



## Rethinking Palliative Care: A New Approach to Managing FTD

### Introduction

**P**alliative care is specialized medical care for people facing serious illnesses. It can be used at any point in the disease to promote quality of life for both people living with FTD and their care partners. (Palliative care during the final stages of a progressive disease is known as hospice care.) Because the use of palliative care is relatively new in dementia,

there are challenges—particularly in FTD, which is less common and less understood than other dementias. As FTD families and their healthcare providers increasingly engage with palliative care professionals, this valuable service will continue to develop and grow for people facing FTD.



## The Case of Mary S.

### Background and Diagnosis

At age 48, Mary Smith, a divorced woman with three adult children, started exhibiting cognitive and behavioral change—her actions became more impulsive, her mood was changeable, and she grew increasingly self-absorbed. She initially resisted seeing a doctor, but, on her husband's insistence, consulted with a family acquaintance who was a psychiatrist. She was diagnosed with bipolar disorder and prescribed lithium. Her symptoms, however, did not improve. Once an active and respected lawyer, Mary began to lose clients—they complained that she failed to follow up with them, and at times made rude or inappropriate comments about them. She became prone to angry outbursts that also affected her ability to function at work, and began compulsively eating unhealthy food. At home she seemed only to be interested in food—buying, eating and looking for snacks throughout the day. She stopped communicating with her husband, Tom, and one day casually confessed that she had had several affairs. Tom, increasingly frustrated and angry at his wife's apparent stubborn indifference, decided to file for divorce. Throughout it all, Mary insisted she was fine.

Now living alone, Mary's difficulties continued. Her adult sons did not understand the changes in their mother and pursued job opportunities and relationships that drew them several hours away. Tom, a physician who worked at a local hospital, maintained occasional contact, both to make sure her bills were being paid and to relay information to their sons. He witnessed growing

changes to his ex-wife's behavior and appearance, including weight gain that he attributed to the overconsumption of fatty foods and sweets. (She had previously been a very health-conscious eater and frequent exerciser.)

Because Mary did not think anything was wrong—and, apart from the weight gain, seemed fairly healthy—Tom was unable to convince her to follow up with the doctor. But after Mary ran a red light in front of a police officer, causing an accident that injured a pedestrian, then denied her involvement, Tom knew he needed to act. He arranged for a comprehensive evaluation at the cognitive neurology clinic in his hospital. At 54 years old, Mary was diagnosed with FTD. Additionally, the evaluation showed that her blood glucose levels were elevated, and she was diagnosed with adult-onset diabetes. Doctors prescribed an oral antidiabetic medication and recommended that she lose weight and adapt a healthy diet.

After her diagnoses, it became clear Mary could no longer safely live independently. She refused the recommended diabetes treatment, and her weight continued to climb. Her hygiene and self-care declined, and she was increasingly seen roaming the neighborhood, looking in mailboxes, car windows, and trash cans. As advocates for her care, Tom and their sons sought alternative living arrangements. Although divorced from Mary for six years, Tom remained her power of attorney for both property and health care, allowing him to act on her behalf. With the family's help, Mary entered a continuing care community's assisted living facility. While unsure of the move, Mary thought it might be nice not to have to do everything herself—as long as she still had her independence and could keep her favorite belongings.



### PALLIATIVE CARE: ELIGIBILITY AND ACCESS

Palliative care is specialized and individualized care for people living with a serious medical condition. In FTD, it can be pursued at diagnosis or any point thereafter—unlike hospice, which can only be pursued at the end of life. One can receive palliative care while being treated for other coexisting conditions, and its availability does not depend on whether your condition is curable. Unlike hospice, palliative care does not have state or federal regulations for physician certification, benefit review periods, or capitations. Currently, eligibility for palliative care is dependent solely on a diagnosis of a serious health condition and a referral from a licensed healthcare professional. An FTD diagnosis is therefore sufficient for eligibility.

(see *ELIGIBILITY*, next page)

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### Transition to Long-Term Care

When first admitted, Mary watched television in her apartment, walked to a convenience store down the block several times a day, and was on time for every meal in the dining room. She received medication assistance and was put on a special diet to manage her diabetes. But fairly soon, her compulsive behaviors around food created challenges for residents, care staff, and the nurse monitoring Mary's diabetes. Mary ate handfuls of cookies and fruit that were made available throughout the facility, and became agitated and verbally aggressive when staff intervened.

