

Hospice Care for ALS

Hospice is a service that provides compassionate care and comfort for terminally ill patients at the end of life. Most people receive hospice care at home, though it is also available in hospice centers, hospitals, nursing homes, and other long-term care facilities.

The ultimate goal of hospice is to provide quality of life at the end of life. It allows families to spend meaningful time together and focus on each other instead of the disease.

Who is eligible?

Hospice care is available for anyone with a terminal illness and a doctor's referral. Your neurologist must certify that you have an estimated six months or less to live. Hospice does not attempt to prolong life through treatment and will not cover the cost of drugs approved to treat ALS. Ask whether you can still take certain drugs or participate in clinical trials while being enrolled in hospice. Hospice is voluntary. You can disenroll at any time.

Who pays?

Insurance will cover hospice services at home. Medicare, private insurance, the VA, and Medicaid should cover standard expenses. Inpatient care at hospice facilities (aside from short-term respite stays) is not covered by Medicare, Medicaid, or private insurance.

What does hospice provide?

Each hospice provider is unique, but hospice care typically includes:

- An interdisciplinary care team led by a medical director
- An individualized care plan
- Pain and symptom management
- Medications, medical supplies, and most equipment
- Home visits by a nurse once a week
- Home visits by a nurse's aide a few times a week to assist with bathing and dressing
- Emotional and spiritual counseling for the patient and/or family
- Bereavement support for surviving family members for one year

Once enrolled, hospice will coordinate everything for you. They will order and provide your medications and durable medical equipment like respiratory devices, a hospital bed, and some bathroom equipment.

How do we get started?

When you and your neurologist or physician agree that it is time, a referral will be sent to a hospice provider—ideally one with experience working with ALS patients. The provider will meet with you to develop a plan that addresses your physical, psychological, emotional, and spiritual (if requested) needs. Service can begin within one to two days of referral, or earlier if urgent. Here are a few tips:

- **Discuss hospice with your loved ones.** Though not an easy conversation, it is important to discuss your wishes with your loved ones as early as possible. This can help avoid confusion down the road.
- **Revisit your advance directives.** Look back at your advance directives to make sure they reflect your current wishes for medical treatment should you become unable to communicate or make decisions.
- **Get your expensive equipment first.** Before enrolling in hospice, talk with your ALS clinic team to make sure you have all the durable medical equipment you need. This is very important, because once enrolled in hospice, you will not be eligible for expensive items like a custom power wheelchair or speech-generating device. If you need to enroll in hospice prior to receiving these items, ask if the equipment is available through your local loan closet.
- **Get a feeding tube first.** If you want a feeding tube, you should get it prior to enrolling in hospice because it won't be covered once you're enrolled. If you decide later that you want a feeding tube, you can disenroll from hospice and have your doctor re-enroll you again after discharge from the hospital.
- **Try hospice's respite care program.** Once enrolled in hospice, you can receive up to five days of respite care in an inpatient facility—at no cost to you—if a bed is available.

Get Local Support



ALS United North Carolina
4 N. Blount Street - Suite 200
Raleigh, NC 27601
www.alsnc.org
(919) 755-9001

Learn More

For additional information on this topic, including video clips with experts, scan the QR code or visit our website at:

www.youralsguide.com/hospice-care

Your
ALSguide

