



About ALS

ALS (amyotrophic lateral sclerosis) is a progressive neurodegenerative disease that attacks motor neurons, weakens voluntary muscles throughout the body, and leads to paralysis. ALS is also known as Lou Gehrig's disease and motor neuron disease (MND). ALS is fatal, and there is no cure. Approved drugs only slow progression modestly. An estimated 30,000 people in the U.S. have ALS at any one time.

ALS progresses differently for each person. Average life expectancy is roughly 3-5 years, though 10% of people with ALS live ten years or longer. There are also different types of ALS, which can affect the prognosis.

Initial symptoms vary from person to person. Weakness in a muscle without any pain is a common early sign. ALS often begins in one limb. Daily activities like walking or buttoning a shirt may gradually become more difficult. For some, ALS begins by affecting the muscles that control speaking and swallowing. Regardless of how ALS begins, it will spread and continue to weaken muscles throughout the body.

ALS and Physical Therapy

Developing an exercise program for a person living with ALS is different. Pushing your client too hard can be detrimental. The "no pain, no gain" approach does not apply. Your client will not get stronger. The goal is to maintain current levels of strength, fitness, and flexibility as much as possible to help extend independence. Your client should not experience fatigue, pain, soreness, or discomfort. Recovery should be quick.

Safety and fall prevention should be a top priority. Weight loss can also be a concern. Your client should not burn more calories than they can consume. If your client has respiratory issues or is having shortness of breath, be conservative with aerobic exercise so you don't overly stress their respiratory muscles.

ALS is different for each person. Be sure to ask questions about your client's current symptoms, respiratory and nutritional status, and energy level. Check in at the start of every visit to see what may have changed. It can be helpful to share tips and ways your client can conserve energy when doing activities of daily living.

Learn More

Your client may attend an ALS clinic with a PT experienced in ALS. Your client may also have support from a local ALS nonprofit that provides support, lends medical equipment, and more. You can always ask your client to connect you with their ALS PT or care team if you have questions or want to be in touch. You can learn more about exercise and ALS by visiting www.youralsguide.com/exercise-and-als or scanning the QR code above. Thank you!

Exercise Guidelines for Neuromuscular Conditions

Exercise can be beneficial for persons with neuromuscular conditions, including ALS. Studies have shown that exercise has the potential to improve muscle and joint flexibility, boost the ability to perform daily tasks, and enhance quality of life. Below are guidelines to consider for each category of exercise to ensure that your body is not working too hard.

Stretching

(often referred to as "Range of Motion/ROM")

- A gentle stretching program performed daily can keep the body limber and flexible.
- Muscles and joints can become tight without regular gentle stretching.
- Shoulders, fingers, hips and ankles are particularly vulnerable to tightness.
- Stretching while reclined (bed, recliner) may make stretching easier by providing extra support.

Cardio/ Aerobic

- These are the exercises that provide a work-out for the heart, lungs, and circulatory system.
- Aerobic activities can include walking, stationary bicycle, and pool therapy as a few examples.
- You want to choose an activity that you can do safely without overexerting yourself.
- You should monitor your breathing to make sure you are not getting too short of breath.

Resistance

- Light resistance training may help muscles stay as strong as possible.
- Focus resistance exercises on muscles that are strong. Weak muscles may become over fatigued.
- Resistance exercises can be done with bodyweight, theraband, theratubing, or light weights.
- Yoga incorporates body weight training, it also focuses on core/abdominal activation and breathing.

Balance

- Balance exercises can be done in sitting or standing.
- Sitting balance activities can help you with daily activities (e.g. getting dressed, sitting in a chair).
- Standing balance exercises/training may be helpful for transfers and/or walking.
- Balance exercises are safest when initiated with supervision/guidance from a physical therapist

Things to consider when exercising (or with daily activities):

- With all activities and exercise, avoid a sense of overexertion, muscle soreness, shortness of breath, or excessive fatigue.
- You want to feel that you have recovered from the activity within 30-60 minutes. If you are still tired or sore for several hours or into the next day, that level of activity was probably too strenuous for your body. Let yourself recover and do less next time. You should feel refreshed after exercise. Sometimes people find their daily activities are their "exercise routine."
- Listen to your body to sense how you are responding to the activities, if you find it is too much you can adjust your exercise routine. This can mean fewer sets, repetitions, exercises, lowering the weight if you are doing resistance, taking more rest breaks, or any other modification to make it easier.
- If your breathing and/or nutritional status are impacted, work with your healthcare team to discuss what amount of exercise and activity is best for you. It's important not to burn more calories than you are taking in, and not to overly stress your breathing muscles.

Working with a physical therapist (PT) and/or occupational therapist (OT) in an outpatient clinic or in your home can be very helpful in developing an appropriate exercise routine for you based on your abilities, energy level, muscle function, and personal preferences. They can help you create a home exercise program and update/modify as needed.

Fatigue Management: Resting (taking breaks, naps) to allow the body time to recover and recharge from exercise can be just as important as the exercise itself. Spreading tasks out over the course of a day or week helps conserve energy so that you have it when you need it.

This page was developed by the Sean M. Healey & AMG Center for ALS at Massachusetts General Hospital.