

AMYOTROPHIC LATERAL SCHLEROSIS (ALS)

Caregiving for any patient with a debilitating illness can be both fulfilling and exhausting, and caring for a loved-one with ALS is particularly challenging. Patients' needs change rapidly as the disease progresses, and impaired communication can make caregiving more difficult. Caregivers for ALS patients are also at increased risk for depression and stress because of the emotional and economic stress of coping with an illness that requires expensive equipment and will result in losing their loved one to this terminal disease.

When patients have both FTD and ALS caregiving becomes more difficult for a variety of reasons. Patients often have poor insight into their ALS symptoms, and as a result may disagree with family about clinical changes, treatment recommendations and the need for necessary equipment. They sometimes have trouble using a communication device or making decisions regarding PEG and BiPAP, which are significant life-sustaining measures. All of these problems confound an already very difficult disease for families and health care providers.

For more detailed information:

- [Family Caregiver Alliance](#)
- [National Alliance for Caregiving](#)
- [National Family Caregivers Association](#)
- [The ALS Association](#)

For Caregivers