

COMFORT CARE AND HOSPICE IN ADVANCED FTD

INTRODUCTION

Frontotemporal degeneration is the most common cause of dementia in people under the age of 60. It typically strikes when individuals are fully engaged in their family, career and social lives, long before giving much thought to advance care planning or end-of-life decision-making. While the clinical presentation and progression may vary, FTD is ultimately a terminal condition. For people living with FTD and their families, learning about comfort care and discussing advance planning are central to ensuring the highest possible quality of life and making informed decisions at end-of-life.

THE CASE OF MARK H.

EARLY ILLNESS

Mark H. was diagnosed with FTD when he was 60 years old, but he had begun exhibiting symptoms about three years prior. His wife Terry, her 30-year-old son Jeff and Mark's long-time co-workers had started noticing unusual changes in Mark's behavior. Mark had had a long and successful career in sales, being twice recognized as his company's top performer, but his job performance was becoming inconsistent. He started ignoring clients' phone calls and missing appointments, and failed to make his sales goals two years running. Terry felt Mark was emotionally withdrawing from the family and was concerned he was depressed. She insisted that he see his doctor, who referred him for a psychiatric consultation. Mark was treated for depression and anxiety for nearly two years without improvement.

Mark's increasingly self-centered decision-making and unusual behavior frustrated Terry. He followed the same routine every day after work: He arrived home at exactly 5:00 p.m., hardly speaking a word, then watched five consecutive game shows and insisted on eating dinner of a cheeseburger, French fries and two bananas. At Terry's insistence, Mark's psychiatrist referred him to a cognitive-behavioral neurologist. After a comprehensive evaluation, the neurologist concluded Mark had behavioral variant FTD (bvFTD) and advised Mark, Terry and Jeff to get Mark's legal affairs in order while he could still participate in the planning.

Mark and Terry had never heard of FTD, nor had they ever discussed a living will or advance health care decisions, thinking that they would have plenty of time to do so when they were older. Terry and Jeff tried to encourage Mark to talk about his care wishes, but Mark showed little interest. There was no reason to plan, he insisted; he was fine. The family learned that Mark's apathy was a sign of bvFTD, and that it would worsen over time. Terry persuaded Mark to meet with their attorney, who helped them complete their wills and durable Power of Attorney (POA) documents. Mark agreed, indifferently, to having Terry as his POA.

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YOUNG-ONSET DEMENTIA AND COMFORT CARE

Professional dementia literature shows that most people would not choose aggressive medical interventions to prolong life if they enter an advanced stage of dementia, but would rather opt for measures to keep them comfortable. Unfortunately, people with terminal dementia often instead receive aggressive medical treatment that does not meaningfully improve quality of life.

Studies of advanced dementia are usually based on elderly people with Alzheimer's disease. People with FTD, however, face an even more difficult road to receiving the comfort care they may prefer. Typically a young-onset dementia, FTD occurs long before many people consider advance care directives. Additionally, FTD poses an acute threat to family stability. Its high emotional, social and financial toll leaves many dedicated family caregivers isolated, exhausted and overwhelmed. The behavioral changes that FTD causes can tear families apart, leaving the person diagnosed without loved ones to advocate health care providers on their behalf.

Departing from customary medical interventions may appear to outsiders as a form of neglect or giving up, especially when the person is younger. But current research suggests that aggressive medical interventions—for infections, fractures, swallowing problems, etc.—may pose more distress and discomfort to those living in the advanced stages of dementia, without improving the quality of their remaining days. Collaboration with quality hospice care presents an opportunity: to empower persons with FTD and their families: to arrange for comfort in a disease that has relentlessly taken it away.



WHAT IS HOSPICE CARE AND HOW CAN IT HELP?

Hospice is a philosophy of care that provides comfort as life nears its end (usually within six months or less), rather than using aggressive lifesaving measures that are unlikely to offer any promising outcomes. Hospice does not provide 24-hour, direct caregiving services. Rather, it augments the care currently being provided in a person's home or residential facility (including long-term care facilities, a common site of death for someone with dementia). Medicare, Medicaid and most private health insurances pay for hospice. Some hospice agencies provide needed care regardless of one's ability to pay.

