



# ALS

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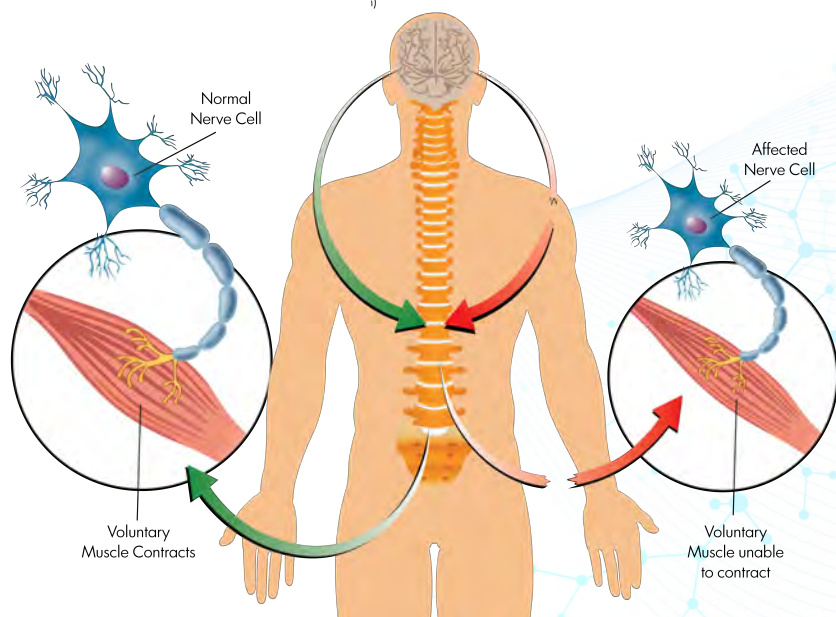
## **Role of Physical & Occupational Therapy**

# WHAT IS ALS?

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease that results in weakness of voluntary muscles that move your body, which may include muscles involved in speech, swallowing, and breathing.

This weakness is caused by damage to the motor neurons. Motor neurons are the nerves that tell the muscles what to do. There are upper and lower motor neurons. Upper motor neurons (UMN) are nerve cells that extend from the brain to the spinal cord. Lower motor neurons (LMN) extend from the spinal cord to the muscles in the body.

Individuals with more UMN damage will experience spasticity (muscle stiffness) and slowness of movement. While those with more LMN damage will present with weakness, atrophy (muscle wasting), and fasciculations (muscle twitching).



# TREATMENT?

Although there is currently no cure, there are helpful treatments for many of the symptoms people with ALS experience. A multidisciplinary/interdisciplinary team can help to optimize treatment throughout disease progression. There is ongoing research aimed at symptom management, slowing disease progression, and finding a cure.

## ROLE OF PHYSICAL AND OCCUPATIONAL THERAPY

Physical therapists (PTs) are movement specialists. Their goal is to work with you to optimize function and participation in activities that are important to you. Occupational therapists (OTs) are specialists who work with you to help optimize your ability to participate in daily activities, including, but not limited to, bathing, dressing, cooking, eating, cleaning, working, and participating in recreational activities.



# WHAT TO EXPECT AT PT AND OT VISITS

The PT/OT will do an evaluation and create goals and a treatment plan. This may include, but is not limited to the following:

- Education
- Stretching/range of motion
- Functional exercises
- Recommendations for equipment and adaptive devices
- Aerobic conditioning
- Gait/mobility training
- Transfer training
- Fall prevention
- Activity modification and energy conservation strategies
- Positioning tips
- Driving assessments
- Recommendations for orthoses (braces and splints)
- Wheelchair and seating recommendations
- Assistive technology

*\*For some of these you may require a referral to a specialty clinic.*



# TIPS FOR MOBILITY AND ACTIVITIES OF DAILY LIVING

## BED MOBILITY

There are ways to modify your regular bed to help make it easier to move around or to improve comfort in bed.

These include, but are not limited to:

- Bed rails
- Wedge pillows
- Body pillows
- Additional pillows
- Blanket cradles

There are also ways to reduce friction in bed, to allow you to move more freely. Ideas include silk or satin pajamas or sheets. Leg lifters can also be a helpful tool to reposition your legs, or to lift them into bed.

If you are not able to get comfortable or move in bed, there are other options you can discuss with your PT or OT, such as adjustable beds, hospital beds, and mattress overlays. Caregivers may find a transfer sheet useful to help with repositioning.

There are also different techniques that your PT or OT can demonstrate that may make it easier for you to get into or out of bed, or for someone to help you with bed mobility. If you are having difficulty with this please talk with your PT or OT.



