Hospice Care for Patients with Amyotrophic Lateral Sclerosis (ALS)



When is the right time to consider hospice?

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, affects each person differently. It can be very difficult to predict what course the disease will take or when to start hospice services.

Patients are eligible to receive hospice services when they have a life expectancy of six months or less, but prognosis is not the only standard for determining hospice eligibility.

VITAS suggests ALS patients be evaluated for hospice if they have experienced a "rapid progression," which is defined as the development of severe neurologic disability over a 12-month period. It is characterized by:

- 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 (toileting, feeding, dressing) to needing major assistance with these tasks

In addition, hospice-appropriate patients are those who do not wish to be dependent on feeding tubes for hydration and nutrition and have chosen to forego supportive ventilation.

All hospice organizations are reimbursed in the same way, so they do not compete on cost. It is the quality of service and spectrum of choices that differentiate one hospice from another. Anyone can inquire about hospice services. Patient, family or physician may request an evaluation to see if hospice is an appropriate option for care. Call now to see how VITAS can help.

Hospice care for patients with ALS

With the assistance of VITAS, patients in the final stages of ALS can be at peace, with their symptoms controlled. The goal of hospice is to relieve suffering, provide comfort, promote dignity and facilitate closure for patients and their families.

And VITAS brings care and comfort to our patients. ALS patients and families—many of whom have struggled to access distant specialized treatment centers or professional expertise even as the patient becomes less mobile—welcome care that comes to them. Whether they live in a private residence, nursing home or assisted living community, VITAS patients can remain at home, in comfortable surroundings.

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/joints caused by immobility
- Skin care issues
- Difficulty swallowing
- Impaired hydration and nutrition
- Difficulty communicating
- ALS-related dementia
- Depression or anxiety
- Financial challenges

Hospice also offers the emotional and spiritual support that is essential to so many loved ones and those who take care of patients with ALS. VITAS provides:

- Education—As patients grow weaker, symptoms increase and communication becomes more difficult, caregivers and loved ones can sometimes feel overwhelmed or helpless. VITAS coaches families on how to care for their loved one.
- Emotional and spiritual assistance—VITAS offers psychosocial counseling and spiritual support tailored to meet the patient's needs.
- **Bereavement support**—Bereavement is the time of mourning after a loss. The hospice care team helps surviving loved ones through the grieving process. Grief and bereavement resources are available for a year or more following a death.

Levels of hospice care

A pioneer in the field of end-of-life care, VITAS is proud to offer unsurpassed service across all four levels of hospice care:

- Routine Home Care—available wherever the patient calls home (residence, nursing home, assisted living community)
- Intensive Comfort Care[®] (continuous care) medical management in the home for up to 24 hours per day when medically appropriate
- **Inpatient Care**—when medical needs cannot be managed at home
- **Respite Care**—allows the patient a brief inpatient admission to provide caregivers a "respite"

Who pays for VITAS services?

VITAS accepts Medicare, Medicaid/Medi-Cal, private insurance and other forms of reimbursement for its hospice services.



Your VITAS care team

Because patients who have end-stage ALS have a broad range of needs, their care is coordinated by a highly trained interdisciplinary team:

- **Physician** who works with the patient's primary care physician in controlling pain and symptoms
- **Registered nurse** who is skilled in assessing and managing pain
- **Social worker** who provides emotional support and helps with financial issues and planning
- **Hospice aide** who can help with personal care and hygiene, light housekeeping, light laundry and occasional shopping
- **Chaplain** who works with the patient's own clergy and offers spiritual support
- **Community volunteer** trained by VITAS to offer time and companionship
- Bereavement specialist who offers grief and loss support and helps with memorial services and other care for loved ones

VITAS Healthcare can help. Call VITAS at 800.723.3233 or visit VITAS.com

Download Our Free Hospice Discussion Guide



• Make the right decisions for you and your loved ones

• Get answers to your hospice questions

• Learn how to start the hospice conversation

Find out more at HospiceCanHelp.com

For more information call 800.723.3233

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