



## 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.