Amyotrophic Lateral Sclerosis (ALS)

Amyotrophic lateral sclerosis (ALS) is sometimes called Lou Gehrig's disease, after the famous baseball player who had ALS. ALS is a rapidly progressive neuromuscular disease. This results in muscle weakness. The weakness can affect muscles around the lungs. These muscles include the diaphragm and chest wall. This muscle weakness can lead to trouble with breathing. Symptoms include:

- A weak cough: This can lead to pneumonia and respiratory failure.
- Poor sleep: This can be associated with depression, fatigue and memory loss.
- Trouble with swallowing and increased build-up of saliva: This can lead to secretions going into the lungs. This is another risk for developing pneumonia.

The diagnosis of ALS is often very difficult for the person with ALS and family members. There are a variety of resources that can be helpful.

Our Team at National Jewish Health
Team members at National Jewish can help. You have been referred to National Jewish Health for the care of your lung issues related to ALS. Our team includes:

- Doctors (pulmonologists): Barry Make MD; Amen Sergew MD
- Dedicated nurse: Lindsey Grant LPN
- Respiratory therapist

What are Management Options?
These are management options that can help you care for your lung issues. If you have questions make sure to ask member of your team.

Secretion management
A variety of medications can help dry out your secretions. We may also recommend a suction machine.
This is similar to what is used in dental offices to suction out saliva. Your durable medical equipment company (DME) can provide this.

**Sleep Issues**
You doctor may recommend further testing to check your oxygen levels (desaturation) at night. Noninvasive ventilation can be helpful when used at night to provide support during sleep.

**Noninvasive ventilation**
These machines provide support for your breathing by using pressure through a mask. This increases air flow to the lungs. National Jewish Health uses the Trilogy® ventilator or BiPAP to assist breathing.

The Trilogy helps your muscles rest and normalizes the blood oxygen and carbon dioxide levels. Noninvasive ventilation is used at night during sleep and in the day with naps.
- The respiratory therapist at National Jewish Health will adjust (titrate) the pressure settings and find the best mask fit for you.
- Your DME Company will provide the ventilator and instruct you (and other caregivers) on the proper use of the ventilator. A company representative will visit regularly.
- Your pulmonologist will follow your progress and make adjustments or additions to your management plan as the disease progresses.

**Weak Cough**
A weak cough may be helped by a cough assist device. This helps improve the quality of your cough. Airway clearance devices can be helpful in mobilizing secretions. They can be used before the cough assist device. The Aerobika® is one airway clearance device. If these devices are recommended by your doctor, the respiratory therapist at National Jewish Health will show you how to use them.

**Muscle Weakness**
Low-impact aerobic exercise can help keep unaffected muscles strong, improve mental health and reduce fatigue. Stretching and range of motion exercises can improve spasticity and contractures. Physical therapists can provide exercises for you. Occupational therapists can suggest devices that can improve your mobility at home and elsewhere. Physical and occupational therapy are important to maintain as long as possible. This service is available through the University of Colorado. It can also be arranged at National Jewish Health or your local hospital.

**Follow-up**
Follow-up with our team at National Jewish Health is recommended every 2-3 months. This can be coordinated with your University appointments. Spirometry measures your lung function. It will be done at every visit (if you are able to do this). We follow the Forced Vital Capacity (FVC), which is a spirometry measure. This is a surrogate measure of your lung volume or lung capacity.
What are other Local and National Resources?

Local ALS Organizations

**ALS Association-Rocky Mountain Chapter**
Website: [www.alscolorado.org](http://www.alscolorado.org)
10855 Dover St., Ste. 500, Westminster, CO 80021
Office: 303.832.2322
Email: info@alsaco.org

**ALS-MDA Rocky Mountain**
Website: [www.alsn.mda.org/](http://www.alsn.mda.org/)
720 South Colorado Blvd., Ste. 380 South, Denver, CO 80246
Office: 303.691.3331 | Fax: 303.691.3379
Email: eNeal@mdausa.org Christina N. Papadimitropoulos or kknoblauch@mdausa.org Kristi Knoblauch

Resources available through local ALS Organizations listed above:
- Equipment Inventory/Loan closet with hospital beds, power chairs, speech devices and respiratory equipment. This is a free service and based on the needs and inventory.
- Connecting families to research updates and opportunities.
- Connecting families to one another as the best way to support each other and share local resources.

National ALS Organizations

**ALS Association**
1275 K Street, NW
Suite 250
Washington, DC 20005
advocacy@alsa-national.org
[www.alsa.org](http://www.alsa.org)
Tel: 202.407.8580
Fax: 202.289.6801

**Les Turner ALS Foundation**
5550 W. Touhy Avenue
Suite 302
Skokie, IL 60077-3254
info@lesturnerals.org
[www.lesturnerals.org](http://www.lesturnerals.org/)
Tel: 888.ALS.1107 or 847.679.3311
Fax: 847.679.9109

**Muscular Dystrophy Association**
222 S. Riverside Plaza
Suite 1500
Chicago, IL 60606
mda@mdausa.org
[www.mda.org](http://www.mda.org)
Tel: 800.572.1717
Fax: 520.529.5300

**Project ALS**
3960 Broadway
Suite 420
New York, NY 10032
info@projectals.org
[www.projectals.org](http://www.projectals.org)
Tel: 212.420.7382 or 800.603.0270
Fax: 212.420.7387
National Institute of Neurological Disorders and Stroke
BRAIN
P.O. Box 5801
Bethesda, MD 20824
www.ninds.nih.gov
Tel: 800.352.9424

Other Resources:
Steve Gleason, an NFL football player, and his friends and family started Team Gleason to generate public awareness for ALS, raise funding to empower those with ALS to live a rewarding life, and ultimately find a cure. www.teamgleason.

The boogie board is a product that may be helpful for a person with severe trouble talking. The boogie board is a pad that allows you to write with your fingertip or stylus and erase with the push of a button. www.myboogieboard.com

Note: This information is provided to you as an educational service of LUNG LINE®. It is not meant to be a substitute for consulting with your own physician. PTE.337
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