

# Patient and Family Resource Guide to ALS

## Section 4 Resources for Daily Living

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# Resources for Daily Living

## Who can help you?

The Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine utilizes a multi-disciplinary team approach where you will have access to an occupational therapist, orthotist, and wheelchair specialist; referrals may be made to meet with a physical therapist. This section will introduce what they do and how they can help you.

### Occupational Therapist

An occupational therapist evaluates how a person with ALS performs daily tasks, including personal care, mobility, recreation, and school and work activities. The assessment is done through interviews and evaluation of function in the ALS Clinic or at home. The therapist recommends needed assistive devices such as hand-wrist supports or braces; home modifications; durable medical equipment such as wheelchairs, hospital beds and bath chairs; and home or outpatient therapies. The therapist can train patients and caregivers to use assistive devices and proper body mechanics, can give instruction in ways to conserve energy, and can provide written guidelines for exercises and range of motion activities. Usually, occupational and physical therapists work together to assess body mechanics, exercise programs and wheelchair needs. You need written prescriptions from your physician for evaluation and treatment from therapists. Check with your insurance company or case manager for information about coverage. Check with your Lois Insolia ALS Clinic therapist for information on Medicare coverage.

### Physical Therapist

A physical therapist evaluates how a person with ALS manages general functional mobility. This includes assessing a person's neck, trunk, arm, and leg strength and the ability to make the motions needed to roll side to side; to assume sitting, kneeling, and standing positions; and for walking and propelling a wheelchair. Assessments of how the strength of muscles and the range of motion at joints affect mobility are usually done in an outpatient clinic or in the home by a therapist. The therapist evaluates the person's strength, balance, and coordination, and then makes recommendations for treatment. The therapist can help you learn to use the appropriate devices and techniques for safely walking and moving from one place to another. A written plan for an exercise program may be worked out that can maintain and possibly improve overall range of motion and muscle strength. Special treatments are available for "frozen shoulders," spasticity, or muscle stiffness and overall weakness.

### Help for the Caregiver

The caregiver may need instructions on how to safely assist a person with ALS. Adequate information and instruction will help improve care, reduce anxiety, and decrease the risk of injury to both the PALS and the person helping. Written prescriptions from your physician are needed for physical therapy evaluations and treatments. Check with your insurance company or case manager for information on policy coverage. Check with your therapist for information on Medicare coverage.

## Conserving Your Energy

You can help yourself by taking charge of how you perform the tasks you need to do every day. How you perform the tasks of daily living can affect how you feel for the rest of the day. The following steps will help you determine what you need to do and how you do it.

- **Consider what routines are necessary.** Decide what you can do, what someone else can do and what can be eliminated from the routine. Examples of routines are dressing, grooming and bathing.
- **Consider the timing or scheduling of your activities.** Your time and schedule and your caregiver's time and schedule are equally important. Plan activity periods and rest periods; pace yourselves.
- **Consider the best use of your energy.** When you climb a mountain, you must have enough energy left to return to base camp. Use assistive devices whenever possible to help reduce fatigue and frustration. Assistive devices include walkers with wheels, wheelchairs for use when shopping, and handicapped parking cards or special handicapped license plates.
- **Eat high-energy foods in small amounts every two to three hours.** Eating large meals is tiring, and takes more time and energy than eating small amounts more often. The use of dietary supplements such as Ensure may be helpful.
- **Place frequently used items in the most convenient place.** Place heavier items on the lowest level that you can reach. This is especially important in the bathroom, kitchen and office.
- **Purchase "gadgets" or other energy-saving devices** based on recommendations from people who are knowledgeable about their actual success rates. Otherwise, you will have wasted time and money. Good information can be found at support groups. However, please keep in mind that not all suggestions at support groups or online will fit your specific problem or situation. Check with your ALS clinic staff or Les Turner home team member since they usually have heard comments or complaints about items or resources. Your occupational therapist can help sort out the good advice and determine if specific recommendations or techniques meet your needs.

## Useful Gadgets

The following sections include examples of equipment, devices, and "gadgets" that can help you with everyday tasks. Examples of sources and suppliers of the items are given, but the supplier lists are by no means exhaustive.

