

Chapter 8

Exercise



WHY IS EXERCISE IMPORTANT?

Exercise can provide a variety of benefits for people with ALS; for some it can have a significant impact on their quality of life.

Particularly in the earlier stages of ALS, many people have found both physiological and psychological boosts from various types of exercise. Along with helping to combat stress, providing a brief escape and being a welcome way to relax, proper exercise is important for preventing atrophy of muscles

from disuse — a key to remaining mobile for as long as possible — and, as long as you're able to exercise comfortably, for keeping your cardiovascular system strong. The key to gaining these benefits is finding the most appropriate exercise for you.

SPECIAL NOTE: It's most important that you discuss any type of planned exercise with your health care team, particularly your doctor and your physical therapist. Exercising under their supervision will ensure that you don't push weakened muscles to the point of doing further damage, or create a dangerous level of fatigue.

While the medical literature has firmly established the importance of exercise for people without serious medical conditions, very little research has been done on the subject of exercise and its role in ALS. In fact, it isn't known whether exercises are beneficial for increasing muscle strength for people with ALS. (Many experts doubt that this is possible.)

However, it's widely accepted among physicians and therapists that specific kinds of exercise help prevent the development of painful *contractures* (the permanent tightening of muscles) and can decrease the *spasticity* (intermittent or constant muscle tightness or spasms) that's common in ALS.

Practicing the healthiest type of exercise for you at each stage of ALS will help maintain your comfort and mobility. For some people, a moderate amount of daily walking in the early stages of ALS may be all that's advisable. As the disease advances, you'll benefit from doing range-of-motion and stretching under supervision of a physical therapist.

THE ROLE OF THE PHYSICAL THERAPIST

As explained in Chapter 4, a physical therapist is a gross motor movement specialist — someone trained to help you perform activities that use major muscle groups, such as walking, rising from a chair, and getting in and out of bed. Physical therapists also are involved in prescribing appropriate exercise programs, with the



goal of keeping you safely functioning at as high a level as possible for as long as possible.

It's essential that you work with a PT who's experienced with ALS. A qualified PT can guide your exercise regime so that it's appropriate for you during every stage of the disease.

EXERCISE PRECAUTIONS

When living with ALS, you should never push yourself past the point of fatigue, or attempt to strengthen already weakened muscles. It isn't clear whether muscles already weak from ALS can be strengthened, but PTs know that weak muscles can be further damaged when pushed too hard.

Again, don't initiate an exercise program, especially one that includes cardiovascular conditioning, without clearance from a physician.

Excessive exercise to the point of fatigue may result in muscular weakness — short-term or permanent. Generally, keep in mind that if you feel worse after an exercise activity, then you've done too much.



Discontinue the activity if you experience any of the following signs of fatigue during exercise:

- shortness of breath
- excessive cramping
- unusually heavy sweating

To decrease the risk of harm, you should *avoid*:

- exercising with heavy weights
- exercising in extreme temperatures
- exercising when fatigued or ill
- moving a limb past the point of pain or significant resistance

Remember to exercise for enjoyment; if exercise causes pain, then stop. Also, if you find you're sore after exercising, or sore the next day, lower the intensity, the duration or both.



STAYING ACTIVE

Exercise programs for people with ALS should be multipronged and contain these components:

- range-of-motion (ROM) exercises
- stretching
- cardiovascular conditioning (only if specifically recommended by your doctor)
- strengthening (only if recommended by your doctor)

Research points toward moderate-intensity, low-resistance exercise as being most beneficial in preserving function in people with ALS. By remaining active with such a program, you'll keep yourself in the best condition possible for the activities of your everyday life.

STRETCHING & RANGE-OF-MOTION EXERCISES

Any area of weakness in your muscles is prone to tightness or contracture, and muscular tightness can interfere with regular activities and the movement of joints in the neck, hips, arms and legs. Both joint structures and other soft tissues (muscles, tendons and ligaments) become tight with lack of motion. Stretching increases



joint mobility and improves or helps to maintain soft tissue extensibility.

All joints in the body need to be stretched. Normal daily activity uses all of the major muscles and joints, but some supplemental stretching may be necessary. If there's an area of weakness, such as your arms, legs or neck, you'll need additional stretching there to maintain joint integrity and prevent pain.

