



# ALS & MOBILITY

A Les Turner ALS Foundation Guide for People Living with ALS

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

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# How ALS affects mobility

We created this guide to help you navigate changes that may occur due to ALS. In this guide you will find information on durable medical equipment (DME).

This equipment will allow you to get around your home and out in the community. This guide is just a general place to start. If you have any questions, please contact your ALS care team.

## Aids for walking



### Straight cane

A straight cane helps provide balance and stability. Using a cane might also prevent people from bumping into you.



### Rollator walker

A Rollator walker has 4 wheels, hand brakes, and a seat. It is a good choice for a person with leg weakness and/or poor endurance. This also allows a person to sit and rest when needed.



### Front-wheel walker

A front-wheel walker is lightweight and folds up. These walkers can be easily picked up and carried. Back gliders or tennis balls can be added for easier mobility. Platforms can be added for arm support if you have hand weakness.



### Folding walkers

Standard folding walkers have no wheels. The walkers can be adapted with either 5" non-swivel wheels or 3" swivel wheels. You can also add back gliders to make pushing a folding walker easier.



## What are the symptoms of mobility weakness?

There are several signs and symptoms of mobility weakness. These include:



### Muscle weakness



### Muscle fatigue



### Difficulty walking



### Slow movements

There are many things to consider in making a selection for a walker.

These include overall **stability, width, and height**. Also consider the **type of hand brake system** if brakes are required. You can also **attach baskets and other accessories** to your walker.

# Leg braces

Leg orthoses (or braces) provide support to the foot, ankle, and leg to improve positioning, balance, and mobility. A prescription for a leg orthosis is required. Your ALS care team will work to provide you with the orthotic that is best for you.



An **ankle-foot orthosis** (AFO) is used to stabilize weak ankle muscles. AFOs prevent drop foot and weak knee extension. It fits inside your shoe and can be custom molded to your leg.

# Wheelchairs

Determining an appropriate wheelchair depends on your short and long-term needs. Your ALS care team will assist you in getting a wheelchair that is perfect for you. Please speak to your ALS care team to determine your needs before purchasing a wheelchair.

## What to think about before getting a wheelchair



**Do you have someone that can help you with your wheelchair?** Consider the abilities of your caregiver, who may have to pick up or push the wheelchair.



**The type of car and its storage space for a wheelchair should be considered.**



**The entrance and exit to your home.** This includes the placement of outside steps, railings, and the possible need for a ramp or a platform lift.



**Measure the widths of exterior and interior doors.** You should also measure the widths of hallways and the space available for turning your wheelchair. Don't forget to measure the bathroom.



## Insurance coverage for wheelchairs

Check your health insurance policy to find out if durable medical equipment (DME) is covered. You can also work with a local DME provider recommended by your ALS care team.

A power wheelchair, needed for independence and weight-shifting, is usually priced at \$25,000 or more.

Most insurance policies will cover only one wheelchair every 5 years. It is recommended to use insurance for a power/electric wheelchair.

Financial assistance or equipment loans may be available through Team Gleason, the Les Turner ALS Foundation or the ALS Association.

**Lightweight, manual wheelchairs are used for transportation.** They can also be useful if you have enough strength to move on your own. Depending on your caregiver's strength, they can also push the chair.



You should not sit in this kind of wheelchair for a long time. The chair must have a pressure-relief seat cushion.



There are many types of manual chairs. These include transport, lightweight manual and ultra-lightweight manual wheelchairs.



**Pressure relief cushions are important in preventing pressure sores if you cannot shift your weight. Pressure relief means moving your body when sitting or lying down to allow your blood to move throughout your body.**

**Talk to your ALS care team to learn more about pressure relief.**

### **Power wheelchairs are used for independent mobility and for independent weight-shifting.**

Independent weight-shifting is important to decrease the risk of pressure sores. Various features are available for these chairs. The chair should be custom-fitted and requires a prescription from your physician.