### For Weakness in Arms and Hands

Wrist and hand muscles may become weak, affecting the strength of the grasp for eating, dressing, grooming, and work activities. Many useful, inexpensive devices and gadgets are

available to help. Assessment of specific needs will help in selecting appropriate items. Hand devices are usually not covered by insurance. Check with the occupational therapist to determine sources and prices for devices. Ask which devices will help.

## Aids for Eating

- Built-up handles on lightweight eating utensils
- Foam tubing on heavy-duty plastic eating utensils
- Utensil holder
- Large handled cup for hot and cold liquids allows all four fingers to fit through the handle, so grasp does not need to be strong
- Offset spoon or fork that can be angled right or left
- Clear plastic, clip-on plate-guard
- "Octopus" suction device, a non-slip disc; or Dycem, a gel pad used to stabilize plates and cups
- Long rigid or flexible straws
- Sports drink container with a straw
- Flexi-Mug
- Food blender
- Food thickener (Thick It, Thick & Easy)

## Aids for Dressing

- Velcro closures for clothing and shoes
- Knit shirts, pull-on pants, fewer closures
- Elastic thread for cuff buttons, elastic cufflinks
- Large-handled button hook
- Stretchy shoelaces
- Long-handled shoehorn
- Fleece socks for cold legs and feet
- Adaptive clothing

- [www.adaptationsbyadrian.com](http://www.adaptationsbyadrian.com)
- [www.buckandbuck.com](http://www.buckandbuck.com)
- [www.silverts.com](http://www.silverts.com)

## Aids for Hygiene

- Baby wipes for toileting
- Toilet attachments for cleansing, such as Lubidet
- Chair urinals
- Foam tubing on toothbrush handle
- Disposable Dentips for mouth cleaning
- Electric toothbrush with rotary brush, plaque remover (Braun, Colgate, Sonicare)
- Electric flosser (Waterpik)
- Electric tongue cleaner
- Hand-held shower hose
- Plunger-type liquid soap dispenser
- Long-handled sponge
- Wall-mount soap dispenser

## Aids for Grooming

- Wall-mounted hair dryer
- Shampoo tray
- Foam tubing on handles of comb and brush
- Large-handled, lightweight comb and brush
- Long-handled comb and brush
- Nailbrush with suction cups
- Nail clippers on stabilizing platform or board
- Nail file holder

- Foam tubing on razor
- Electric shaver

## Aids for Recreation

- Adjustable-height tilt-top over-the-bed table
- Card holders
- Electronic games or gadgets, with hand controls
- Computer games
- Electronic books
- Page turners
- Book holders
- Rubber finger tips for help in turning pages in books, magazines, or newspapers

## Telephone and Monitor Aids

- Telephone adaptations such as headset, receiver holder, speakerphone, memory keys for dialing frequently used phone numbers or a voice activated phone
- Emergency call device (some are worn around your neck, some on your wrist)
- Infant monitor, walkie-talkie, wireless pager, portable doorbell for in-home communication

## Devices for Computer Use

- Computer arm supports
- Keyboard aid (pointer), Futuro wrist brace
- Foot-operated computer mouse
- Head- or eye-control electronic/computer device
- Voice activated programs such as Dragon Speak

## Other Useful Devices

- Voice-activated house controls (Google home, Alexa, etc.)

- Wide pen or pen with grip
- Key holder
- Hand Keyper (key holder, tab lifter, letter opener, magnet, nail file)
- Door handle levers
- Touch light switches
- Offset hinges for doors that widen the doorway without reconstruction

## Mobile Arm Supports

These supports can be attached to an adjustable-height table on casters for use anywhere in the home. The supports allow horizontal and vertical arm motion, for reaching the plate and the mouth. They also work well over the computer keyboard. Table-mount clamps attach the arm support to a table or computer desk. A supinator attachment allows some rocking motion of the forearm trough. A T-bar attachment can be added to support a weak wrist. A therapist must order these attachments and can demonstrate their use.

## Leg Supports

Many kinds of devices, braces, and durable medical equipment, or DME, are available to assist a patient with hip, knee or ankle weakness. The extent of weakness and of endurance should be properly evaluated before any recommendations for equipment are made. Check with the insurance company or Medicare about coverage and which preferred providers or vendors they use. Gait, or manner of walking, should be evaluated by a physical therapist in an outpatient clinic to test stability and safety when using the appropriate walking aid. A prescription and a letter of medical necessity are needed, that can be written by either the therapist or the physician, but must be signed by the physician.

