PATIENT HANDOUT

Lou Gehrig's disease



for Coping With ALS

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is characterized by a progressive degeneration of motor nerve cells in the brain and spinal cord. Although there is no cure for ALS, and researchers are not sure what causes this disease, learning as much as possible about the disease can improve the patient's quality of life.

Distinguish between the two. There are two types of ALS: familial and sporadic. Familial ALS is the inherited form of the disease. Sporadic ALS, the more common form of the disease, can affect anyone, anywhere.

Expect fatigue. ALS leads to muscle fatigue, which may manifest as general fatigue. Some people with ALS sleep for more hours than usual, and some people with ALS sleep for 12 or more hours per day. Try to prevent daytime naps from interfering with nighttime sleep.

Practice range-of-motion exercises and stretching. Exercise and stretch either alone or with the help of a family member or caregiver. This activity can help prevent or relieve muscle tightness and joint stiffening and assist with maintaining mobility. Also give attention to other parts of your body, such as your fingers, elbows, hips, wrists, ankles, and toes.

Take nonsteroidal anti-inflammatory drugs (NSAIDs). NSAIDs such as ibuprofen can help relieve inflammation. Steer clear of products that contain aspirin, unless directed by a doctor, because they can cause bleeding and ulcers. **Keep nutrition in mind.** Seeing a nutritionist is important for people with ALS, because they may lose weight. Having ALS increases the need for calories and food. Problems with swallowing also may make it difficult to eat.

Notice cognitive changes. Approximately half of all people with ALS will not exhibit cognitive or behavioral disruptions. The other half will show some signs of fronto-temporal dementia. In most cases, but not all, the signs will be subtle.

Knowledge is power. You should consider seeing a genetic counselor if you have a family history of ALS. Obtaining a proper diagnosis of ALS can be difficult because symptoms can vary from patient to patient.

Include your primary care physician. Have a primary care physician for care that does not involve ALS. Ask this doctor to consult with your ALS specialist when necessary. Regular medical checkups, pneumonia vaccinations, and flu shots are essential for preventing respiratory complications, which are the major cause of death in people with ALS.

This page is part of an ongoing series of practical tips for patients with neurologic disorders. If you have compiled clinically relevant tips that you wish to share, please contact the editor at info@neurologyreviews.com.

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