As experts in end-of-life care, hospice teams offer knowledge and support to long-term care staff as they collaborate to serve the best interests of the resident and family. Hospice teams can complement a busy facility's staff by offering one-on-one time with the patient and their family.

CHALLENGES IN FTD

Even though criteria exist for hospice, it is still often difficult to accurately predict the last six months of life for a person with any type of dementia. Additionally, the criteria for hospice eligibility do not fit the person with FTD because they are based on the progression of Alzheimer's disease (AD), which does not match the progression of FTD. For example, memory impairment is generally less severe in FTD. Additionally, people with FTD are generally younger and more physically robust, and have fewer chronic illnesses.

In 2011, FTD experts identified red flags that may indicate that an FTD patient is in the last six months of life. These red flags, which can be important catalysts for discussing hospice enrollment, include:

- The need for assistance with all activities of daily living (eating, dressing, personal care, etc.).
- Difficulties with swallowing and chewing—including food pooling in one's mouth, which can trigger coughing and choking episodes and increased risks for aspiration pneumonia.
- Severe language impairment.
- Immobility that poses increased risks of tissue breakdown and blood clots.
- Incontinence of bowel and bladder, which may lead to infections and sepsis.
- Frequent falls that may lead to fractures and other serious injuries.
- Significant weight loss and wasting.
- Signs of motor neuron disease causing more rapid decline.

Shortly after his diagnosis, Mark was asked to quit his job; he had made numerous mistakes and received mounting complaints about his impulsive and apathetic behavior. Meanwhile, Terry and Jeff learned everything they could about FTD through AFTD's website (www.theaftd.org) and attended a local FTD caregiver support group. They vowed to make the sacrifices necessary to keep Mark at home for as long as possible. Terry quit her job and Jeff spent much more time at his parents' home.

TRANSITION TO RESIDENTIAL CARE

For the next two years, Mark's family worked tirelessly to provide him with the best care possible. But Terry became chronically exhausted from the caregiving burden, developing health issues of her own. Jeff married and he and his wife soon had an infant, which left him with little extra time to care for Mark. When Terry found herself physically unable to care for Mark at home, she made the difficult decision to move him to a residential care facility.

After a thorough search, Terry moved Mark into a dementia care unit 30 minutes from home, where he lived for the next two-and-a-half years. Terry resumed her full-time job and visited Mark twice a week; Jeff tried to visit every other week. They both continued their active involvement in Mark's care and communicated their concerns to facility staff.

SIGNS OF ADVANCED FTD

Whenever Terry asked about the progression of Mark's illness and what to expect next, his doctor would respond that it was "hard to say in FTD." Indeed, as the months passed, Mark's symptoms continued to develop in ways that concerned and confused Terry:

- He became incontinent of bowel and bladder.
- He had increased difficulty swallowing, often choking on food or liquids. Staff arranged for a speech-language pathology consult to discuss ways to facilitate successful swallowing. The staff changed the textures of liquids, used the "chin tuck" technique, and avoided feeding Mark when he was fatigued. In spite of these interventions, Mark continued to occasionally choke.
- Mark's verbal abilities diminished. He no longer initiated speech and responded to others' questions with short phrases.
- Mark ate less food, often refusing to eat entirely. He lost weight; his clothes hung more loosely. A dietitian recommended Mark consume small, nutrient-dense snacks and fluids, but he showed little interest.
- Mark grew weaker, preferring to sit or relax in bed. He walked with an unstable gait and required assistance to



move even short distances. Against a physical therapist's suggestion, Mark refused to use a walker for safety. Staff, however, were encouraged to use a gait belt when walking with or transferring Mark.

- His confusion increased. Staff modified their communication techniques to allow Mark to better express himself and understand others. They also modified his physical environment to reduce his stress.
- He fatigued more easily and slept 16 or more hours a day. A physical therapist recommended a bed and chair designed to maximize his comfort and safety.
- Although staff members diligently monitored his skin and frequently repositioned him to relieve pressured areas, Mark's skin showed areas of redness and potential breakdown.
- In the most recent 12 months, he had had a UTI and an upper respiratory infection.

