

What to Do About...ALS with FTD

Over the last ten years, there has been increasing recognition of a continuum between ALS and frontotemporal degeneration (FTD). Up to half of people with ALS also show symptoms of FTD, while up to 30% of people diagnosed with FTD develop motor symptoms consistent with ALS. People diagnosed with either ALS or frontotemporal degeneration (FTD) may feel overwhelmed by their situation and miss or overlook possible signs of the other syndrome. But a potential dual diagnosis is important to consider due to its impact on treatment, prognosis, and understanding the genetic risks involved.

Evaluation and Diagnosis

- Know the **signs and symptoms** of ALS and FTD, and be observant for changes consistent with both.
- Prepare for doctor visits. Keep a log of troubling behavior, language difficulties and muscle or motor changes to take to the doctor. ALS and FTD are both diagnosed by ruling out other possible disorders.
- Seek a second opinion at an academic medical center with specialists in cognitive neurology and neuromuscular disorders, if possible.

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If you are a military service member who has ALS with FTD, the VA may cover the cost of your care.

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- Request testing to rule out ALS if troubling signs are noticed (slurred speech, muscle weakness, stiffness or muscle cramping, early swallowing difficulty, etc.). Note that some of these symptoms can also be part of FTD without ALS, so a specialist is the best option for obtaining a diagnosis.
- Advocate for diagnostic clarity, as diagnosis of ALS with FTD impacts prognosis, treatment decisions and the support needed.
- Apply for Social Security benefits. The Compassionate Allowances program expedites the review process for people with both FTD and ALS diagnoses.
- If you are a military service member who has ALS with FTD, contact the Department of Veterans Affairs (VA). The VA may cover the cost of care for veterans diagnosed with ALS.
- Become informed on the genetics of ALS with FTD and consider possible family inheritance. Consult with a genetic counselor.

Care Planning

- Discuss with the individual their wishes regarding the use of a feeding tube, ventilator, or other standard treatments in ALS as soon as possible. FTD's cognitive impairment complicates these decisions as the disease progresses.
- Complete key documents (healthcare power of attorney, end-of-life wishes) to maximize the involvement of the person who has ALS with FTD.
- Seek support from an ALS Association or Muscular Dystrophy Association clinic for a team approach to care and adaptive equipment related to the muscle disorder.
- Inform all members of the care team that treatment decisions must include the caregiver/healthcare power of attorney due to the individual's cognitive impairment.
- Seek an early palliative care consultation for help with key decisions, recommendations for appropriate care in degenerative motor disease, and a discussion about hospice.
- Think through recommended ALS interventions in light of the FTD diagnosis. A person with dementia may not understand how to use adaptive equipment and/or lack judgment to use it safely. Work with your care team to find alternate solutions if needed.
- FTD can increase dependency on the primary caregiver, so introduce home health services, physical therapy, occupational therapy and potentially hospice early to assist with activities of daily living. The earlier you can bring in help, the more time the person diagnosed has to adjust to people in their home. The person diagnosed may not be as agitated or resistant to accept assistance as the routine is being established.

Care Planning (cont.)

- Consult a speech-language pathologist (SLP) for a bedside evaluation of swallowing difficulties (is it due to muscle weakness or inattention?) and recommendations about nutrition, food consistency and assistance with meals. An SLP can also provide strategies to maximize communication in persons diagnosed with primary progressive aphasia. Conduct research into residential care early to identify nursing homes that, if needed, would consider someone who has ALS with FTD.
- Interview hospice providers long before their services are needed. Respite for the family care partner is one benefit of hospice, among others, but the details can vary by provider. For more information, consult the Fall 2016 edition of Partners in FTD Care, entitled “**Comfort Care and Hospice in Advanced FTD.**”
- Focus on, and advocate for, quality of life.
- Establish a backup caregiving plan in case the primary care partner has health needs and is unable.

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The Importance of Support

- Identify sources of emotional support. Managing the logistics of care and making decisions on behalf of a person diagnosed is stressful for family care partners.
- Consider joining AFTD's telephone support group for care partners of someone who has ALS with FTD (contact AFTD's HelpLine at 866-507-7222 for more information), or an ALS, FTD or general caregiving group.
- Tell everyone what is going on.
- Ask for and accept help in all forms. Contact the Area Agency on Aging, the ALS Association or the Muscular Dystrophy Association.
- Remind caregivers they cannot do everything. Support their thoughtful choices, which they are trying their best to make in the face of numerous treatment recommendations and often feelings of guilt.
- Use respite services for the health and well-being of the caregiver (free with hospice).
- Empower the family to understand how an FTD diagnosis may impact standard ALS interventions. Listen to their concerns. Help a care partner decide to accept, request or refuse interventions based on their understanding of the wishes of the person diagnosed.
- Recognize that accidents (falls, choking spells, etc.) will happen in this complicated care situation, and that they are no one's fault.
- Encourage the caregiver to take time to consider how they prefer to spend time with their loved one.