Once, while Mary was on the hunt for a sweet treat, she tripped and fell, dislocating her shoulder. While in the hospital, the effects of her uncontrolled diabetes were evident, and her need for more supervision and hands-on assistance became clear. She would not be able to go out alone, thus eliminating her main activity, and would need one-on-one assistance for showering, meals, and medication. Her interactions with other residents would also need to be monitored.

The assisted living community had a dementia program, but they hesitated to accept Mary because the program had only older residents and the staff lacked experience with FTD. Tom knew finding a program would be difficult and did not feel he had the knowledge to do so alone. He learned from his colleagues that palliative care might help him manage difficult aspects of Mary's care and transitions as her disease progressed. He asked her attending physician at the hospital about getting a referral. The physician said he was not sure how much palliative care would help, but nevertheless gave Mary a referral for a consultation.

Tom and Mary were connected with Liam, a palliative care nurse practitioner from a community-based hospice and palliative care provider that specialized in caring for persons with dementia. He described the goals of the initial palliative care consultation and subsequent visits: to address pain and symptoms, to provide education about a specific dementia diagnosis, and to address the emotional and spiritual needs of persons diagnosed and their families. He noted that visits generally take place each month and are covered, in part or in full, by Medicare, Medicaid and most private insurance; they can also take place while Mary is receiving treatment for her diabetes.

Tom and the palliative care team determined that Mary's immediate needs were to stabilize and adjust for her injury, manage her diabetes, ensure proper residential care placement, and relieve her increasing anxiety. Working to repair Mary's fractured relationship with her family was a secondary, but no less important, goal.

Over several visits, Liam taught Mary and her family about her health conditions and prognosis. Together, they talked about their

(ELIGIBILITY, continued)

Palliative care was recognized by the American Board of Medical Specialties as a subspecialty in 2006, and physicians in several specialty disciplines could seek palliative care certification beginning in 2008. But because palliative care is not yet well recognized, particularly within dementia, gaining access to it can be challenging and requires advocacy by family and other providers. (Health providers do not need to be certified in palliative care to embrace its principles.)

Palliative care is as much about supporting the family as it is about caring for the person with FTD. It focuses on increasing quality of life and providing extra support for symptom management of both physical and non-physical symptoms, open discussions about goals of care and treatment choices, coordination of care with new and existing healthcare providers, and emotional and spiritual support. Palliative care can be offered in a variety of settings, including community-, hospital- and facility-based settings.

Healthcare providers can make a referral for palliative care services. Most private insurance plans partially cover these services, just as they would other medical services. Out-of-pocket expenses can include modest co-pays for office visits, treatments, medications, and durable medical equipment. Medicare and Medicaid also typically cover palliative care under advanced disease management services. Concerns about the cost of palliative care can be addressed by a social worker, care manager, or financial advisor at your local hospital.

In FTD, the use of palliative care has been limited. Many healthcare professionals simply do not know about or understand the role palliative care can play in FTD care. In some instances, opportunities to consult with a palliative care team may come only in an inpatient hospital setting.

Looking forward, clinicians must prioritize demystifying common misconceptions around palliative care, removing the stigma that often surrounds it, and presenting it as an option as soon as possible. Doing so will lead to more timely referrals, and ultimately, better quality of life for persons diagnosed with FTD and their families. ■

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goals for Mary's care at this point in her life. What are the most distressing symptoms she experiences? Does she feel safe and comfortable? What would give her pleasure and meaningful engagement? And looking ahead, what type of medical intervention do they want should she develop complications (from a fall or infection, for example)? Liam helped the family develop advanced care planning documents and gathered the information needed to help Mary and her family feel more equipped to make care decisions based on their goals, values and preferences.

Before Mary returned to the continuing care facility, Liam convened her family and the facility's dementia program staff to discuss ways to provide care at the greater level Mary now required while maintaining her quality of life. Tom and their sons wanted her to be as content as possible. They chose to continue administering her oral diabetic medicine for as long as possible, and to continue with her special diabetic-friendly meals. They also allowed her to eat as many diabetic-friendly snacks as she wanted, from a container accessible only to her. The family stated they preferred that staff not initiate insulin injections if Mary's diabetes worsened. And they requested staff stop monitoring her glucose levels with finger sticks three times a day.