After Terry pressed the care team for a comprehensive evaluation of Mark's condition, his physician visited him on the unit to examine him closely. She looked for any treatable conditions that could be contributing to his decline, such as dental problems, possible negative reactions to medications and other common ailments that Mark would no longer be able to self-report. If she had discovered a treatable condition, she would have asked Mark's family about his health care wishes for guidance on how to proceed. But the physician did not find any reversible conditions. She concluded that Mark's condition had become very advanced.

INTRODUCING COMFORT CARE

The memory care unit director began a sensitive discussion with Mark's family, to clarify what his health care wishes would be in his advancing neurodegenerative condition. Terry was confident that Mark would "never want to live like this." Mark would ask to be kept comfortable, to live with people who know and care about him, and to stay out of emergency rooms and hospitals. But he would want to avoid anything that prolonged the inevitable, Terry said.

The director gave Terry the booklet *Advanced Dementia: A Guide for Families* (see Resources in this issue), which addresses the most common issues facing advanced-dementia caregivers. She planned to review thoroughly and discuss each issue in the booklet with Terry and Jeff, knowing that such discussions are critically important, yet often painful and difficult.

Terry and the director invited the memory care unit's nurse to join the conversation about Mark's revised plan of care. This was important: The unit nurse would then update the facility's entire

staff, including weekend and night staff, on how to deliver care that aligned with Mark's wishes.

They discussed what could realistically be expected for someone at Mark's stage of FTD. The director introduced the concept of hospice. Terry and her son had no experience with hospice care, but were open to learning how Mark and how they might benefit from it. Terry worried that switching the focus of care to comfort measures could be misperceived by some as "giving up" or neglecting Mark. Indeed, Mark's primary care doctor bristled when Terry mentioned hospice, arguing that at 65, Mark was not an old man. Several of his friends were also opposed, even citing newspaper articles about potential treatments in development for FTD.

The memory care unit's nurse explained that hospice had benefitted other past residents, and reviewed the limits of medical interventions in treating severely advanced brain disease. Terry and Jeff found it very helpful to learn about comfort care and hospice, and to have gentle conversations with the director and nurse, both of whom who understood the emotional nature of their questions. Terry also talked with members of her FTD caregiver group who had faced similarly difficult decisions. After much reflection, Terry felt that at his advanced stage Mark would choose aggressive comfort care over futile medical interventions; this would be the best way to comply with his wishes for comfort, peace and dignity at the end of his life.

END-OF-LIFE CARE

Mark was formally referred to hospice after his physician attested that he had approximately six months to live. After interviewing local hospice program administrators (see *Choosing a Hospice*), Terry and Jeff chose a local hospice that best fit Mark's needs. The hospice nurse and social worker visited Mark and his family to clarify his care plan and address all questions and concerns. They focused on cultivating a trusting, collaborative relationship with Mark and his family, and gathered information to help customize an approach that would fit their unique preferences. They then shared this information with all members of the interdisciplinary hospice team.

BEST PRACTICES IN DEMENTIA COMFORT CARE

Based on the revised goals of care, the hospice medical director and nurse collaborated with Mark's family and the facility nurse to implement best practices in dementia comfort care and go over advance directives. Terry was especially determined to ensure that

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The hospice nurse and social worker focused on cultivating a trusting, collaborative relationship with Mark and his family.



the facility staff would understand the revised plan and how to coordinate with the hospice team.

Terry signed “do not resuscitate,” and “no antibiotics” because she was confident Mark would not want his life prolonged during the terminal stage of FTD. She marked the choice indicating “do not hospitalize,” because she knew being in a hospital would frighten and frustrate him. She marked the line indicating “no feeding tubes.” Feeding tubes have not been proven to benefit people with advanced dementia; they actually pose a risk of infection and other complications. The hospice RN explained that people with dementia could still be carefully hand-fed small amounts of their favorite foods—ice cream, in Mark’s case—in order to feel pleasure, satisfaction and comfort in their final days. Although it was emotionally very difficult for Terry to complete and sign these advance directives, she was confident that Mark would have chosen these options for himself.