## Aids for Walking

- Early in the disease process, a straight cane such as the Hurry Cane, helps provide balance and stability. Even if it seems unnecessary, using a cane will help make other people more careful and less likely to bump into you.
- Rollator walkers are a good choice for persons with leg weakness, stiffness or poor walking endurance. This type of walker provides a stable base while ambulating and allows a person to sit and rest.
- A standard walker, the lightweight, folding type can be easily carried in a car. Swivel front wheels and back gliders can be added if needed.
- Considerations in making a selection for a walker include: overall stability for your height (the three-wheeled walkers are not as stable), adjustability of the height of the hand grips, the type of hand brake system, ease of operation and stability, ease of turning

the walker, folding feature for easy transport in a car, and seat and basket options. Standard folding walkers can be adapted with front casters either 5" non-swivel casters or 3" swivel casters and back gliders.

## Aids for Transfers

- A gait belt is used around the person's waist so a caregiver can assist with standing or sitting. Some belts have buckle closures, some have Velcro and some also have handles. Check with your clinic occupational therapist or physical therapist for the appropriate style for you and for training in its use.
- Transfer boards are used to move between a wheelchair and a bed or the seat of a car.
- The BeasyTrans® is a sliding transfer board, which consists of a sliding disc on a transfer board.
- Hoyer lift – this is a hydraulic lift mechanism that utilizes a sling to safely transfer a patient in/out of bed, into a chair and/or onto the toilet. This requires a prescription and letter of medical necessity from a physician which is then submitted to insurance. Once you receive the equipment, training from a physical therapist is needed. Medicare will usually cover the cost of a manual lift but not an electronic lift.
- The Easy Pivot Lift is a mechanical lift. This lift tilts the person forward to make dressing and toileting easier when the person cannot stand. However, it can place pressure on a person's diaphragm which could affect breathing. In addition, a PALS must be able to hold on to the handles and have good head control.
- The Lyko Lift is a power lift that stands a person before transfer. This lift may possibly be purchased through insurance with a prescription and a letter of medical necessity.
- **Note:** Medicare and public aid will not cover the cost of the Easy Pivot or Lyko Lift but they may be covered by private insurance.
- For information on hydraulic and power lifters and ceiling track lifters, talk with your occupational therapist about what device would be most appropriate.
- Seat-lift recliner chairs assist the patient to a standing position, change position to make the patient more comfortable when sitting or reclining, raise the legs and feet to reduce or avoid swelling, or change position to support the head and neck in a reclined, comfortable position. Insurance should cover the cost of the electronic portion of the chair with a prescription and letter of necessity from your physician.

## Aids for Swelling in Lower Extremities

- TED hose are used to reduce mild swelling in feet, ankles and legs. They also promote circulation to help reduce the risk of blood clots. These are available by prescription from

your physician and can be obtained at your pharmacy.

- Jobst garments are used to control or reduce mild to moderate swelling in feet, ankles and legs. They require a physician prescription and measurement for accurate fit.
- Sequential compression devices require a physician's prescription. Phlebopump, Ace /pp-1000 (1 888 4PHLEBO) is used for severe swelling of lower extremities.

## For Weakness in Both Arms and Legs

A variety of devices, some of which are listed below, are available that can make doing everyday tasks easier when you have weakness in both arms and legs.

### Aids for Toileting

- A raised toilet seat, made of molded plastic 4 to 5 inches in height, fits snugly inside the rim of the toilet on most toilets. It has all smooth surfaces and can be easily cleaned. It can be removed easily when other family members use the toilet. It can be carried in a zippered bag or shopping bag for use when visiting other homes.
- A standard commode can be placed over the toilet to provide a raised seat and armrests.
- A shower commode chair on wheels can be rolled over the toilet to provide a raised seat and armrests as well as being used in the shower.