The facility nursing staff was uncomfortable with the idea of not actively treating Mary's diabetes. But her family strongly felt that, as her FTD progressed, the additional medical interventions would confuse her (she would not understand the need for such frequent finger sticks) and become challenging to implement (she would not be able to self-inject insulin). They asked Liam to facilitate a discussion between them and the facility's physician, during which they developed and signed a "negotiated risk" document, which outlined in writing Mary's amended care plan. This allowed the facility staff to honor the wishes of Mary and her family while absolving them from blame if something went wrong (as long as they followed the care plan). Staff and family all agreed that Mary move to the facility's dementia care unit to receive the more comprehensive care she needed.



### Progression and Decline

As Mary's FTD progressed, she engaged less with family and friends during visits; facility staff also noticed rapid weight loss (10 pounds in three months) along with decreased verbalization and mobility. She spent much of her day moving around in her chair, standing and sitting incessantly. Interventions that once helped ease her restlessness (using a more comfortable chair and bed, looking at photos of her loved ones) no longer seemed to comfort her.

Liam was brought in to perform a physical evaluation of Mary and to review her medical history and current medications. He

### A CARE PARTNER'S PERSPECTIVE: FTD CARE TAKES A VILLAGE

By Sharon Hall, FTD Care Partner

"You have frontotemporal degeneration, or FTD. It is a progressive disease and there are currently no treatments. Get your legal affairs in order." Hearing these words from a doctor is a gut punch, and it does not get easier from there—I call the first year after my husband's FTD diagnosis my "hair on fire" year. But we were fortunate that Emory Healthcare, where he was diagnosed, has an integrated memory care clinic that includes a primary palliative care clinic, which guided us through the diagnosis, offered support groups and classes, and managed all of our care needs. It even has a hotline staffed 24/7 by nurse practitioners.

Palliative care has been a tremendous resource as we face the stress, questions, and changes of FTD. It gave our family the support we needed to navigate complicated legal paperwork, advance directives, and simply understanding this disease. It offered support, both emotional and spiritual, and a team approach to decipher the complex medical system we found ourselves in.

Your primary care physician can make a referral to palliative care. If they say you are not "ready" for palliative care, you need to tell them you are, because dementia is a qualifying diagnosis for palliative care. A local palliative team will be able to refer you to support groups, therapists, and resources to help with this journey.

No one can successfully manage FTD alone. It is so necessary for care partners to get respite, learn about the disease, and take care of their own medical needs. A local palliative team can guide this process. It is the ultimate person-centered care to add to your support team. ■

## BEST PRACTICES FOR PALLIATIVE CARE IN FTD

The University of Colorado's Neurology Supportive and Palliative Care Clinic is another innovative model of palliative care for individuals living with incurable neurological diseases, like FTD and PPA, and their families. This outpatient clinic was founded in 2012 by Dr. Benzie Kluger, an assistant professor of neurology and the chief of the Neurology Supportive and Palliative Care Clinic.

The goals of the neuro-palliative clinic are to improve quality of life and reduce suffering for individuals and families by helping them with challenging medical symptoms, psychiatric symptoms, and psychological issues, as well as with caregiver support, spiritual well-being and planning for the future. The care is person- and family-centered, meaning that persons diagnosed and their families direct the goals and plans of care.

A common myth about palliative care says that it is reserved for people who are dying. (See Table 1, produced by Dr. Kluger, for additional myths and realities about palliative care.) In fact, people can be referred to palliative care at any stage of their diagnosis.

At the Neurology Supportive and Palliative Care Clinic, a care team—comprising a neurologist, a social worker, a chaplain, a

physician's assistant, a nurse, a patient care advocate and a care coordinator—visits with a person diagnosed every three to six months throughout the course of their disease. The team develops a partnership with the person diagnosed and their family, as well as the other doctors treating the person diagnosed. Working together, the palliative care team helps to manage symptoms, gives guidance on treatment choices, and highlights community resources. They also lend emotional and spiritual support and facilitate conversations about disease progression and end-of-life decisions. Throughout, the care team remains focused on the health and safety of the person diagnosed, and the well-being of their family caregivers.