Mark’s list of medications was reviewed and revised to include only those essential for comfort. Mark’s calcium supplements as well as cholesterol and blood-pressure drugs were deemed extraneous, and he began to taper off the trazodone that had been prescribed previously for nighttime agitation and was closely monitored for negative side effects. To ensure round-the-clock comfort, Mark was placed on routine acetaminophen for stiffness (due to immobility), and was closely monitored for negative side effects.

NEARING END OF LIFE

Mark’s decline continued over the next five months. His interest in eating and drinking diminished; the staff gently offered him small amounts of his favorite snacks, but did not pressure him when he refused. When Mark did accept food or fluids, he often coughed or choked on them. He continued to lose weight and became less active physically, spending most of his time propped up in a chair or bed. He napped frequently, and when awake, he was difficult to engage for even short periods of time. Aside from a rare one- or two-word response, he stopped speaking.

The facility staff and hospice team continued to provide customized sensory experiences for comfort. They focused on his residual abilities to derive pleasure from favorite tastes and smells, as well as soothing forms of touch. Favorite poems and hymns

comforted him spiritually. Terry played uplifting songs designed to remind Mark of when they first met and fell in love. These sensory experiences helped Mark sustain a sense of meaningful connection with others, without him having to struggle with his diminished verbal language abilities. Such experiences also helped keep him calm without medication.

Eventually, Mark developed an aspiration pneumonia. Based on his advance directives specifying comfort care, he was not sent to an ER or hospital, nor was he given antibiotics. Instead, he remained with the people who knew him best and would care for him until the end. The facility staff and hospice team worked to maximize his comfort in body, mind and spirit. Medication helped to alleviate any fever symptoms, pain or restlessness. Mark eventually stopped eating and drinking; he became non-responsive, appearing as if in a deep sleep.

As Mark declined, the interdisciplinary hospice team offered information and support to both his family and the facility staff, who were also grieving. Mark’s room was kept peaceful so that everyone who entered could find comfort. As his favorite songs played, Terry and Jeff sat close by, gently stroking his hands and softly whispering tender sentiments. Through it all, the staff’s highest priority was to closely monitor him for any signs of distress and to administer medications as needed. Mark died surrounded by those who loved and cared for him, appearing peaceful and comfortable. Terry knew from her support group how frequently a coroner lists “pneumonia” or “failure to thrive” as the cause of death. The memory unit director helped Terry ensure that Mark’s death was listed as being related to FTD.

Members of the hospice team supported the family and staff, honoring and recognizing the many ways people express their grief. After Mark’s body was prepared for the ride to the mortuary, a few members of the facility staff provided respectful accompaniment to the vehicle. A single rose was placed on Mark’s bed. Terry, Jeff, the hospice team and the facility staff found solace knowing they did an honorable job letting Mark live out his days in comfort by drawing upon the best of both the art and science of caregiving.

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 • Lisa Gwyther, LCSW, Duke Family Support Program • Barbara Harty, GNP, UNTHSC • Susan Hirsch, MA, HCR ManorCare • Jill Shapira, PhD, RN • Rebekah Wilson, MSW, Alzheimer’s Tennessee
- AFTD extends special thanks to this issue’s special guest contributor, Maribeth Gallagher, DNP, FAAN, Dementia Program Director at Hospice of the Valley in Scottsdale, Arizona.
- For permission to reprint this material in whole or in part, contact partnersinfldcare@theaftd.org.



Questions for Discussion:

What does comfort care mean?

Comfort care refers to methods that focus on preventing or relieving suffering, and optimizing one's quality of life in realistic ways that honor the wishes of an individual who has a serious illness. In hospice settings, caregivers work to maximize individual comfort rather than working to cure or even treat underlying illnesses. For Mark, who had FTD, comfort care involved specifying that he would rather "allow natural death" than be resuscitated. Comfort care meant declining hospitalizations, feeding tubes, and further treatments with antibiotics, and Mark's medications were simplified to include only those that managed his discomfort. Mark's caregivers used pleasant, soothing care techniques to improve his quality of life during his final days.

Were there special considerations regarding hospice admission for Mark because of his FTD?