A Tilt-in-Space seat in a power wheelchair can be tilted back to relieve pressure on the buttocks or lower back. It requires special electronics to move the chair forward and change the seat position.



Other possible seating features will be based on your specific needs. These include custom supports, headrests, pressure relief cushions, leg movement, and desk attachments. The joystick control can be modified for different degrees of hand weakness. Head or foot control can be used if hand control is not possible. Breath control can also be an add on feature. All features must be assessed by a physical therapist and a wheelchair company representative.



A tilt and recline system allows the seat back to fully recline.



Adjustable seat height allows you to raise and lower the seat from the wheelchair base.



Specialty wheelchair features can be added or changed over time as your needs change.

# Transportation Options

There are many things to think about when using a manual or power wheelchair.



If you are using a power chair only around your house and neighborhood then a van may not be necessary.



You may need to consider an accessible minivan, adapted SUV or full-size van if you are planning on taking trips or if you plan to go into the community frequently.



For the occasional trip out with your powerchair, you can rent a van or use an accessible taxi service.



An accessible vehicle may not be necessary if you can transfer from wheelchair to car seat.



It is also important to consider your caregiver's strength and ability to assist with transfers.

If you have a garage, make sure your garage door is tall enough for the van. You may also need to put a ramp or platform lift in your garage in order to enter the house. If you park on the street, you may need a special parking zone sign from the city for your parking area.

## Aids for transfers

Transfer is a term used to describe safely moving from one position to another. Some examples are moving from a wheelchair to recliner or from a bed to a commode.



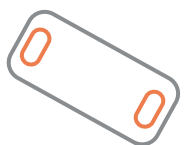
### Gait belts

A gait belt is used so a caregiver can assist with standing or sitting. Check with your ALS care team for gait belt training.



### BeasyTrans®

The BeasyTrans® is a sliding transfer board. It consists of a sliding disc on a transfer board.



### Transfer boards

Transfer boards are used to move between a wheelchair and a bed or chair. Have your caregiver with you during these transfers because they can be difficult and require additional strength.



### Sliding sheets

A sliding sheet is a sheet made with slippery material that helps you transfer more easily.

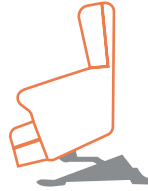
# Types of patient lifts and seat-lift recliner chairs

There are many different kinds of patient lifts available. The most common types of lifts are manual, hydraulic and electric. Patient lifts can be portable or can be installed in your home.



## Hoyer lift

The Hoyer lift transfers a person from one place to another. A Hoyer lift can be manual or electric. You need a letter of medical necessity from a doctor for insurance. **Medicare will usually cover the cost of a manual lift. If you would like an electric lift, you can upgrade your lift by paying out of pocket.** Once you receive the lift, training from a physical therapist is needed.



## Seat-lift recliner chairs

Seat-lift recliner chairs help you into a standing position. A seat-lift recliner can also change position to make you more comfortable. The chair also raises the legs and feet to reduce or avoid swelling. Some people choose to sleep in their recliner. Insurance should cover the cost of the electric portion of the chair with a letter of necessity from your doctor.



If you would like more information on lifts that require installation visit our home modification guide.

[lesturnerals.org/home-modifications](http://lesturnerals.org/home-modifications)

# Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, [lesturnerals.org/resources](http://lesturnerals.org/resources).

## My ALS Decision Tool™

If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options. To learn more, visit: [alsdecisions.org](http://alsdecisions.org).

**MY ALS  
DECISION  
TOOL**

## ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research, visit: [alslearningseries.org](http://alslearningseries.org).

**ALS  
LEARNING  
SERIES**

## My ALS Communication Passport to Quality Care

My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit: [lesturnerals.org/passport](http://lesturnerals.org/passport).

**MY ALS  
COMMUNICATION  
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TO QUALITY CARE**

## Support Groups

We facilitate support groups to provide people living with ALS, their caregivers and family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS. To find out more, visit: [lesturnerals.org/support-groups](http://lesturnerals.org/support-groups).

