



Hospice Clinical Appropriateness:

End-Stage
Amyotrophic Lateral Sclerosis (ALS)

VITAS[®]
Healthcare



Partner with the nation's hospice leader

Patients depend on their physicians to guide them in making some of the most important decisions they will ever make. When it's time for hospice, refer them to a provider with a proven record of administering the highest quality of clinical, spiritual and emotional support services. Partner with VITAS.

Physicians, hospitals, nursing homes, assisted living communities and home health agencies refer to VITAS because they trust our protocols. Developed over more than 35 years of caring for patients at the end of life, our expertise and resources ensure comfort, peace, and satisfaction for patients and patients' families. Clinicians know we work with our referral sources in a multidisciplinary team environment to give every patient excellent care and symptom management.

Hospice as part of the continuum of care

Hospice services are designed to supplement the high level of care attending physicians and clinical staff bring to their patients. Partnering with VITAS has many benefits:

- VITAS staff actively monitors and manages changes/declines in the patient's condition.
- VITAS support reduces emergency calls to the physician, which minimizes the burden and stress on office/facility staff.
- VITAS services reduce calls to 911 or unnecessary transfers to the hospital/ED.
- VITAS clinicians are available as an experienced end-of-life resource at all times.
- VITAS care plans are dependent upon the attending physician's approval, and we welcome the physician's input on care.

Incidence of Amyotrophic Lateral Sclerosis (ALS)

Approximately 5,600 people in the U.S. are diagnosed with ALS each year. It is estimated that as many as 30,000 Americans may have the disease at any given time. Although the life expectancy of an ALS patient averages about two to five years from the time of diagnosis, this disease is variable and many people live much longer. About 20 percent of people with ALS live five years or more and up to ten percent will survive more than ten years.¹

Hospice for end-stage ALS

An increasing focus on palliative and end-of-life care has made a significant difference for individuals with ALS and their loved ones. With the assistance of hospice, patients in the final stages of the disease are at peace, their symptoms managed. Many can remain in the comfort of their homes. Hospice is designed to support and supplement the efforts of the primary physician in relieving suffering, providing comfort, promoting dignity, and facilitating closure for patients and their families.

Clinical characteristics of ALS make decisions regarding the timing of end-of-life care somewhat difficult. A limited prognosis is typically triggered by “rapid progression” of ALS, which is defined as the development of severe neurologic disability over a 12-month period. (For a list of rapid progression characteristics, please see page 5.)

ALS may be complicated by secondary and comorbid conditions. Secondary conditions, such as dysphagia, pneumonia and pressure ulcers, are a direct result of the impairment of respiratory functions, swallowing, muscle power and muscle tone that are common in ALS. Comorbid conditions, which often accompany the rapid progression of ALS, include chronic obstructive pulmonary disease (COPD), phelonephritis or upper urinary tract infection, septicemia and fever after recurrent antibiotics.

In recent years, there has been an increasing recognition that some people with ALS also have a degree of cognitive dysfunction, abnormality or even dementia. Dementia from damage to the frontotemporal lobe differs from the dementia in Alzheimer’s disease in that it is more subtle. According to the ALS Association, researchers are now finding





that this dementia appears to accompany ALS and may even precede it in some cases. The cognitive dysfunction can further impair a patient's reasoning and ability to communicate. This is another reason it is vitally important that physicians initiate early and regular discussions in order to establish and understand the ALS patient's wishes regarding end-of-life care.

Knowing when a patient with ALS is ready for hospice

Developments in medical science and technology have led to therapies and a variety of computer aids that have enhanced the quality of life of ALS patients. As severe neurologic dysfunction sets in, however, patients vary in their desire to become dependent on feeding tubes, ventilators and computer technology.

Even before hospice is considered...

a VITAS physician is available for a consultation. We have the time to listen to the concerns of the patient and family, describe the progression of the advanced disease, explain care options and outline a realistic plan of care. You are informed of the outcome and we maintain communication with patient and family.

VITAS helps to reduce hospitalization

A partnership with VITAS provides resources that can reduce unnecessary rehospitalization:

- **Visit frequency**—VITAS' interdisciplinary team members coordinate support based on the individualized plan of care
- **VITAS Telecare**[®]—24-hour direct access to trained clinicians provides around-the-clock resources and peace of mind for patients, families, and clinical staff members in nursing homes and assisted living communities.
- **Intensive Comfort Care**[®]—Medical management is provided in the patient's home, nursing home or assisted living community, up to 24 hours per day when medically appropriate.



Patients are eligible for hospice care when a physician makes a clinical determination that life expectancy is six months or less. In end-stage ALS, two factors are critical in determining prognosis: ability to breathe and ability to swallow. In the case of ALS, feeding tubes can be a normal part of treatment. G-tubes and ventilator support prolong life expectancy. Hospice-appropriate patients are those who have chosen to forego supportive ventilation, artificial hydration and nutrition.

Plan of care for end-stage ALS

The hospice plan of care addresses the patient's physical and psychosocial well-being and seeks to manage a wide variety of ALS symptoms, including:

- Shortness of breath; respiratory dysfunction
- Pain resulting from stiff joints, muscle cramps, pressure on skin and joints caused by immobility
- Skin care issues
- Difficulty swallowing
- Impaired hydration and nutrition
- Difficulty communicating
- Depression or anxiety
- Financial challenges

Refer your patients to
VITAS Healthcare
Call 800.93.VITAS

Easy online referrals now available
at [VITAS.com/referral](https://www.vitas.com/referral)

¹ALS Association, www.alsa.org. Accessed July 2014.



Hospice admission guidelines for patients with end-stage ALS

Patients are considered to be in the terminal stage of ALS if they meet any of the following criteria:

BOTH rapid progression of ALS and critically impaired ventilatory capacity:*

- Vital capacity < 30% predicted
- Significant dyspnea at rest
- Supplemental oxygen needed at rest

BOTH rapid progression of ALS and critical nutritional impairment:*

- Artificial feeding not elected or discontinued
- Oral intake insufficient with continued weight loss
- Dehydration and hypovolemia

BOTH rapid progression of ALS and life-threatening complications such as:*

- Recurrent aspiration pneumonia
- Decubitus ulcers, multiple, stage 3-4, particularly if infected

- Upper urinary tract infection, e.g., pyelonephritis
- Sepsis
- Fever recurrent after antibiotics

VITAS provides these guidelines as a convenient tool. They do not take the place of a physician's professional judgment.

*Rapid progression of ALS:

- Progression from independent ambulation to wheelchair or bed bound
- Progression from normal to barely intelligible or unintelligible speech
- Progression from normal to blenderized diet
- Progression from independence in most or all activities of daily living (ADLs) to needing major assistance in all ADLs

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