Accurately predicting the end of life is difficult for a person with any type of dementia, but particularly FTD. Complicating matters, people with FTD generally do not match the established dementia criteria for hospice admission. Compared to people with Alzheimer's disease, people with FTD contract fewer chronic illnesses, have less severe memory impairments and may not look as ill or frail as they near the end of life. People with FTD are generally younger and more physically robust, and may even still ambulate. Many people, therefore, do not recognize that FTD is a terminal condition. It is important to recognize signs of late-stage FTD that would support consideration of hospice as early as possible (see Challenges in FTD in this issue). When Mark started showing these signs, his family, facility staff and physician discussed how to offer him the best possible care based on his advanced condition. Because the health care system is generally unfamiliar with FTD, it is all the more important for family members to serve as fierce advocates for their loved ones, and educate those who participate in their health care decisions.

How did the memory care staff and hospice team coordinate care?

The memory care facility's careful documentation of Mark's decline provided concrete evidence justifying his eligibility for hospice services, even though he did not look like a "typical hospice patient." The hospice staff then worked closely with Mark's family and the facility to learn how to help customize their care to fit his unique needs and preferences. The hospice and facility staff communicated frequently on all the details of Mark's most current

care plan, including whether the equipment provided by the hospice aligned with facility regulations. Hospice staff encouraged the facility staff to call at any time with questions or concerns, and worked diligently to build trusting relationships with the facility staff and family. Open communication was important: On several occasions it was necessary to clarify with facility direct-care staff that they—and not the hospice aide—remained responsible for daily care.

The interdisciplinary hospice staff shared their expertise and provided information, education and support for both the family and facility staff throughout Mark's decline. When he became minimally responsive, the hospice team modeled ways that caregivers could both maximize Mark's comfort and continue communicating their affections and respect. The hospice team reassured all involved that that they were offering Mark the best possible care. After Mark's death, hospice offered bereavement services for the family and facility staff.

OUTCOMES AND BENEFITS *(continued from sidebar pg.2)*

Switching the focus from routine health care to comfort care requires a detailed risk/benefit analysis of every health care decision, including those regarding medications, current treatments, screenings, CPR, hospitalizations and feeding tubes. It frequently involves simplifying routine medications, ending routine screenings, diet liberalization, frequent assessments for discomfort and administering effective analgesia, along with other non-pharmacological and sensory measures to keep the person comfortable at all times.

Research studies on hospice* are based primarily on people in the end-stages of more common forms of dementia, such as Alzheimer's disease. These studies indicate that the benefits of hospice for people with dementia and their families include:

- Interdisciplinary support for patients and families.
- Lower rates of restraints, feeding tubes and hospitalizations.
- More effective symptom management.
- Respite care.
- Dying in their place of choice.
- Lower health care costs.
- Families' perception of higher quality of care leading up to death.

Anecdotal reports from FTD caregivers show that replacing aggressive end-of-life medical intervention with comfort care can give them a long-awaited—albeit limited—sense of agency over the disease. After being at FTD's mercy for so long, many family caregivers say that choosing comfort care can provide a sense of control and resolution in the disease's end stage.



TROUBLES & TIPS

A divorced 58-year-old woman with behavioral variant FTD has been in our specialized memory care unit for two years. In the last six months she has had two trips to the ER and her condition is declining rapidly. She has no advance directives and her daughter, 25, is overwhelmed by the responsibility of making care decisions. How can we help?

Many caregivers of persons with FTD experience extreme isolation and guilt, and wonder if they are doing everything they can to provide good care. They may have trouble absorbing that FTD is ultimately a fatal disease. An understanding provider can help the daughter discern and articulate her mother's care wishes in ways that both empower the daughter and promote comfort and compassion at the end of this difficult journey.

The memory care team can review the mother's medical status with her physician, and document the nature and apparent rate of her decline. The director, senior nurse or staff member most familiar with comfort care, hospice and surrogate decision-making can reach out to the daughter with information and support.

Discuss any current treatable medical conditions and ask what the daughter thinks her mother's health care wishes would be. Make sure the daughter understands that FTD is a fatal disease, and answer any questions she may have about its progression. Provide AFTD's website (www.theaftd.org) and AFTD's "secret" Young Adult Facebook group (email youngadults@theaftd.org to gain access) as resources.

