storm out mid-session. The social worker relayed these concerns to the psychiatrist—who, because of her FTD expertise, had already anticipated the possibility of such behaviors.

The entire family, including her husband, Charles, attended the appointment. As they told the psychiatrist about the financial scams and the stress it caused, Jane showed no emotion. She demonstrated profound impairment of judgment, insight and abstract thinking. The psychiatrist placed her on a low dose of citalopram, an SSRI antidepressant, to address impulsivity and disinhibition; the dosage could be slowly increased as needed. Its possible side effects include nausea, lightheadedness, diarrhea and/or constipation.

The antidepressant may make Jane's behaviors easier to address, but likely will not make the symptoms go away entirely, the psychiatrist said, adding that it would likely take some time before the family notices a difference. In any case, Jane will still need supervision, the doctor said. She asked Eli and Maddie to keep a log of Jane's reactions to the medication and whether any new symptoms emerge.

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The psychiatrist re-emphasized that medication alone would not address all of their concerns, nor would medication alone keep her safe.

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Finally, Eli asked about a medication to improve her thinking. The psychiatrist explained that medications available to improve cognition for people with Alzheimer's disease were unfortunately counter-indicated for those with FTD.

At the follow-up appointment three months later, Jane's children reported that their mother was less hostile overall on the new medication, although she had erupted at the recent court appearance at which her husband was granted guardianship. Eli also shared some of her more troubling new behaviors: absentmindedly burning pots on the stove, drinking alcohol during the day and driving erratically. The psychiatrist assessed that the SSRI had minimal impact on Jane's behavior, so she added divalproex, a mood stabilizer, to her regimen.

Charles appeared frustrated with his wife for her disruptive and unsafe behaviors, and with the clinic for being unable to stop them. The psychiatrist re-emphasized that medication alone would not address all of their concerns, nor would medication alone keep her safe. Jane should stop driving and should not be left alone, the doctor reiterated, and suggested meeting with the facility social worker to discuss support options. The doctor also gave the family her phone number and encouraged them to call at any time with questions.

Aside from occasional visits from neighbors and friends, Jane was mostly alone during the day. Despite encouragement from the psychiatrist, the social worker and his children, Charles remained convinced that his wife would refuse a hired caregiver, and that she would not fit well into an adult day program. (He also thought such services were too expensive.) After a scary driving incident, in which Jane tried to speed past an on-duty ambulance, Maddie decided to leave her job to care for her.

### REFERENCES

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### Adjusting with disease progression

Friends pulled away. Jane was increasingly difficult to be with—insulting others, acting restless. She developed hyper-orality; she craved sweets and was unable to regulate how much she ate. (After talking to the social worker and psychiatrist, Maddie started locking the pantry, limiting portions and keeping snacks in her purse to distract her mother when needed.) She impulsively pulled a fire alarm at church, causing the fire department to show up. Family began to carry items for Jane to fidget with as a distraction, and used **AFTD's Awareness Cards** to request patience with her behavior in public.

Maddie started attending an FTD support group; her father reluctantly joined her the following month. Both felt relieved to learn their family was not alone on the FTD journey. Other spouses of people with FTD welcomed Charles with open arms—they understood and validated his experiences, allowing him to share his feelings. He learned that his assumption that Jane would react negatively to hired caregivers was preventing her from getting the care she needed.

Caring for her mother every day, Maddie observed that the divalproex had decreased Jane's aggression but did not affect her impulsivity and compulsive behaviors. Jane developed a new fixation with picking up sticks and trash from their street, even with traffic present. She would obsessively check the mailbox, and open and close the fridge. Maddie tried to engage her mother—and keep her safe—by leading her to her past interests, including gardening, doing crossword puzzles and walking.

At the next psychiatry visit, Maddie asked about medication to dampen the intensity of these compulsive behaviors, which might let them hire a home care worker or attend a day program with less resistance from Jane. The doctor suggested adding quetiapine, an atypical antipsychotic, to her regimen, but noted it carried the risk of increasing falls, particularly at higher doses. Desperate to control Jane's impulsivity, her family agreed to the change.

Jane responded well to the new medication, so—with the encouragement of his support group—her husband agreed to try a day program. To his surprise, it went well. Jane was active and mentally engaged. She no longer resisted showering, and she slept better at home.