### Aids for Bathing

- A shower commode chair on wheels has a padded seat and back and floor brakes or wheel locks. Padded arm troughs can be ordered if needed. Some commode chairs have tilt seats with headrests, reclining backs or straight backs. They can be used at the bedside, over the toilet and in shower stalls.
- Bath benches are set up across the side of the tub; they can be plastic or padded. They cannot be used with tubs that have sliding glass doors unless the doors are removed and a shower curtain has been installed. The bench also cannot be used if a vanity is located next to the tub because the patient does not have enough legroom to turn while sitting. Benches are available through numerous resources such as [www.performancehealth.com](http://www.performancehealth.com), Amazon, Walgreens, CVS, etc.
- A tub seat is a small seat that can be placed inside the tub. It can be used with tubs that have sliding glass doors. A tub seat can be used only if the patient can step into the tub. It must be placed in the tub after the patient steps over the side of the tub.
- High-back resin deck chairs with arms can be used in the shower stall if the stall is large enough. They are very lightweight.
- A simple wooden bar stool can be placed in the shower stall to provide a high seat, making it easier for the patient to stand up.

- A hand-held shower hose attached to a showerhead or faucet allows water to spray from an appropriate height.
- Soap dispensers can be suctioned to a tiled wall to hold shampoo, conditioner, or soap. There are no bottles or caps to turn or drop.
- Long-handled scrubbers can be used to clean feet.
- Long foam-handled razors provide better grip and length.
- Grab bars securely fastened in the shower wall at the appropriate height can provide a "shelf" for weak arms to rest on while washing your hair, shaving, washing your face.
- Tub rail clamps securely to the side of the tub for stability while climbing into and out of the bathtub, approx. 12 inches to 15 inches high.

## Resources/Catalogs

- Performance Health (formerly Patterson Medical)
  - [www.performancehealth.com](http://www.performancehealth.com)
  - 1-800-323-5547
- Gold Violin
  - [www.goldviolin.com](http://www.goldviolin.com)
  - 1-877-648-8466
- Harriet Carter Catalog
  - [www.harrietcarter.com](http://www.harrietcarter.com)
- QUEST Magazine: Muscular Dystrophy Association
  - [www.mdausa.org](http://www.mdausa.org)
  - 520 529 2000
- AliMed
  - [www.alidmed.com](http://www.alidmed.com)
  - 1 800 225 2610
- Amazon
  - [www.amazon.com](http://www.amazon.com)

## **Chicago Area Suppliers of Durable Medical Equipment (DME)**

- Walgreens – various locations
  - [www.walgreens.com](http://www.walgreens.com)
- Mark Drug Medical Supply – Wheeling
  - 847 537 8500
- Fitzsimmons Surgical Supply – Tinley Park
  - 708 532 1199

For those PALS seen at the Lois Insolia ALS Clinic or by a member of the home and community team, please contact your clinic nurse or Patient and Family Advocate for assistance before ordering equipment.

## **Orthotics**

Orthotics are orthopedic appliances such as splints and braces that are used to support or straighten weak areas of the body. In ALS, orthotics may be used for weakness of the neck, trunk, arms, and legs. A certified orthotist evaluates a patient's need for a specific orthotic. Orthotics usually require a prescription from your physician. Your insurance company may require that you use only a particular supplier or suppliers, such as one in the insurance company's network. Contact your insurance company or case manager to check on suppliers before making an appointment. Insurance may not cover shoes, or shoe inserts depending on the specific diagnosis. Medicare covers most orthotics. Check with the orthotic company.

## **Orthotics to Support, Protect and Rest Weak Neck Muscles**

- A buddy pillow is a buckwheat travel pillow with a fleece cover. It supports the neck in bed, in the recliner chair, in the car, or on the plane.
- A soft cervical collar is a simple, inexpensive orthotic that can be purchased at Walgreen's, CVS, Bed, Bath and Beyond, Osco or any medical supply house. The collar may restrict swallowing if too snug. It is not covered by insurance.
- A plastizote collar is lightweight, flesh-colored, firm foam, two-piece collar with a chin support. The chin support is not movable. The collar may cause pressure under the chin or on collarbones. It does not restrict swallowing or feel tight around the throat, but does not allow the patient to speak or eat. A prescription from your doctor and a fitting by an orthotist are required.
- Aspen, Miami J, or CervMax collars are light, gray, foam-lined, two-piece collars with washable liners. The structure is less firm than the Plastizote, but more comfortable. It does not restrict swallowing or feel tight around the throat. A prescription from your doctor and a fitting by an orthotist are required.

