



**HUMMINGBIRD  
HOSPICE**  
BECAUSE EVERY MOMENT MATTERS

## What to Expect During End Stages of ALS

Amyotrophic lateral sclerosis, also called ALS or Lou Gehrig's Disease, is a progressive nervous system disease that attacks and weakens the muscles and leads to complications with physical function. Some cases are likely genetic, although the cause for most is hard to determine. The early symptoms of ALS are minor. In the early stages, patients often experience muscle weakness, involuntary twitching, weakness of the limbs, and slurred speech. It progresses relatively quickly, and there is no known cure.



Most patients progress to the end stages of ALS within two to five years from diagnosis, and the disease is eventually terminal. The following is a review of what patients and their families can expect during the end stages of ALS.

### Symptoms Of End Stages Of ALS

The symptoms of the end stages of ALS vary for each case and depend largely on the specific neurons affected. The disease typically begins in the hands, feet, and limbs before progressing to the rest of the body. Some of the more common symptoms in the end stages of the disease include:

- Paralysis of voluntary muscles
- Inability to talk, chew and drink
- Difficulty breathing
- Potential heart complications

Almost all ALS patients are unable to walk or use crutches in the late stages of ALS and require a wheelchair and assistance moving around. This is due to paralysis of the limbs caused by the disease attacking the muscles. Many also experience an inability to talk, eat or drink and require a feeding tube.

The most common cause of death for ALS patients is respiratory complications caused by an inability to breathe. Heart complications are also possible in certain cases.



## Mitigating Symptoms with Comfort

Since there is no known cure, the goal of treatment in the end stages of ALS is to manage discomfort and other symptoms. Many health professionals recommend hospice care to help those in the end stages of ALS improve their quality of life and remain relatively comfortable.

Excessive pain is not a concern for many ALS patients, but muscle spasms and joint stiffness is often an issue. Through pain relief medication, therapies, and other care methods, our hospice team can help keep pain at a tolerable level.

## What Families Can Do for Their Loved Ones

The main priority of family members is to simply be there for their loved one who is going through the end stages of ALS. This lets the person know that they are loved and helps them feel comfortable as they are surrounded by people they care about.

Family members should also cherish the time they have left with their loved ones suffering from ALS. Create memories with them, even if it is by simply watching a movie with them while holding their hand. Small moments like this can leave a meaningful and lasting memory.

## Benefits of Hospice Care for Patients with ALS

Improve the quality of life for patients with ALS is accomplished by managing the late-stage symptoms, helping families deal with their concerns, and promoting social interactions between the patient and their loved ones. The most notable benefits of hospice care for ALS patients include:

- **Pain and symptom management** – As discussed, the end-stage symptoms of ALS are severe. The patient requires help with daily activities due to symptoms, which our care teams provide.
- **Comfortable care within the home** – Patients in the end stages of ALS can receive care within their own home, allowing for a more comfortable and practical experience.
- **Family counseling and guidance** – Seeing a loved one who was fully healthy less than ten years prior go through the end stages of ALS is heartbreaking. Hummingbird Hospice care teams help families who are grieving.
- **Mental and spiritual assistance** – Preparing for death is never easy, but mental and spiritual counseling and guidance can help.

Of course, the benefits for every patient and family differ. To find out how hospice care can help you or your loved one with ALS, contact Hummingbird Hospice to speak with a care specialist directly.