The Neurology Supportive and Palliative Care Clinic is working to raise the standards of care and offer the best possible life for persons diagnosed with progressive neurological diseases like FTD. In addition to providing team-based care to persons diagnosed regardless of ability to pay, the clinic is conducting palliative research and training the next generation of leaders in the field. ■

**Table 1. Palliative Care Myths and Realities**

<i>Palliative Care Myth</i>	<i>Palliative Care Reality</i>
Palliative care is the same as hospice.	Hospice is just one type of palliative care, namely palliative care for persons near the end of life.
Palliative care is just for people who are dying.	Palliative care can start at any time. In fact, palliative care needs are often high around the time of diagnosis.
Palliative care means giving up on persons diagnosed.	Palliative care provides intensive services for persons diagnosed and their families, including aggressive treatment of medical symptoms (e.g. pain), caregiver support and counseling of persons diagnosed.
Palliative care is just for people with cancer.	Palliative care is appropriate for any serious illness.
Palliative care can only be provided by specialized teams.	A palliative care approach may be taken by any healthcare provider. Referral to a palliative care specialist may be helpful for persons with complex problems or advanced diseases.
One should wait for the "right time" to start talking about palliative care.	Waiting for the "right time" to have important conversations often means these conversations are happening too late (e.g. after a person diagnosed loses their ability to communicate) or not at all.

Source: Dr. Benzie Kluger, chief of the Neurology Supportive and Palliative Care Clinic, University of Colorado

also talked to her family, her attending physician and the facility staff to identify their concerns, so that he could help modify her care plan accordingly. After the family said they were alarmed by her changing behavior, her rapid decline and her overall quality of life, Liam arranged a meeting between them, Mary's attending physician and the facility's dementia program director. They discussed care preferences and behavior triggers, and agreed to assess Mary's response to music therapy, aromatherapy and massage; they also talked about making changes to her medication in order to increase comfort and decrease restlessness. Liam also facilitated spiritual support and grief counseling for Mary's family, who were struggling with her decline.

During palliative care follow-up visits over the next several months, Liam noted that new interventions like music therapy and gentle touch therapy seemed to make Mary more engaged and increased her quality of life. Music therapy was particularly beneficial: As she softly sang along to her favorite songs, her restlessness and constant movement both decreased. However, Mary's weight, verbalization, mobility and posture all continued to decline, and long-term care facility staff reported that she was starting to have difficulty swallowing.

Mary's clear and rapid decline indicated that her FTD was progressing into its late stage, and that she could be eligible for hospice care. After discussing care options with Tom, Liam and the palliative care team requested a hospice evaluation. Like palliative care, hospice focuses on comfort care. But in hospice, medically focused treatments and medications that no longer appear to be helpful will be stopped. Hospice is recommended when a person is determined to have six months or less to live.

On hospice care, Mary became totally dependent on others to perform nearly all activities of daily living (she remained able to hold a glass and drink from it). Her problems with swallowing food continued to worsen as her condition progressed. Tom asked staff to reevaluate her medications and discontinue those that were no longer needed based on her changing symptoms. He also asked them to discontinue her oral diabetic medication, even though this carried a risk of complications.

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## APPLYING PALLIATIVE CARE APPROACHES IN FTD

Palliative care has its roots in hospice care, which emerged in the 1960s and largely focused on the needs of cancer patients.<sup>1</sup> In 1990, the World Health Organization recognized palliative care as a distinct specialty focused on relieving suffering and improving quality of life for people with life-limiting illnesses or serious injuries. It identified the goals of palliative care as "the prevention, assessment, and multidisciplinary treatment of physical, spiritual, and psychological problems."<sup>2</sup> Over the last 10 to 15 years, advocates have worked to make physicians aware that palliative care skills—such as effective doctor-patient communication and the management of distressing symptoms throughout an illness, not just at life's end—complement the care persons diagnosed are already receiving.