Sensitively introduce common complications of FTD, e.g. aspiration pneumonia as a result of swallowing difficulties, or serious injury from falls. Ask her to consider how trips to the hospital or ER would impact her mother: Do their benefits outweigh the risks and suffering that may result? Introduce the concept of hospice/comfort care as an alternative to aggressive medical interventions that produce diminishing returns. Offer printed material on hospice and comfort care in advanced dementia (see the Resources section of this issue), and connect her with hospice providers, and/or an FTD caregiver support group to further discuss questions and concerns. Staff support can be critical for her to understand that there is no "right" or "wrong" choice when deciding between aggressive medical interventions or "comfort measures only." What matters is having confidence in her understanding of her mother's preferences.

Initiate a care-planning meeting to document in the service plan the agreed-upon approaches. The plan should include physician's orders that reflect the mother's wishes (as conveyed by the daughter) regarding referral to hospice, emergency room visits, medication prescriptions, etc. A well-documented plan of care and doctor's orders can proactively address common concerns for state surveyors who may not understand hospice services and comfort care. A plan is also critical in communicating the individual's wishes to everyone involved in delivering care.

OUTCOMES AND BENEFITS *(continued from sidebar pg.5)*

A sense of closure can be similarly provided via the loved one's death certificate. FTD deaths are seldom officially characterized as such ("pneumonia" or "failure to thrive" are more commonly listed). Hospice and facility care staff can help families advocate for FTD's inclusion on the death certificate, in order to improve government data tracking in advanced dementia.

*Fulton et al., 2011; Goldfeld et al., 2011; Jones, 2013; Kiely et al, 2010; Miller et al, 2012; Mitchell et al., 2009; Shega & Tozer, 2009; Teno et al., 2011

RESOURCES

- For an overview of hospice approach and services, considerations in FTD and end-of-life symptoms in FTD, visit: <https://www.theaftd.org/life-with-ftd/managing-health-care/hospice-end-of-life>
- *Advanced Dementia: A Guide for Families*—This free downloadable booklet is based on professional literature about people with more common forms of dementia, such as Alzheimer's disease. It is a general, evidence-based guide for the complex decisions that typically arise in advanced dementia. <https://www.grouphealthresearch.org/files/3714/6430/3009/DementiaGuide-final-2015.pdf>
- *How to Talk to Families about Advanced Dementia: A Guide for Health Care Professionals*—A free downloadable booklet for staff. <https://www.grouphealthresearch.org/files/4114/6428/8174/DementiaProfBookletV11a.pdf>
- *Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care*—A report that highlights the important role of long-term care providers in bringing comfort to people with advanced dementia, their families and their friends. http://www.caringkindnyc.org/_pdf/CaringKind-PalliativeCareGuidelines.pdf

ARRANGING COMFORT CARE AND HOSPICE IN FTD

Many people state that if they had advanced dementia they would decline aggressive medical interventions to prolong life. Arranging comfort care in FTD can be challenging. The typically younger age of onset means that fewer people have considered advance care planning prior to diagnosis. And as the disease progresses, the person will be less able to participate in their own planning, leaving family to make emotionally sensitive decisions on their behalf. Health care professionals and family members should consider these steps to ensure that they provide care that aligns with the wishes of the person diagnosed.

ADVANCE CARE PLANNING

- Encourage the person with FTD to discuss preferences with their primary caregiver(s) early on to maximize participation.
- Identify a medical power of attorney (POA) to serve as an advocate when the person can no longer communicate.
- Document the person's wishes so that family members, health care providers and facility staff can use them to guide all future medical decisions.
- Ask if family members and health care providers are aware of the person's wishes and willing to honor their decisions. If there are disagreements, it is important to recognize them early and seek support to resolve conflicts and ensure a clear plan of care.
- Consider specific wishes in all areas of care: resuscitation, emergency room visits, hospitalization, placement of feeding tubes, and use of antibiotics for infection.
- To facilitate shared decision-making, educate care providers about disease progression, usual causes of death and common complications.
- Consult the advance care plan to prevent snap decisions when unexpected events occur (e.g. a fall that causes serious fracture).
- If the person with FTD and their medical POA have chosen comfort care over traditional medical intervention, remind health care providers of this repeatedly.
- As the condition progresses, distribute copies of the advance directives to everyone who might participate in decision-making processes.
- Be prepared to advocate for the person's comfort-care wishes. The desire for hospice/comfort care may be misunderstood by some medical professionals, who may focus solely on lifesaving efforts.
- Support the medical POA's decisions. He or she will best know what their loved one would have chosen, despite resistance from friends, family members or providers.