Maddie began staying with Jane and Charles overnight to help out in the evenings. However, when Jane started waking up every day at 3 a.m., she decided she could no longer provide care overnight. At the next neurology clinic visit, the social worker recommended evening home care, and suggested ways to help Jane adjust to this change. She also outlined long-term care options for Jane. The psychiatrist, meanwhile, started to taper the dosage of divalproex and added oxcarbazepine, a different mood stabilizer.

Thanks to an **AFTD Comstock Respite Grant** that covered the cost of care for a weekend, Jane's husband and children went to the cabin they had traditionally visited each summer. This long overdue break allowed Charles to rest and think more clearly about both what he needed and what was best for his wife. He agreed to a plan that included hiring evening care, and resolved to speak up when he could no longer care for Jane in their home.

That point came six months later, when Jane stopped letting others bathe her, brush her teeth, or touch her at all. The family moved Jane into a local nursing home facility. The clinic social worker and psychiatrist suggested to the family ways to support both Jane and themselves as they prepared to make this transition.

### PREPARING TO TALK TO THE DOCTOR

Effective pharmacological management of FTD depends on careful, ongoing observation of problematic behaviors and frank discussions between care partners and doctors. The participation of the person diagnosed (to the extent they are able) and their care partners is essential to developing and implementing any medication plan. At each medical visit, care partners should be prepared to discuss all medications their loved one takes (particularly if there has been a recent adjustment) and any notable side effects, as well as recent behavioral or symptomatic changes. Considering the following questions will help to prepare for appointments with the prescribing physician:

#### What behaviors trouble you the most?

For each behavior:

- Provide specific examples.
- Rate its severity on a scale of 1-10 (1 indicates little bother, 10 a great deal of bother).
- Specify its frequency (several times a day, daily, weekly, etc.).
- Specify the behavior's duration (10 minutes, 1 hour).
- Indicate whether the behavior raises safety concerns for the individual, family members or others.
- Identify possible triggers of the behavior, including the presence of other individuals, environmental factors (noisy location, unfamiliar place, visual trigger), and time of day.
- Describe how you attempted to manage the behavior—what makes the behavior better or worse?

(see *PREPARING*, next page)

### Late-stage disease

At 59, Jane moved into the local nursing home's memory care unit. The staff, which had FTD experience, were able to engage her and limit how her behaviors impacted other residents. There were occasions, however, when Jane became confused and acted aggressively, hitting and pushing them or taking their food. She grew more confused and afraid; and, due to her aphasia, she could not communicate her needs. The clinic psychiatrist suggested a gradual increase of the quetiapine. The family understood the increased fall risk, but hoped that it would ensure her safety and the safety of others.

Jane went on to experience several falls, including one severe enough to put her in the hospital, where she greatly declined. Charles asked that her psychotropic medication be stopped due to both the falls and the fact that her behavior had become much less disruptive.

When Jane returned to the nursing home she was incontinent and unable to communicate, had difficulty swallowing and was no longer able to walk. Consequently, she met the criteria for hospice care. The hospice care team worked to ensure her comfort and dignity at the end of her life, providing holistic medical care to minimize her pain and discomfort. The hospice chaplain and social worker also offered Charles, Eli and Maddie spiritual support; they helped the family process their sadness and grief at seeing Jane so changed from the wife and mother she had been.

Despite their struggles over the course of the disease, Jane's family agreed on what she needed most, and eventually found ways to honor the person she was before the onset of FTD. Jane died three months later on hospice care at the nursing home with her family by her side. ■

## ADDITIONAL RESOURCES

### From AFTD

- Information for healthcare professionals on clinical presentations of FTD, diagnosis and treatment: [www.theaftd.org/for-health-professionals](http://www.theaftd.org/for-health-professionals)
- The Daily Care Snapshot: a tool to empower families to help healthcare professionals facilitate the transition into a facility or community-based setting, and to promote individualized care: [www.theaftd.org/wp-content/uploads/2018/03/Packet-Daily-care-snapshot.pdf](http://www.theaftd.org/wp-content/uploads/2018/03/Packet-Daily-care-snapshot.pdf)
- To find an FTD center near you, visit [www.theaftd.org/get-involved/in-your-region](http://www.theaftd.org/get-involved/in-your-region) or contact the AFTD HelpLine: 1-866-507-7222 or [info@theaftd.org](mailto:info@theaftd.org)