# TRANSFERS

It can be challenging to stand up, to transfer from one chair to another, to get on and off the toilet, and to get into and out of the car. Your PT and OT can work with you to develop strategies to improve these transfers for you.

Some common tips include:

- Avoid low surfaces
- Raise furniture heights with furniture risers
- If you can, use armrests to push off
- Widen your stance by putting your feet more than hip width apart
- Lean forward to get your nose over your toes

If someone is helping you:

- Use a gait/transfer belt
- Have the person helping you stand in front and slightly to one side of you
- The person helping you should be close to you, but not so close you don't have room to stand



## EQUIPMENT SOME PEOPLE AND CAREGIVERS FIND HELPFUL INCLUDE:

- Gait/Transfer belt
- Pivot discs
- Transfer boards
- Sit to stand aids
- Seat elevators
- Lift chairs
- Mechanical lifts with slings



\*Your PT or OT should help determine which devices are safe for you and can educate you on what may be covered by insurance.

There are many different safe transfer techniques and not one that will work for everyone. Your PT and OT can work with you and your caregivers to determine which transfer techniques are safe for you.

# AMBULATION

If you are having difficulty walking, your PT can recommend different assistive devices that may help.

There are also bracing options discussed in the “Bracing” section that may improve safety.

Assistive devices for ambulation include:

- Cane
- Walking stick
- Walkers
  - Rolling walkers with two wheels in front
  - Rollator walkers with four wheels, brakes, and a seat
  - Platform walkers with elevated platforms for arms to rest on
- Forearm crutches



## ALTERNATIVES TO WALKING

If it is not safe for you to be walking, or if it is becoming too fatiguing to walk everywhere, there are options to allow you to continue to get around or out of your house.

Options include:

- Transport Wheelchairs
- Manual Wheelchairs
- Electric/Power Wheelchairs

There are strict insurance requirements for wheelchairs and it is important to discuss options with your PT and OT before ordering a wheelchair through insurance. Your PT and OT can also help determine which wheelchairs are appropriate to meet your needs, and where best to get them. Some may only be available for purchase, others through an equipment loan closet, and others through insurance.

Insurance typically pays for only one wheelchair in a five year time period. For the custom power or manual wheelchairs, changes and adaptations can be made to meet most evolving needs with disease progression.



## HOME MODIFICATIONS

Home modifications can make getting around your house much easier for you and your family.

Some modifications are temporary, while some may be more permanent. Some may also be inexpensive while others are more expensive. Discuss options with your rehabilitation team and family to help you prioritize what may be most beneficial given your personal situation.

Some of the more common modifications include:

- Widen doorways
  - Offset hinges
  - Barn doors
- Use a half-step to decrease demand required to step up onto a larger step
- Ramps
  - Threshold ramps
  - Portable loading wheelchair ramp
  - Wood or metal semi-permanent ramp to access home
- Stairlift
- Elevator
- Ceiling lifts

## BATHROOM EQUIPMENT

We spend a lot of time in the bathroom, so it is important to create a safe space for completing grooming and daily hygiene.

Showering: There are many ways you can improve safety while bathing.

Some of the more common modifications or pieces of equipment include:

- Shower chairs
- Non-slip mats
- Handheld shower heads
- Grab bars (helpful around shower and/or toilet)
- Zero entry showers

Toileting: Toilets can be very difficult to stand up from.

Ways to modify your toilet to make it easier include:

- Get an ADA compliant toilet (they are higher off the ground)
- Raise your toilet up with a riser or platform under the toilet
- A freestanding commode seat or toilet riser can be added for increased height and handles
- Install a bidet on your toilet to help with hygiene (cannot be used with bedside commode or raised toilet seat options)



# AIDS FOR ACTIVITIES OF DAILY LIVING

There are many different pieces of adaptive equipment that may help with your activities of daily living.

Your PT and OT can help determine which may work best for you. Below are some of the more popular items.

## Eating

- Foam for utensils to improve grip
- Adaptive utensils
- Non-slip surfaces to keep dishes from sliding
- Adaptive dishes and cups
- Universal cuff

## Dressing

- Button aids
- Zipper pulls
- Alternative shoelaces
- Adaptive clothing (i.e. with Velcro® or magnets)

## Hygiene

- Adaptive or electric toothbrushes
- Long handle sponges
- Handheld shower heads

