

What Do I Need to Know?



Some Facts

What is Amyotrophic Lateral Sclerosis?

Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's disease, is a rapidly progressive neurological disease that attacks the nerve cells (neurons) responsible for controlling voluntary muscles. The disease belongs to a group of disorders known as motor neuron diseases, which are characterized by the gradual degeneration and death of brain and spinal cord cells involved with coordinating motor skills like walking and grasping. In patients with ALS, the neurons eventually die, resulting in muscle atrophy, twitching, and eventual loss of voluntary movement.

Treatment may include:

No cure has been found for ALS. However, the Food and Drug Administration (FDA) has approved the first drug treatment for the disease that is believed to reduce damage to motor neurons, but does not reverse damage already

(continued on back)

Physical and Mental Changes to Expect

Amyotrophic lateral sclerosis (ALS) does not affect the Veteran's ability to see, smell, taste, hear, or recognize touch and patients usually maintain control of eye muscles and bladder and bowel functions.

Physical therapy and special equipment can enhance the Veteran's independence and safety throughout the course of ALS. Physical therapists can recommend exercises that provide benefits without overworking muscles. Occupational therapists can suggest devices such as ramps, braces, walkers, and wheelchairs that help the Veteran to conserve energy and remain mobile.

ALS patients who have difficulty speaking may benefit from working with a speech therapist who can teach adaptive strategies, such as techniques to help them speak louder and more clearly. As ALS progresses, the Veteran may lose the ability to speak or produce vocal sounds. Speech therapists can help to develop nonverbal communication mechanisms.

There are also a range of ventilation support devices available to help the Veteran breathe when the muscles that control breathing weaken. Before choosing a ventilation device, Veterans and their Caregivers should be fully informed about the various types of ventilation devices and the limitations and long-term effects of each device.

Physical changes may include: loss of control of muscle movements; muscle spasms and muscle loss; difficulty speaking or slurred speech; difficulty breathing as the disease progresses; fatigue; excess saliva and phlegm; pain; constipation

Mental changes may include: difficulty with decision-making and memory

Emotional changes may include: depression; sleep disturbances

What Does This Mean for Me?

Being a Caregiver of someone with ALS is a very important role. The role will require increased responsibility, a large time commitment, high energy, patience, and knowledge about ALS treatment, support, and resources. Caring for someone with ALS can also cause lots of worry and concern due to the level of care the Veteran may need.

While most Caregivers are proud to be providing care and support, it can still be very challenging to balance everything. Recognizing that certain tasks and

(continued on back)

Created 12/11



expectations can take a toll on you can help to avoid heading down the path to burnout. Developing a plan for your own self care can enhance your quality of life and the quality of life of the Veteran. The more relaxed and fulfilled you feel, the more easily you will be able to provide the necessary care to the Veteran.

Caregiving Tips

1. Knowledge is empowering. Get as much information about ALS and caregiving as you can. The more you know, the better prepared you will be to provide care and support for the Veteran.
2. If the Veteran you care for is experiencing cognitive or behavioral problems, try using simple and straight-forward language to communicate clearly and directly.
3. Establish a regular schedule for respite care. Respite is very important because it gives you an opportunity to have time to recharge.
4. Eat nutritious foods, get sufficient rest, and exercise routinely. It is important for you to maintain your health so you can provide the best care for the Veteran.
5. Pay attention to your body's signals of stress. In order to reduce stress, try practicing stress-management strategies, such as breathing exercises, yoga, and meditation.
6. Develop a strong support system. Surround yourself with supportive friends and family. Attend a support group where you can share your concerns and feelings.
7. See a counselor or therapist if you are in need of more extensive mental health support. Make conscious decisions about how you want to spend your time; acknowledge your priorities and build your life around them. It is all right to say "no" to activities and commitments. You don't have to do everything.



I have more questions. Where can I go for help?

VA knows that being a Caregiver can be both rewarding and hard. You can always find more information at www.caregiver.va.gov, including contact information for the VA Caregiver Support Coordinator near you.

You can also call VA's Caregiver Support Line
toll-free at 1-855-260-3274.

The Caregiver Support Line is open
Monday through Friday, 8:00 am – 11:00 pm ET,
and Saturday, 10:30 am – 6:00 pm ET.

Call to talk to caring professionals who can:

- Tell you about assistance available from VA.
- Help you access services and benefits.
- Connect you with your local Caregiver Support Coordinator at a VA Medical Center near you.
- Just listen, if that's what you need right now.

Amyotrophic Lateral Sclerosis (ALS); Minneapolis VA Health Care System http://www.minneapolis.va.gov/services/scidc/scidc_als.asp

Amyotrophic Lateral Sclerosis (ALS); Fact Sheet: http://www.ninds.nih.gov/disorders/amyotrophiclateralsclerosis/detail_ALS.htm

ALS Association: www.alsa.org/als-care/resources/publications-videos/factsheets

ALS Association: Resource Guide to Living a Fuller Life with ALS