### Other resources

- The Medicare Senior Health Insurance Informational Program: Assists individuals and families with questions related to paying for medication in Medicare, among many other things: [www.caregiver.org/senior-health-insurance-information-program-shiip](http://www.caregiver.org/senior-health-insurance-information-program-shiip)
- Information on medications used in dementia, including FTD, from the University of California, San Francisco Memory and Aging Center: [memory.ucsf.edu/medications-dementia](http://memory.ucsf.edu/medications-dementia)

(PREPARING, continued)

### What can I expect if medications are used to manage behaviors associated with FTD?

- Set realistic goals with the physician. Discuss which behavior(s) may be helped by medications, possible side effects and your expectations for treatment.
- Understand how medications are managed. The physician will usually start with a low dose and wait a sufficient amount of time before increasing it. Some medications take several weeks before they take effect.
- Recognize that symptoms and behaviors of FTD change over time. Continuing re-evaluation allows for adjustments in the type of medication or dosage. As the disease progresses, specific medications may no longer be needed.
- Continue to use proven behavioral management approaches in conjunction with medications—consult past issues of AFTD's *Partners in FTD Care* for more information on specific challenging behaviors.

### What observations help determine the effectiveness of a specific medication?

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

Communication and coordination across the care team is especially important in FTD due to variable understanding of the disease among providers. If medications are managed by a neuropsychiatrist or neurologist at a specialty clinic, that provider should (if possible) communicate with primary care physicians and other care providers who are treating the patient in the community. Providers and care partners should know the possible troubling side effects and when to follow up. If a person diagnosed needs more urgent care or hospitalization due to unmanageable behaviors, the medical care provider should call ahead to the emergency room or hospital to share this information with inpatient staff. ■

# Questions for discussion

## What were the family's expectations about medication, and how did they adjust them over the course of the disease?

The family hoped to find a medication that would reduce or eliminate Jane's behaviors. With the help of clinic staff, and based on their own caregiving experiences, they came to understand that the medications work in conjunction with non-medical interventions. The family also came to appreciate that it takes time to find the most effective medications—and even then, they are subject to constant re-evaluation and adjustment. They learned the importance of documenting the changes they saw, and of staying in close contact with the psychiatrist.

## In what ways did the family and care team work together?

The family was fortunate to have access to an interdisciplinary care team made up of social work, psychiatry, behavioral neurology and neuropsychiatry. While not available in every area, this type of comprehensive care ensured that the different disciplines were consulting, communicating and making recommendations together.

Staff educated the family about FTD and set realistic expectations around medications before any writing any prescriptions. While the family waited to see the psychiatrist, Jane's children met regularly with the social worker to learn how best to interact with their mother, how to adjust her environment, and how to process their feelings of sadness and loss.

## What was most effective about the care team's approach to Jane and her family?

Staff understood that each family member was processing Jane's FTD at different paces. The psychiatrist realized that Jane's children were more receptive to her suggestions than her husband. She understood the magnitude of the emotional struggle for Jane's husband, and over time earned his trust by being available by phone to talk about symptoms or to make medication adjustments between visits. She referred them to the social worker when she sensed that Jane's family needed more disease education, new ideas for behavioral strategies and support for themselves. They made a point to stay connected to the family, helping them simultaneously navigate community care options and medication management. Over time, the family became open to introducing greater levels of supervision and care that best supported Jane.

## A CARE PARTNER'S PERSPECTIVE: THE IMPORTANCE OF ADVOCACY

*In her late 40s, Donna, a research chemist/geologist began acting differently. Diagnosed with clinical depression in 2006, Donna was prescribed an antidepressant and told to attend counseling, but did not agree to do either. After her supervisor at work told her she needed to improve her performance or face termination, she seemed to recognize that she had a problem and asked for help. Following is an account of obtaining an FTD diagnosis and determining her best course of medication, written by her husband and primary care partner, Phil.*

Donna's primary care physician suspected she may have some type of young-onset dementia, but blood tests were inconclusive. After a CAT scan and MRI—also both inconclusive—a neurologist referred Donna for a neuropsychological evaluation. He also prescribed the antidepressant escitalopram (Lexapro), which helped: My wife seemed like her old self.

At her neuropsychological appointment, in November 2007, Donna was diagnosed with "executive cognitive dysfunction with marked impairment in multiple aspects of language processing, very suggestive of an early primary progressive dementia or FTD." Subsequent PET scans confirmed the FTD diagnosis. Donna was 50, and our daughters were 9 and 13 years old.