## Grooming

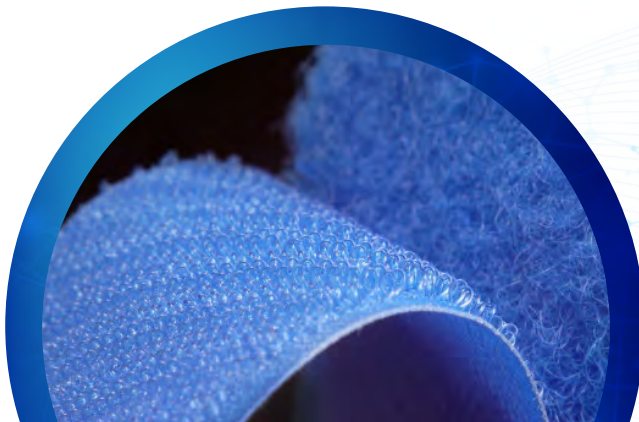
- Electric razors
- Hair dryer holders

## Writing

- Adaptive pens
- Foam for pens to widen grip



*Note: This is a VERY small sampling of the potential items available, so discuss any changes in function with your PT and OT. There are also options for assistive technology that may be available to help with daily activities. It is important to discuss this with your PT and OT, and may require referral to a specialty clinic with therapists who specialize in assistive technology.*



*Please note: Insurance may not cover many of the equipment items listed above. PT and OT can help determine what may or may not be covered.*

# BRACING

For some individuals, bracing may be beneficial to improve positioning, comfort, and/or function. PTs and OTs can work with you and an orthotist to determine which may be most appropriate to meet your needs.

Some of the more commonly used braces include:

- Neck braces
- Back braces
- Ankle braces (ankle foot orthoses)
- Resting foot/ankle splints
- Shoulder supports
- Hand/Wrist orthoses



## PAIN MANAGEMENT

ALS does not cause pain directly, but pain can be a common secondary impairment due to decreased movement or increased stiffness. If you are experiencing any pain, please speak with your PT or OT and they may recommend some of the following to help manage the pain.

- Stretching
- Proper positioning
- Pressure relief
- Bracing/Taping
- Frequent position changes
- Appropriate cushions
- Heat or ice
- TENS machine (PT/OT can help with setup)
- Talk with your doctor about medications



# SHOULD I EXERCISE?

Appropriate exercise is very beneficial for the following reasons:

- To prevent joint stiffness and pain by maintaining joint mobility and allowing for easier performance with self-care tasks
- To keep unaffected muscles healthy and strong (healthy muscles can better support the weak muscles)
- To maintain cardiopulmonary fitness as much as possible
- To possibly delay muscle atrophy (decrease in muscle size due to the disease)
- To assist with edema management

Beneficial types of exercise (within individual activity tolerance):

- Stretching
- Active movement/range of motion exercises
- Passive and assisted movements (movements in which another person helps you or moves the limb for you)
- Low impact activity, such as stationary bicycle, pool exercises, walking
- Resistance exercises as recommended by your therapy team
- Balance exercises (including yoga and Tai Chi)

## Do's and Don'ts for exercise:

- Do take short rest periods throughout the day and space activities out to conserve energy
- Do save energy for necessary daily activities
- Do exercise so that if you rest for 30-60 minutes you feel fully recovered
- Don't perform exercise to the point of severe fatigue
- Don't "feel the burn" or push yourself until you are sore after exercise or the next day

Note: You should not feel pain, sore muscles, or exhaustion from any exercise performed the day before. If you do, you are exercising too hard. An exercise program should not interfere with ability to complete daily tasks. A good rule of thumb is if you rest for 30 minutes to 1 hour after exercise, you should feel like you could do the exercise again (back to baseline level of energy).

Your PT and OT can help you develop an exercise program that is individualized to meet your needs. This program will be based on your baseline level of activity as well as your current level of activity. It may be impacted by nutrition and respiratory status, and should be updated throughout the disease course.



# FALL PREVENTION

Falls can result in minor bumps and bruises, but can also result in more serious injuries, such as head injuries and broken bones. In the case of falling, prevention is the best treatment. Although there is no way to prevent all falls, there are a number of tips to help reduce your risk of falling.

**Lighting** It is much easier to avoid falling if you can use your vision to help with balance.

- Maintain adequate lighting (especially at night)
- Use night lights in bedrooms, hallways, and bathrooms

## **Floors:**

- Remove scatter rugs whenever possible
- Any rugs that are not secured on the edges should be taped or tacked down securely
- Tape down electrical, extension, and telephone cords that run across the floor with easily visible tape
- Minimize clutter in walking paths
- Remove thresholds wherever possible, or if removal is not feasible, clearly mark thresholds with brightly colored strips of tape
- Avoid polishes that make floors slick

## **Bathrooms :**

- Install grab bars (NOT TOWEL RACKS) in and outside of the tub and around the toilet
- Make sure grab bars are attached to the studs in the wall
- Use a non-skid mat in the shower stall
- Use a shower chair or bath bench in the shower
- Convert the shower to a hand-held shower head
- Avoid slippery floors by placing a non-skid bathmat outside of the tub