You should perform all of the stretching and range-of-motion movements on your own if you can, or with assistance of a physical therapy professional where needed. Your PT can train your caregiver in performing these stretches. It's very important that you continue to move or have your limbs moved every day even if you're too weak to do it on your own. When a caregiver is assisting you with the activities, continue to participate as fully as you can.

See Chapter 9 for a full description and illustrations of range-of-motion exercises.

Special Concerns

In ALS, the shoulders are particularly prone to becoming "frozen," a painful condition called *adhesive capsulitis*. For



more on stretching techniques for this area, see “Spotlight on Shoulders,” page 107, and exercises described on pages 115, 118 and 121.

CARDIOVASCULAR CONDITIONING

Cardiovascular or aerobic exercise is any activity that elevates your heart and respiration (breathing) rates. Some typical activities include walking, swimming, bicycling and aerobic-type fitness classes. Again, only undertake this type of exercise if, and for as long as, your health care team agrees it’s safe for you to do so. Any component of aerobic exercise may need to be modified or reduced over time as ALS advances.

When doing these activities, keep in mind the FIT guideline: frequency, intensity and time; in other words, how often, how hard and how long you should perform them. Moderate-intensity, low-

impact performance may be best for those with ALS.

Warming up slowly (for 5 or 10 minutes) and doing light stretches before you exercise, and cooling down slowly afterward, can help prevent injuries. Staying hydrated is also important; drink plenty of water, being sure to take sips before you feel thirsty.

If you exercised regularly before you received an ALS diagnosis, it’s wise to modify your exercise routine to a level that’s still beneficial but doesn’t promote soreness or fatigue. If you didn’t exercise before ALS, it’s now OK to try some new activities, but be sure to first talk this over with your doctor or physical therapist.

Walking

Walking is an excellent exercise. The speed, duration and terrain may be easily varied to suit your ability and strength. Walking is convenient and you can do it in the city, the suburbs or the country. Even small amounts — as little



as 5 minutes — of walking can be beneficial to your quality of life.

When you walk, go at a steady, comfortable, safe pace with your arms swinging, if possible. This will maximize the cardiovascular benefit.

You also can perform walking activities on a treadmill or an elliptical training machine. Use exercise machines with caution, and be sure to seek training from appropriate experts for how to control and stop these machines. Again, your doctor or physical therapist can help you determine an appropriate duration for walking, and how to monitor the intensity of this type of exercise.

Water-Based Exercise

Water-based activity as a low-impact form of exercise can be very helpful. The buoyancy of water and resistance to movement decreases the risk of injury to joints, muscles and tendons while allowing the benefits of exercise.

Exercise in the water is beneficial



to both swimmers and nonswimmers. Simple water exercise — even as basic as walking around in the pool — or swimming laps, if you have experience, can provide aerobic conditioning.

Spending time in the water can be extremely relaxing, but that in itself can increase the muscle weakness of ALS. If you reach the “wet noodle” stage, you may have difficulty getting out of the pool. For safety’s sake, a pool with supervision and a lift are recommended.

In later stages of ALS, doing aquatic exercises with the help of a PT can continue to provide cardiovascular benefits.

See “In the Water,” page 105, and Chapter 9 for some specific aquatic exercises.

Bicycling

Both stationary and regular bicycling can be good for people with ALS, although *stationary biking* has certain advantages. You can do indoor biking in a climate-controlled environment where you can monitor your fatigue and take rest breaks with greater ease.

If you were an experienced cyclist before ALS and you choose to continue to ride a bike outdoors, use special caution, as balance and endurance could each become unexpected problems while you're out on the road. Avoid hills and uneven areas, and use moderation in bicycling so that you never ride to the point of fatigue.

If you decide to ride a stationary bicycle with adjustable resistance, contact your physician or PT for intensity and duration recommendations.

Along with stationary bikes, other types of equipment can enable you to bicycle indoors. With a *wind trainer*, you can attach an ordinary bicycle to a stand and ride in one place, with your tires rolling against an adjustable wheel.

Exercise cycles, which are pedaling machines that you can use on any flat surface, are another option for people



who aren't able to mount a traditional bicycle. Some of these cycles feature a passive/active component: An electronic motor assists in moving the user's legs or arms and shoulders through the exercise



Spotlight on Massage Therapy

massage therapy can be beneficial, especially if you have joint stiffness or muscular tightness. Many people with ALS report that receiving regular massages assists them with relaxation and comfort.

