

MEDfacts

An Educational Health Series From National Jewish Health®



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.

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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

Your 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

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/

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

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 

Tel: 202.407.8580

Fax: 202.289.6801

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

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

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

info@als.net

www.als.net 

Tel: 617.441.7200

Fax: 617.441.7299

Prize4Life

P.O. Box 5755

Berkeley, CA 94705

contact@prize4life.org

www.prize4life.org 

Tel: 617.545.4882

**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.com**.

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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