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 that 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 therapy

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

Resources available through local ALS Organization 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
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/
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
Tel: 800.572.1717
Fax: 520.529.5300

Project ALS
3960 Broadway
Suite 420
New York, NY 10032
info@projectals.org
www.projectals.org
Tel: 212.420.7382 or 800.603.0270
Fax: 212.420.7387

ALS Therapy Development Institute
300 Technology Square
Suite 400
Cambridge, MA 02139

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