

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