The neuropsychologist recommended a series of anticholinesterase drugs, generally used to treat Alzheimer's. Donepezil (Aricept) had little to no effect, and Donna was taken off it. Memantine (Namenda) seemed to help. Then Donna began taking rivastigmine (Exelon), a cholinesterase inhibitor. After an apparent allergic reaction to its latex-patch version, she began taking it orally—first at a relatively low dose of 3 mg, gradually raised to 12 mg, then lowered slightly after the higher dose caused vomiting and nausea. Both Namenda and Exelon seemed to help, and I think may have slowed her FTD progression.

Donna qualified for disability retirement in July 2008, and began spending her days at home alone while our children attended school and I worked. She watched television, worked on her computer, did word search puzzles, took photographs and played with the cat we adopted to keep her company. Occasionally, she would walk unaccompanied to the local CVS and Safeway, seven blocks from our house. However, her aphasia grew progressively worse and she was unable to explain to me what she had done during the day, which was a safety concern.

(see CARE PARTNER, next page)

(CARE PARTNER, continued)

In February 2011, I brought Donna to a clinic that specializes in FTD. A doctor there concluded that her “clinical picture of a progressive dementia with early symptoms of language disorder, impaired executive function and changes in social comportment all support a diagnosis of frontotemporal dementia both language and behavioral subtype,” and that the “PET scan is fully supportive of the diagnosis of frontotemporal lobar dementia.” He added that while there is no evidence that cholinesterase inhibitors help with FTD’s cognitive or behavioral symptoms, he supported their continued use.

Donna’s FTD symptoms advanced slowly, over the course of several years. In 2013, I could no longer work full-time and take care of Donna, so she began going to an assisted living group home a few days a week. By December 2013, she lived there full time. By that point, she was taking 28 mg of Namenda XR and 30 mg of Lexapro daily, and she began taking alprazolam (Xanax) as needed, for agitation. She also took medication for thyroid function and elevated cholesterol.

In November 2016, Donna was kicked out of the group home for agitation, which the group home doctor could not manage with medication. She ended up in the psych ward of a geriatric hospital in Baltimore for six weeks. The resident psychiatrist there loaded her up with antipsychotic meds, including Haldol (1.5 mg), Depakote (1,000 mg) and Seroquel (25 mg). He agreed to discontinue Namenda, after I argued Donna had taken it far longer than is typically prescribed.

The new antipsychotic medications had an undeniable impact on Donna—reducing her mobility, as intended. Before her hospitalization, Donna and I took many long walks together, and she could still form some words and phrases. Afterward, however, her ability to walk rapidly declined, and she spoke very few complete words.

I worried that these new antipsychotic medications were causing rapid decline, and that her FTD symptoms per se were not directly responsible. As the advocate for my wife, I was frustrated that she was prescribed such powerful medicines without my being fully aware of their capabilities and side effects.

During a meeting of a local FTD support group, I heard a presentation by the director of the FTD clinic (and a member of AFTD’s Medical Advisory Council). When I asked him about the antipsychotic medications that Donna was taking, he warned me that they can cause neuroleptic-induced parkinsonism.

I now take Donna to see that specialist about every six

months. The long drives to the clinic are not easy, and I need to pay for someone from Donna’s group home to go with me to help out. But the specialist’s insight to Donna’s medication needs have been invaluable. He phased her off of Haldol, Depakote and Seroquel sequentially over about two years, while adding the antidepressant Zoloft. Fortunately, her agitation has not re-emerged, and her mobility and language ability have somewhat rebounded. Occasionally she even says a whole sentence, and seems to understand some spoken words.

Donna is not completely off of all prescriptions. In addition to the 100 mg of Zoloft she takes daily—which is working well to address Donna’s behavior and mood—she also takes the anti-seizure drug Keppra (she experienced a major seizure that warranted a three-day hospital stay in October 2018); a drug to treat a thyroid condition unrelated to FTD; and a low dose of Crestor to help with elevated cholesterol, also unrelated to FTD. We hope to gradually decrease the Zoloft dosage in the coming months.

Our philosophy for medications is “Less is more,” and my advocacy for her best possible care will continue. ■

## 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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To join the Partners in FTD Care mailing list, or for permission to reprint this material in whole or in part, contact [partnersinfthdcare@theaftd.org](mailto:partnersinfthdcare@theaftd.org).



## 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.