

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 progressive neuromuscular disease. This results in muscle weakness. The weakness can affect muscles around the lungs. These muscles include the diaphragm and muscles within the 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 buildup 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. We can take care of your medical issues related to ALS. Our team includes:

- Doctors: pulmonologists, neurologist
- ALS Nurse Coordinator
- ALS Navigator
- Palliative care specialists
- Respiratory Therapists
- ALS Care Coordinator
- Social workers
- Physical, occupational and speech therapists
- Nutritionist

What are Management Options?

These are management options that can help you care for you lung issues. If you have questions, make sure to ask a 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 (DME) company can provide this.

Oral hygiene is important to keep bacteria from building up in the mouth. Increased bacteria in the mouth can lead to pneumonia. We recommend an electric toothbrush. Also consider a toothbrush that can attach to a suction catheter if oral secretions are excessive. Also consider tongue scrapers/cleaners.

Noninvasive ventilation (NIV)

The earliest manifestation of diaphragm (the muscle that helps us breath in) weakness occurs during sleep. Your doctor may recommend further testing to check your oxygen levels (desaturation) at night. Noninvasive ventilation (NIV) (which can also be called Positive Airway Pressure (PAP)) can be helpful when used at night to provide support during sleep. These machines provide support for your breathing by using pressure through a mask and pushing air into your lungs. NIV prolongs life when used by ALS patients by normalizing the blood oxygen and carbon dioxide levels. NIV is used at night during sleep and in the day with naps or when you are

fatigued or sleepy.

- The respiratory therapist at National Jewish Health will adjust 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.
- Bring this machine and your mask to follow up appointments so that your pulmonologist and respiratory therapist can make adjustments.

There are three general types of masks used with ventilators:

- Full-face mask covers your nose and mouth.
- Nasal mask is a smaller version of the full-face mask and only covers the area around the nose.
- Nasal pillow has soft silicon 'pillows' snug up to your nostrils. As with the nose mask, this mask allows speaking and, usually, wearing glasses.

Breath Stacking

Breath stacking is the process of opening up the collapsed portion of your lungs and can help prevent infection. It can be done using an Ambu bag or with a cough assist machine. The Ambu bag is often used early on in the disease process and is more portable. Later in the disease patients can develop a weak cough may be helped by a cough assist device. This helps improve the quality of your cough and helps prevent infections. A DME company will provide your cough assist machine and will show you how to use it. Bring this machine and your mask to follow up appointments so that your pulmonologist and respiratory therapist can make adjustments.

Follow-up

Follow-up with our team at National Jewish Health is recommended every 2-3 months. This can be coordinated with your other appointments. Call the ALS Team directly if you have trouble getting appointments. Spirometry measures your lung function. It will be done at every visit (if you are able to do this). We also follow the Forced Vital Capacity (FVC), which is a measure of the amount of air you can blow out.

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

Resources available through ALS Association:

- 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](http://www.alsa.org)

1275 K Street, NW

Suite 250

Washington, DC 20005

advocacy@alsa-national.org

www.alsa.org

Tel: 202.407.8580

Fax: 202.289.6801

[ALS Therapy Development Institute](http://www.als.net)

300 Technology Square

Suite 400

Cambridge, MA 02139

info@als.net

www.als.net

Tel: 617.441.7200

Fax: 617.441.7299

[Les Turner ALS Foundation](http://www.lesturnerals.org/)

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](http://www.projectals.org)

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

National Institute of Neurological Disorders & Stroke BRAIN

P.O. Box 5801

Bethesda, MD 20824

www.ninds.nih.gov

Tel: 800.352.9424

Other Resources Provided by ALS Patients:

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.org.

Visit our website for more information about support groups, clinical trials and lifestyle information.

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NOTE: This information is provided to you as an educational service of National Jewish Health. It is not meant to be a substitute for consulting with your own physician.

National Jewish Health is the leading respiratory hospital in the nation. Founded 123 years ago as a nonprofit hospital, National Jewish Health today is the only facility in the world dedicated exclusively to groundbreaking medical research and treatment of patients with respiratory, cardiac, immune and related disorders. Patients and families come to National Jewish Health from around the world to receive cutting-edge, comprehensive, coordinated care. To learn more, visit njhealth.org.