- A headmaster collar is a wire-foam collar with padded tubular frame, a chin support, and more open areas around the throat and neck.
- An oxford collar is made from wire and foam. It provides support for the chin and the back of the neck, and allows side-to-side motion of the head and bending and stretching of the neck. A prescription from your doctor and a fitting by an orthotist are required.
- Soma-occipital-mandibular-immobilizer provides firm chin and neck support and has a chest harness to support the weight of the head over the shoulders. It is more important for walking than sitting. A prescription from your doctor and a fitting by an orthotist are required.

## **Orthotics that Help Arm and Hand Weakness**

Shoulder supports must be evaluated by your physician and therapist. Assessment of shoulder joint mobility, circulation, and range of motion is needed for proper selection of the correct orthosis.

- A wrist-hand orthotic (WHO), also called a forearm or resting hand splint, is used to support weak wrist and hand muscles during the day or at night. The splint should be as lightweight as possible. Most splints can be pre-formed, but some must be custom made. The occupational therapist will choose an appropriate splint depending on how much muscle weakness or stiffness is present. Wearing a splint on each hand while you sleep is usually not advisable, since one hand should be free. Alternate wearing splints on right or left hand each night or day. The Futuro wrist brace is available in Walgreens, Osco, and CVS. Sammons/Preston wrist braces; Neutral position WHO, and TheraPlus hand positioners are available from [www.performancehealth.com](http://www.performancehealth.com).
- A thumb-wrist support, or wrap, is a functional hand orthotic (FHO), which supports the thumb and index finger to improve fine coordination. It does not place the thumb and index finger in pinch position, and it does not make the hand stronger. It is usually made from neoprene or very lightweight splinting material. Examples include the Neoprene thumb/wrist support or wrist/thumb wrap available from [www.performancehealth.com](http://www.performancehealth.com).
- Slings for severely weak arms and hands will support shoulder joints and decrease the risk of shoulder subluxation or stretching of the shoulder joint with subsequent pain.

## **Trunk Supports**

Trunk supports are used to support weak trunk muscles, improve posture, and relieve muscle pain from strained muscles while sitting or walking.

- Elastic abdominal supports provide mild to moderate support to abdomen and low back. Good hand strength or assistance from a caregiver is needed to put one on. Supports are available from local pharmacy such as Walgreens, Osco or CVS. No prescription is needed.

- Lightweight corsets give support to the trunk and low back but require more dexterity to put on. When wearing a corset, less trunk flexibility is possible when rising from a seated position. The corset must be ordered from an orthotic company and requires measurement and adjustment for a correct fit. A prescription from your doctor and fitting by an orthotist are required.

## **Leg Braces Help Foot, Ankle and Leg Weakness**

- A knee-ankle-foot orthotic (KAFO) is a long leg brace. It is not recommended with persons with ALS because they are usually unable to take a standing position with the knee in a locked position.
  - An ankle-foot orthotic (AFO), which used to be called a short leg brace, is used to stabilize weak ankle muscles, as in drop foot and in weak knee extension. It fits inside your shoe and usually should be custom molded to your leg. You might need an articulating ankle on this orthotic to allow movement at the ankle joint, or floor-reaction, which assists knee extension and helps lock the knee joint. This modification will help in climbing stairs.
  - A supra-malleolar orthotic (SMO) is used to stabilize the ankle and forefoot.

## Sources for Orthotics

- Ballert Orthopedics [www.ballert.com](http://www.ballert.com)
    - NW, 233 E. Erie, Ste 200, Chicago 312 787 4400
    - 2434 W. Peterson, Chicago 773 878 2445
    - 125 E. Lake Cook Road, Buffalo Grove 847 459 9006
    - 141 Front Street, Wood Dale 630 694 9305
  - Scheck & Siress [www.scheckandsiress.com](http://www.scheckandsiress.com)
    - Rush, 1725 W. Harrison, #220, Chicago 312 942 2011
    - 1525 E. 55<sup>th</sup> St, #204, Chicago 312 757 5270
    - 2835 N. Sheffield, #301, Chicago 773 472 3663
    - University of Illinois, 1740 W. Taylor, Rm C100, Chicago 312 996 6450
    - 1551 Bond Street, Ste. 311, Naperville 630 637 4638
    - One S. 376 Summit Ave., Ct E, Oakbrook Terrace 630 424 0392