The needs of people with FTD and their families are not those that palliative care typically addresses. Notably, control of physical pain is not the most pressing need in FTD. But the principles of palliative care nevertheless point toward valuable opportunities to improve FTD care. The following scenarios show how palliative approaches can help manage some of the distressing situations that arise in FTD:

- Many people undergo a lengthy period of uncertainty before receiving an FTD diagnosis. Palliative care can help them and their family to process the stress and other emotions that accompany this period, and to adjust to the diagnosis. Education, support, and clarification of goals can help families identify a holistic and individual- and family-tailored approach to life with FTD.
- People with FTD may experience compulsive behaviors and impaired judgment and decision-making. These changes do not respond to medication, but can be managed with environmental changes: limiting access to the computer, phone or bank accounts; removing guns, power tools or other potential risks; preventing the person with FTD from driving. For families, taking these actions can be distressing; palliative care principles can help facilitate difficult interventions.

(see *APPROACHES*, next page)

While remaining alert, Mary became minimally verbal. Due to instability she experienced while moving, she spent much of her time in a recliner for comfort and support. The hospice interdisciplinary team visited her several times a week, and called Tom at least once a week to provide support and updates on her conditions, which helped the family improve the quality of their visits.

Mary nevertheless continued to decline, and, shortly after her 58th birthday, she died at the facility, from aspiration pneumonitis. Since Liam had frequently talked to her family about loss, grief and bereavement in the years leading to her death, they were better prepared to cope with her dying process. Throughout, they recognized and appreciated the palliative approach to her care.

After Mary's death, they told other FTD families about their experiences with palliative care, noting how they benefited from all the support they received in designing positive approaches to distressing behaviors, facilitating productive interdisciplinary care conversations, addressing grief, and maintaining Mary's comfort. They found the benefits of palliative care to be cumulative, and that it helped to mitigate much of the anguish and suffering associated with dementia care.

## 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:

**Sandi Grow**, RN, caregiver, AFTD Board Member

**Lisa Gwyther**, LCSW, Duke Family Support Program

**Susan Hirsch**, MA, HCR ManorCare

**Mary O'Hara**, LCSW, Rocky Mountain Neurobehavioral Associates

**Marianne Sanders**, RN, University Hospitals

**Jill Shapira**, PhD, RN

AFTD extends special thanks to this issue's special guest contributor, **Nancy Flowers**, MSW, LCSW, the Community Education Program Manager and Dementia Project Manager at the LIFE Institute for Learning at Rainbow Hospice and Palliative Care. She is also on the Social Work Steering Committee of the National Hospice and Palliative Care Organization.

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

### (APPROACHES, continued)

- As the disease progresses, families may face questions and decisions around routine diagnostic tests: Do the benefits of these procedures outweigh the confusion or stress they can cause in the person diagnosed? Palliative care team members can help family members understand the rationale for specific tests; consider them in light of their personal values, goals, and needs; and facilitate discussion with medical providers.
- The choice of whether to continue or stop treatment for co-occurring medical conditions, such as diabetes, can be a vexing one. With the help of the palliative care team a family can have extended conversations and support around treatment decisions. One family may choose to forgo diabetes treatment as their loved one's FTD reaches its late stage. Another may choose to continue with oral medication, limiting food intake and structuring daily exercise despite resistance.
- As swallowing difficulties develop, a person with FTD may cough when drinking liquid, which increases risk of aspiration and can be troubling to their family members. Pre-thickened beverages, including coffee and tea, are available and can be helpful, but some people with swallowing difficulties may find them unappealing and unpalatable. A palliative approach might suggest permission to drink regular liquids through a straw, despite the increased aspiration risk.
- Emergent medical issues—for example, surgery following a fall or accident, or rapid decline due to aspiration pneumonia or infection—may necessitate unexpected decisions around end-of-life care. Palliative care professionals can provide guidance and support for the family to make choices based on the preferences established by the person and the family's cultural values and goals of care. ■

1 Ruder, Debra Bradley. "From Speciality to Shortage." March-April 2015, [www.harvardmagazine.com](http://www.harvardmagazine.com), *Harvard Magazine*.

2 "Palliative Care, Yesterday and Today." University of Pittsburgh Medical Center Palliative and Supportive Institute, 2014.

After Mary's death, her family told other FTD families about how they benefited from palliative care.