## **Communication:**

- Use a portable telephone or cell phone and keep it on you at all times (either in a belt clip or your pocket)
- If you live alone or are alone for long periods, consider an emergency system (Lifeline or similar response system)
- Some smart watches can be set up to detect a fall and call for assistance

## **Stairs:**

- Install or firmly secure existing railings on both sides of stairwells
- Place contrasting (bright colored) strips of tape along the edge of each stair to help you see it better
- Firmly secure any rugs that run on stairwells
- Keep the stairs free of clutter

## **General:**

- Wear supportive, wide-based, rubber-soled shoes that lace or close with Velcro®
- Avoid walking barefoot or in socks
- Use slippers with non-skid rubber soles when walking in the house or at night
- If you use an assistive device (cane, walker), make sure it is in easy reach of wherever you are, especially when you are in bed
- Try to keep items you use often in easy reach and near waist level (in the kitchen and bathroom cabinets, on shelves, etc.)
- Avoid reaching or bending whenever possible, even if it means rearranging things a little

If you follow the steps above and are careful about where and how you walk, you may be able to prevent yourself from getting into situations that may cause you to fall. If a slip or fall does occur, try to determine what caused it and whether there is an environmental change you can make to prevent it from happening again. If you find yourself tripping over your feet or consistently having difficulty with walking and balance, you may need an assistive device or brace to increase your stability. You may also benefit from seeing a PT to work on balance training. Be sure to discuss this with your PT or OT.

# HOME MANAGEMENT

Your PT and OT can also offer tips and equipment recommendations to help with activities related to home management. Included here are suggestions for some tasks. Be sure to talk with your PT and OT if you are having difficulty with these or other household tasks.

## Laundry

- Rolling carts
- Dressing sticks
- Pods versus heavy detergent jugs

## Pet Care

- Non-pulling harnesses
- Attach the leash to a wheelchair if you cannot hold it (or to your waist if your balance is okay)
- Reacher to pick up bowls from floor
- Use PVC pipe or wrapping paper tube to pour dry food from waist level into bowl
- Automatic water/feeders
- Brushes with larger handles and Velcro® loops to keep in your hand

## Cleaning

- Long handled dustpan, lightweight broom
- Lightweight vacuums, Roomba®
- Swiffer® versus mop
- Paper/plasticware to avoid loading/emptying dishwasher
- Long handled scrubbers for toilet/shower/tub
- Cleaning products that require less scrubbing
- UV light cleaner for BiPAP/Trilogy tubing, wipes for mask

## Medication Management

- Day/week/month pillboxes
- Automatic pill dispensers
- Ask pharmacist for "EZ-open" tops (NOT childproof)
- Put pills in applesauce, yogurt, pudding for easier swallowing (consult with SLP)



# LEISURE

Your PT and OT want to help you do the activities that are important to you for as long as possible. It is important to talk with your therapists about what activities are important to you.

## Gardening

- Garden kneeler with handles
- Adapted tools (lighter, longer, special grips)
- Use larger pots or raised beds
- Soaker hose

## Fishing

- Automatic casters and reels
- Holders for walkers and wheelchair
- Fish from pier if the boat is too challenging
- Needle nose pliers in each hand for tying flies

## Golfing

- Adapted clubs
- Golf gloves for increased grip (can add Velcro® to fingers and wrist to keep tighter grip)
- Modify the seat on the golf cart
- Drive up onto the green
- Teach others to golf and you can keep score and socialize
- Host a party to watch Masters (or other sporting events you enjoy watching)



## Reading

- Use clipboard to help secure pages you have completed
- Use rubber bands or chip clips around pages remaining (leave out a few at a time as you read)
- Use a finger cot (rubber) to turn pages
- eReader, tablets, computers
- Read newspapers online or tape a string down the inside middle to secure to a table
- Many holders/easels on the market



## Knitting/Crochet

- Larger needles, foam over needle
- Loop Velcro® around finger to keep tension on yarn
- Clamp on/suction cup clamp to hold one needle when one side is weak

**Adaptive Sports:** Programs exist in many areas for adaptive sports (tennis, golf, sailing, court sports, skiing)

**Accessible Travel:** There are resources for accessible travel (domestic and international). Please be sure to discuss this with your PT and OT if you would like to travel.

***Find something that gives you quality of life! Volunteer, help others, and consider alternative ways to enjoy the things that you like to do.***

***Special thanks to the NEALS PT/OT Committee members who worked to develop and write this guide.***

**NEALS**

Northeast Amyotrophic  
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Consortium

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## ALS: A GUIDE TO PT AND OT

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