- 401 Harrison Street, Oak Park 708 383 2257
- 8641 W. 95<sup>th</sup>, Hickory Hills 708 599 8336
- 6629 W. Lincoln Hwy Rte. 30 Suite 1, 219 864 9501  
Schererville, IN
- Shirley Ryan Abilities Lab [www.sralab.org](http://www.sralab.org) 312 238 2810  
(formerly the Rehabilitation Institute of Chicago)  
345 E. Superior, Room 1764, Chicago
- Marionjoy Rehabilitation Center [www.marionjoy.org](http://www.marionjoy.org) 630 909 8000  
26W171 Roosevelt Road, Wheaton

## Hospital Beds, Mattresses and Lifts

Hospital beds and appropriate mattresses can help in positioning and in preventing such pressure-related problems as bedsores. Hospital beds require a prescription and a letter of medical necessity from your physician in order to receive insurance coverage.

### Hospital Beds

- Manual frame: The mattress height can be set at low or high position; manual cranks are used to change the position of the head and foot sections.
- Semi-electric frame: The height can be set at a low or high position. A power switch raises the head and foot positions.
- Full electric frame: A power switch adjusts the bed frame height to make transferring possible either from the wheelchair or from standing at the bedside, as well as adjusting head and foot positions. Full electric frame does not mean a full-size bed.
- Side rails: Full-length or half-length side rails give you leverage to turn yourself from side to side if this is difficult. Half-length rails make it easier to transfer to and from the bed.

### Pressure-Relief Pads or Mattresses

- Egg-crate foam is used under the bottom sheet. It does not provide enough pressure relief for long-term use.
- Artificial sheepskin can be used under the sheet. Use on top of the sheet allows more air circulation. It is washable and more buoyant than egg-crate foam.
- An alternating pressure mattress is used under the sheet. It works with an electric compressor to raise and lower pockets of air under the body area. A prescription and

letter of medical necessity is required.

- Thermorest air mattress is used under sleeping bags, provides insulation and pressure padding. A nylon cover allows easier movement in bed when the mattress is placed under the sheet. Various depths are available from sporting goods stores and from L.L. Bean.
- Roho mattress is available as a low-profile or high profile air mattress. It can be a sectional (three sections for a hospital bed) or a full-length bed mattress. A prescription and a letter of medical necessity are required.
- Temperfoam mattress, a gel-foam mattress or pad provides maximum pressure relief. It is heavy once in place, and needs a prescription and letter of medical necessity.
- A low air-loss mattress moves air from one side of the mattress to the other to reduce pressure under the shoulders, hips, knees and ankles. A prescription and a letter of medical necessity are needed for insurance coverage.

## Patient Lifts

- Hydraulic patient lifts, such as Hoyer and Invacare, are used with a separating sling. This type of lift supports the person in a seated position. The separating sling can be placed under a patient who is sitting or lying down without physically lifting. It also can be removed without lifting the patient. The Easy Pivot® lift uses two straps behind the shoulder and knees and tilts the person forward for transfers.
- Power patient lifts (Hoyer and Invacare), are similar to the hydraulic lifts, but are used with a battery-powered source attached to the lift. The Lyka Sabena Ilee® support and stands the person before transferring to a wheelchair.
- Ceiling track patient lifts use electric power.

## Wheelchairs

Determining what kind of wheelchair is appropriate depends on the person's short-term as well as long-term needs.

## Insurance Coverage

Check your health insurance policy to find out if durable medical equipment (DME) is covered or ask your insurance case manager. Most insurance policies will cover only one wheelchair; therefore, it is recommended to use insurance for a power/electric wheelchair. A manual wheelchair, needed for transportation and safety, is usually priced between \$200 and \$2000 if custom made. A power wheelchair, needed for independence and weight-shifting, is usually priced at \$25,000 or more. Medicare will cover a manual or a power wheelchair but usually not both; once a manual wheelchair has been covered; it is unlikely that a power wheelchair will be covered. Check with your therapist before you need a wheelchair to plan the best strategy.