WHEN AND HOW TO CONSIDER COMFORT CARE AND HOSPICE

Be aware that established hospice criteria are based on progression in Alzheimer's dementia -- not FTD. People with FTD may not "seem" as advanced due to: having less severe memory impairment; being younger, mobile and physically robust; and having fewer chronic medical conditions. FTD thus may not be recognized as a terminal illness.

- Identify the best person (e.g. family member, nurse, facility director) on staff to speak patiently and compassionately with the primary family caregiver about sensitive and emotional decisions.
- Sensitively acknowledge the importance of maximizing quality of life and comfort throughout progression of FTD, in light of it being an irreversible terminal disease.
- Identify early the designated POA or legal next of kin to participate in discussions of advanced care planning. In some cases FTD has torn a family apart and the responsibility may fall to a young adult. Develop a clear plan of care; if there are disagreements, work to resolve them by providing assistance, referral and support as needed.

- Be familiar with the natural progression of FTD, the common causes of death associated with it, and its similarities and differences from Alzheimer's disease.
- Be familiar with comfort care and hospice services, particularly the eligibility criteria for hospice care.
- Introduce the concept of comfort care in advanced dementia to the caregiver/medical POA, and provide printed information for consideration.
- Work with the primary care clinician to advocate for hospice services.
- Review periodically the overall status of progression and changes in the person, keeping careful documentation of the person's decline in cognition, functioning, sleep schedule, food and drink habits, weight loss, etc. This information can provide evidence for admission to hospice. Recognize and record changes to show progression, even when it is slow.
- Assess for other health concerns (newly developed medical conditions, unrepaired fractures, recurrent infections, etc.) that could hasten death.
- Note any significant change in the rate of progression. Has there been a recent rapid decline?

CHOOSING A HOSPICE

- Ask the hospice provider if they have experience serving patients with FTD and what they learned from working with them.
- Ask about their eligibility criteria for a person with FTD.
- Ask about the specific services they will provide. How much care will they provide? Will they provide care on an established schedule? How will care differ depending on where hospice is delivered (at home, in long-term care or in a residential hospice)?
- Ask if hospice staff is available around the clock and on weekends, if needed.
- Ask how long it will take them to respond to emergencies after hours.
- Determine if the hospice staff will provide hospice and medication training to the family and/or the facility staff.
- Determine how the hospice staff will coordinate and collaborate with the family and long-term care staff. If disagreements occur, how will they be resolved?
- Ask if the family can opt to use their primary provider. How will that work?
- Ask if there are volunteers available who understand how to meaningfully interact with a person who has end-stage dementia. Are they aware of the different types of dementia? How are they screened and educated?
- Ask if the hospice staff will teach family and long-term care staff what to expect as the person approaches death, and how they can best offer comfort.
- Ask what to expect after the person dies.
- If the person's brain has been pledged for research, or if an autopsy is requested, ask the hospice staff how they will facilitate these wishes.
- Ask the hospice if they will work to have the official cause of death listed as being related to FTD (or a specific subtype if known).
- Ask which grief and bereavement services the hospice offers, and for how long.
- Ask about costs, insurance coverage and out-of-pocket expenses. Clarify the ways in which Medicare coverage for hospice may affect the coverage for long-term care or other services.

SENSITIVELY ACKNOWLEDGE THE IMPORTANCE OF MAXIMIZING QUALITY OF LIFE AND COMFORT THROUGHOUT PROGRESSION OF FTD, IN LIGHT OF IT BEING AN IRREVERSIBLE TERMINAL DISEASE