# Discussion Questions

## 1. What were the benefits of palliative care in Mary's case?

Introducing a palliative care specialist as part of the care team, to support early transitions in care and provide her and her family support, proved to be valuable to her care and quality of life. Some of its benefits included: Designing positive approaches to distressing behaviors, facilitating productive interdisciplinary conversations, addressing grief, advocating for the family's care preferences, and maintaining Mary's comfort. Palliative care helped to inform and facilitate their decision making and reduced the associated anxiety and isolation that is often experienced in FTD care.

## 2. What are three ways the palliative care nurse practitioner supported Mary and her family?

Liam, the palliative care nurse practitioner, followed Mary's care intimately, from diagnosis to death. He assisted Mary and her family in the areas of support, comfort, education, and symptom management. Three specific examples of how he supported Mary and her family are:

- Palliative care was consulted when Mary was hospitalized after a fall. Her need for physical assistance and supervision made semi-independent living no longer a safe option. Liam helped the family find alternative living arrangements for Mary. With his help, Mary was accepted and transitioned effectively to the dementia unit of the continuing care facility.
- As an advocate for Mary and her family's wishes for her care—some of which differed from recommendations made by the facility physicians and nurses—Liam facilitated care conversations to help create a “negotiated risk” document, allowing staff to safely care for Mary according to her family's preferences.
- As Mary's FTD progressed and her diabetes worsened, her family became increasingly concerned with her comfort and quality of life. Liam helped them coordinate with the residential care team. He facilitated a care planning meeting at which Mary, her family, and the continuing care staff agreed on an individualized plan of care that prioritized music therapy, massage, and medication changes. Seeing the family's distress over her decline, he offered and arranged for grief counseling and spiritual support, delivered by other members of the palliative care team.

## 3. Why was Mary referred to hospice?

Mary's family and long-term care staff observed a continued decline in Mary's weight, verbalization, mobility, and posture, as well as increased difficulty with swallowing that made taking oral medications an uncomfortable struggle. To the palliative care team, Mary's deficits in activities of daily living, as well as her clear and rapid decline, reflected signs of late-stage FTD and potential eligibility for hospice care. Like palliative care, hospice focuses on comfort care. However, in hospice, medically focused treatments and medications that no longer appear to be helpful will be stopped.

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### RESOURCES

The Center to Advance Palliative Care (CAPC) is a nonprofit organization affiliated with the Icahn School of Medicine at Mount Sinai, 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 get quality, person-centered care. Some of those resources include:

- The website **GetPalliativeCare.org**, to help you find a palliative care team near you
- A seven-course training module on palliative care best practices in dementia care and caregiver support, available at **[www.capc.org/training/best-practices-in-dementia-care-and-caregiver-support](http://www.capc.org/training/best-practices-in-dementia-care-and-caregiver-support)**
- A toolkit with information about implementing best practices in palliative care for persons with dementia: **[www.capc.org/toolkits/implementing-best-practices-in-dementia-care](http://www.capc.org/toolkits/implementing-best-practices-in-dementia-care)**



## What to Do About... Palliative Care for FTD

Palliative care is specialized medical care for people facing serious illnesses, and can be particularly valuable for people with FTD and their families. Its goals are the assessment, management, and, when possible, prevention of illness-related distress, whether physical, spiritual or psychological. Palliative approaches emphasize effective communication and multidisciplinary treatment of symptoms throughout the illness. Consulting with a palliative care provider can support decisions that promote quality of life for the person living with FTD, as well as their care partners and family.

### Guidance for Persons with FTD and Family Caregivers

- Consider the benefits of having a team of specially trained palliative care physicians, nurses, social workers and others, all working with primary care or specialty physicians and family members to make FTD care more effective.
- Start a conversation about palliative care with your provider as soon as possible to foster timely access to services.
- Ask the diagnosing physician if the medical center has a palliative care team. Some dementia programs have palliative care available from time of diagnosis.
- Inquire where palliative care services are available in your area, or visit [GetPalliativeCare.org](http://GetPalliativeCare.org).
- Advocate for palliative care services if necessary. Not all doctors are familiar with palliative approaches in dementia care.
- A physician referral is necessary for palliative care—ask your doctor for one when you are ready.
- Discuss your palliative care team's experience with FTD. Managing care decisions and symptoms in FTD differs from other diagnoses or conditions (pain management, for example, is a less important component of palliative care in FTD).
- Provide FTD resources and educational materials to the palliative care provider as necessary. Introduce them to AFTD via [www.theaftd.org](http://www.theaftd.org).
- Ask your insurance provider about palliative care coverage. Medicare covers consultation once a month under “advanced disease management services,” and coverage for additional specific services may be possible.