## **Factors to Consider When Buying a Wheelchair**

- Your age and the age, health, and strength of your caregiver, who may have to place a manual wheelchair in the car
- The type of car and its storage space such as hatch back, minivan, full-size van, and van with wheelchair conversion; and the space available in the garage and driveway
- The entrance or exit to your home, including placement of outside steps, inside steps, railings, deck, outside porch, and enclosed porch; and the possible need for a ramp or a porch lift
- The widths of the front and back doors and of the interior doors, especially the bedroom and bathroom
- The widths of the hallways and the space available for turning into and in the bedroom and bathroom

## **Wheelchair Features**

- Lightweight, manual wheelchairs are used for transportation to and from the car. They can also be useful if the patient has retained enough strength to move himself about or if a caregiver is available to push the chair. However, patients should not sit in this kind of wheelchair for a long period of time. The chair must have a pressure-relief seat-cushion. Other useful features include detachable armrests and swing-away footrests. Some manual wheelchairs have four small wheels, others have quick-release large back wheels; both of these kinds are easier to place in a car. Types of manual chairs include: transport type, lightweight manual, and ultra-lightweight manual wheelchair.
- Power wheelchairs are used for independent mobility and for independent weight-shifting to decrease risk of pressure sores. Various features are available for these chairs. These chairs should be custom made and require a prescription from your physician for insurance coverage.
- Tilt-in-Space seat in a power wheelchair can be tilted back to relieve pressure on the seat or lower back. It requires special electronics to move the chair forward and change the seat position. It usually needs standard footrests.
- A tilt and recline system enables the seatback to be fully reclined. Elevating leg rests may be needed in the reclined position.
- Adjustable seat height allows the seated position to raise and lower from wheelchair base.

Other seating features include molded back inserts, tall back inserts, custom contoured back inserts, lateral supports for weak trunk muscles, head rests, molded seat inserts, custom contoured seat inserts, various kinds of pressure-relief cushion fillers including air, gel, gel-foam, and foam; adjustable height armrests; desk-length armrests; full-length armrests; regular arm

pads; trough arm pads with hand supports; swing-away footrests; heel loops; elevating leg rests; and angle-adjustable footrests. Electronic environmental control devices can be used to turn on lights or to access TV, VCR, stereo/CD, computer, and telephone.

The joystick control can be modified for different degrees of hand weakness. The joystick control box can be placed to the right or to the left or in the center of the wheelchair base, depending on the person's ability to manage it. Varying drive speeds can be programmed as well as varying amounts of pressure needed to push or pull the joystick. Head or foot control can be used if hand control is not possible. An attendant control can be placed near the headrest. Breath control is used for some persons with ALS. All features must be assessed by both the therapist and the wheelchair specialty representative.

## **Motorized Scooters or Carts**

Scooters and carts are known as power-operated vehicles for Medicare coverage. They are usually not recommended for persons with ALS because they do not provide adequate back support, head support, or arm support.

## **Van Conversions**

When you are considering using a manual or power wheelchair, you must consider how you will transport it in your present car or vehicle. You may need to consider a mini-van or full-size van, depending on the person's ability to transfer from the car to the wheelchair, the strength and ability of the caregiver, and your lifestyle and resources. Get good advice before purchasing the wheelchair or van. Consider that your garage may need a ramp or other modification. If you do not use a garage and you park on the street, you may need a special parking zone sign from the city for your parking area.

- New Ability Inc. [www.newabilityinc.com](http://www.newabilityinc.com) 708 345 3939
- Mobility Works [www.mobilityworks.com](http://www.mobilityworks.com) 630 782 1900 or 847 673 4300
- Sherman Dodge [www.shermandodgeillinois.com](http://www.shermandodgeillinois.com) 888 430 3783

## **Home Modifications**

Each person with ALS has a different course of disease progression, a different lifestyle, different resources and different family commitments. Decisions about modifying the home to ease care and mobility problems should be made with careful consideration of both short-term and long-term needs of the patient and the family. Trilevel, bilevel and two-story homes with turning stairways are the most difficult challenges. Solutions depend on family resources. Moving the person with ALS to the most accessible level of the home and to make modifications on that level to meet needs for toileting and bathing may be the most feasible solution in the long run. Check with companies that use Americans with Disabilities Act (ADA) guidelines and modify homes in your area.

- Extended Home Living Services, Inc.
  - [www.ehls.com](http://www.ehls.com)
  - 847 215 9490
- Given the Ability, Inc
  - [www.giventheability.com](http://www.giventheability.com)
  - 866 568 9704
- Home Access Services, Inc
  - [www.homeaccessservices.com](http://www.homeaccessservices.com)
  - 877 491 5525
- 101 Mobility
  - [www.101mobility.com](http://www.101mobility.com)
  - 847 906 8897
- Home for Life Advantage, Inc
  - [www.homeforlifeadvantage.com](http://www.homeforlifeadvantage.com)
  - 630 466 2611

Easy access to the home for walking or using a wheelchair must be considered. Keep an open mind and look at all the options. A platform area for the wheelchair is needed for safety and stability inside and outside the entrance doorway. This platform must be at the same level as the doorsill.