Gentle massage methods, as opposed to techniques that mobilize deep tissues, are recommended for people with ALS. Always use a licensed massage therapist and notify him or her of your condition before treatment.

motion, even when the user is entirely passive.

Restorators are another rehab tool that can simulate the motions of pedaling. This pedaling mechanism is mounted on an adjustable stand so it can be placed in front of a chair, and can be used for arm or leg exercises. Many restorators have adjustable tension.

Arm *ergometry* (cycling with the arms) is a low-impact aerobic alternative to traditional bicycling. This type of cardiovascular exercise really challenges the heart, so be sure to do it with supervision and a doctor's clearance.

EXERCISE EQUIPMENT

In the past, the swimming pool, the treadmill and the stationary bicycle exhausted the possibilities of exercise equipment useful to those with ALS. Although exercises derived from the motions associated with swimming, walking and riding remain the most productive, the ways to carry out those exercises have expanded. A wide range of equipment is now available, from the simplest aid in aquatic workouts to sophisticated machines that assist with both active and passive exercise.

A version of some or even all of the following equipment may be of use to you:

In the Water

Aqua Step:

A small platform submerged in water lets you step up and down.

Flotation Belt:

Usually made of foam and worn around the waist, these belts provide enough buoyancy for walking or jogging in deep water.

Foam Barbells:

Foam “weights” are attached to a padded handle. They can be used at the surface for stability or flotation, or under water for resistance exercises.

Kickboard:

When your body is prone, this floating board provides upper body support so you can kick and exercise your legs exclusively.

Noodle:

These popular water toys — long foam tubes — can also be used for stretching and resistance exercise.

At Home or in the Gym

Active-Only Exercise Cycles:

The user can assist the motor with his or her own muscle strength to help push pedals.



Active-Passive Exercise Cycles:

With this exercise device, the electric motor senses when a user tires and the machine compensates for reduced effort. Using it can help prevent atrophy of muscles and can help keep joints loose and tendons stretched.

Passive-Only Exercise Cycles:

The legs are rotated by the electric motor in an orbital motion similar to that used in cycling.

STRENGTH TRAINING

Even leading experts are undecided about the advisability of strength training (weight lifting) for people with ALS. In his book, *Amyotrophic Lateral Sclerosis*, Hiroshi Mitsumoto, director of the Eleanor and Lou Gehrig MDA/ALS Center at Columbia University Medical Center in New York, writes that it's not known whether muscles affected by ALS can be improved through strengthening exercises.

Lifting heavy weights may lead to overuse, fatigue, or temporary or permanent loss of the use of the muscle. Yet decreased muscle activity can lead, through disuse, to weakness and atrophy greater than that caused by ALS itself.

SPECIAL NOTE: Any strength training/weight lifting should be performed using only very light weights. It should be prescribed for unaffected muscles, and be done under the guidance of a physical therapist or physician.

ALTERNATIVE EXERCISES

Over the years, other types of exercises also have come into vogue that may be beneficial for those with ALS. Yoga, Pilates and tai chi are all low-impact activities that involve movement of the entire body and often include a mental component that can be meditative or stress relieving.

But remember that low-impact doesn't mean low-intensity. Use caution to avoid fatigue and injury, and if you're in a class, make the instructor aware of your medical condition before starting.

As with any exercise program, modification may be necessary over time. Please continue to update your health care team on what exercise regimen you're involved in so they can make adjustments as needed to assist in maintaining your mobility and safety.



Spotlight on Shoulders

Weakness of the muscles around the shoulders makes this area particularly susceptible to joint tightness and pain. The shoulder joint depends upon its muscles to keep it intact.

When ALS makes shoulder muscles weak, you're at risk for a condition called *frozen shoulder*, in which the shoulder joint capsule "freezes up" from immobility. It's characterized by severe stiffness in the shoulder joint, especially in the motions of shoulder flexion (flexing) and external (outward) rotation. You may also experience pain with movement, pain with activities of daily living such as dressing and bathing, and difficulty sleeping at night.

Active or passive range-of-motion exercises should be performed to prevent the development of frozen shoulders. See pages 115, 118 and 121.

It's very important that you notify your health care team if you have these symptoms. Frozen shoulder is a treatable condition. With appropriate exercises and treatment, you and your team can restore passive range-of-motion to the joint and reduce the pain.