- Request a palliative care consultation if you are receiving inpatient care. Hospitals may have palliative care services that extend after discharge.
- If there are no formal palliative care services available, ask your healthcare provider if they can suggest approximate care and support.

### Guidance for Medical Treatment Teams and Community Providers

- Learn about palliative care principles and practices in dementia. Consider the benefits of having a team of specially trained palliative care physicians, nurses, social workers and others working with you to provide more effective FTD care.
- Research local dementia palliative care options, and establish relationships with them to ease referrals.
- Determine the extent to which the person with FTD and their family need disease education, assistance with navigating medical systems, and conversations about what it means to have a progressive terminal disease.
- Introduce palliative care disease management as an additional service, especially if the person with FTD has experienced problematic side effects from a medical treatment, problems with eating and/or swallowing, safety issues such as falls, and/or frequent emergency room or hospital admissions for the same symptoms within a 12-month period.
- Refer to palliative care soon after diagnosis to connect the family to additional supports.

## Guidance for Medical Treatment Teams... (cont.)

- Explain that palliative care disease management takes a holistic approach to improving quality of life for both the person diagnosed with FTD and their family.
- Consult with the palliative care team as symptoms, care decisions, and the emotional needs of the family change over time.
- When necessary, participate with the palliative care team in family mediation to enable communication and help manage difficult care decisions.
- Encourage people interested in participating in FTD research to also consider palliative care. Receiving palliative care does not exclude someone from taking part in clinical research studies.
- Observe the actions and routines of the person diagnosed to identify triggers of distressing behaviors.
- Use music, massage, exercise, mindfulness and other sensory approaches to promote the well-being and comfort of the person diagnosed and their care partners.
- Connect with local resources to help make necessary modifications to the home environment, in order to reduce sensory stimulation or reduce fall risk.
- Assist family and/or facility staff to problem-solve safety issues and concerns with neighbors or other facility residents.
- Support families as they weigh the necessity of specific medical procedures against the need to provide comfort care for their loved ones. Examples include: whether to pursue medically necessary surgery, the use of a feeding tube, or the continued administration of insulin.

## Guidance for Palliative Care Staff Providing FTD Care

- Tell the provider what to expect from palliative care services. Disease education is a common entrée to additional palliative care services.
- Help the family to better understand and navigate the complex medical system. Talk about the legal paperwork necessary to receive financial benefits, make advance directives, etc.
- Discuss what “quality of life” means for the family in light of the FTD diagnosis; engage the person with FTD to the greatest extent possible.
- Answer questions, and offer information and support as the family considers treatment options and care in late-stage FTD.
- Learn about FTD symptoms and the family’s specific needs to help expand palliative care’s traditional focus on pain management.
- Connect family caregivers to resources that can help to support the person living at home. Assist with transitions in their living situation.
- Design individualized and engaging daily activities and routines that best support the person diagnosed.
- Make sure that care interventions address distressing behaviors and ensure safety while also honoring the family’s personal and cultural values and preferences. (Some situations that can be particularly challenging in FTD are those involving eating, disinhibited actions, incontinency, ambulation, and intrusive behaviors.)
- Connect families with the palliative care social worker or chaplain to help them explore their feelings of loss, guilt and/or anger, and to talk through difficult decisions.
- Facilitate discussions between family members and physicians or long-term care providers about supporting the family’s care preferences.
- Provide support around specific medical decisions (for example, those regarding surgery and anesthesia, treatment of concurrent medical conditions, swallowing and feeding tubes, special diets, catheters, colostomy) and how those decisions fit with the person’s prior preferences and cultural/religious beliefs.
- Consider creative alternatives to help reduce symptoms or disruptive behaviors (e.g. personalized music playlists, weighted blankets, aromatherapy, therapeutic exercises, art therapy).
- Determine whether palliative care team members have an opportunity to offer emotional, spiritual or religious support. Family members experience grief and loss throughout the disease; support during this time can enhance their quality of life.