## Ramps

A platform at least 36 x 36 inches will allow the wheelchair to safely sit outside the door before going up or down the ramp. A handrail or wheel rail should be attached along the sides of the ramp. Ramps for outside the home can be constructed from deck wood; for inside the garage or home they can be made from plywood. The maximum recommended angle, or grade, for indoor ramps is 12 inches of ramp for every 1 inch of rise or a 1:12 ratio. A 12-foot ramp is recommended for a 1-foot rise. Sometimes a sharper, steeper rise is needed because there is not enough space for a longer ramp. Remember who is pushing the wheelchair up or down the ramp; more strength is needed to control the wheelchair on a steeper ramp. Ramps outside the house should use a 1:20 inch ratio (a 20-foot-long ramp for a 1 foot rise), which provides a generous, long ramp. Walkways along the side of the house may allow space for such a long ramp. A "Z"-shaped ramp is necessary where short front yards or backyards do not provide enough space for a long, safe straight incline. A 5-foot flat area at the bottom of the ramp is recommended for stopping and turning the wheelchair. Local building ordinances must also be taken into account in planning a ramp. Portable, folding, aluminum ramps are commercially

available. These can be taken in the car or van for use when you go to a place that has one or two steps and no ramp.

- Handi-Ramp, Inc. [www.handiramp.com](http://www.handiramp.com) 800 876 7267  
Constructs aluminum and galvanized steel ramps and concrete decks for homes and businesses.
- Performance Health Catalog [www.performancehealth.com](http://www.performancehealth.com) 800 323 5547  
Has portable aluminum ramps
- American Ramp [www.americanramp.com](http://www.americanramp.com) 800 649 5215  
Provides affordable ramps for rent or purchase
- RampNow – sales and rentals [www.RampNow.com](http://www.RampNow.com) 630-892-7267
- Access Living 312 253 7000  
Assists Chicago residents with the cost of ramps based on need and available funds

## Porch Lifts

Porch lifts can be placed at doorways inside or outside the home, depending on the placement of stairs and the space for the lift itself. Porch lifts can be placed inside bi-level and tri-level homes and allow use of two levels without major renovation to the home. The installer will assess construction requirements.

## Stair Lifts

Stair lifts can be rented or purchased and can be fitted to straight or curved stairs. Costs depend on length and curve of the track. Sitting balance and neck weakness of the patient must be considered. Some stair lifts have a fold-up seat. A wheelchair or other mobile chair at the top and bottom of the stairs is needed if the person cannot stand.

- Acorn Stairlifts [www.acornstairlifts.com](http://www.acornstairlifts.com) 888 211 1245
- Bruno Independent Living Aids, Inc. [www.bruno.com](http://www.bruno.com) 800 882 8183
- Extended Home Living Services [www.ehls.com](http://www.ehls.com) 847 215 9490
- Home for Life Advantage, Inc [www.homeforlifeadvantage.com](http://www.homeforlifeadvantage.com) 630 466 2611
- Stannah Stair lift [www.stannah.com](http://www.stannah.com) 800 877 8247

Installs new and used stair lifts, sale and rental, for homes and businesses.

## Ceiling Patient Lifts

Ceiling lifts can be installed over the bed, in the bathroom, or at the top and bottom of stairs to meet individual needs.

- Sure Hands Lift Systems [www.surehands.com](http://www.surehands.com) 800 724 5305
- Barrier Free Lifts [www.bfl-inc.com](http://www.bfl-inc.com) 800 582 8732
- Home for Life Advantage, Inc [www.homeforlifeadvantage.com](http://www.homeforlifeadvantage.com) 630 466 2611
- Waverly Glen System, Ltd. [www.waverlyglen.com](http://www.waverlyglen.com) 800 265 0677

## Elevators

Elevators can be installed for two or three levels within a home but assessment for adequate space is necessary

- Extended Home Living [www.ehls.com](http://www.ehls.com) 847 215 9490

## Door Width and Halls

A doorway must be least 32 inches wide with a door that swings inward. Offset door hinges can replace regular door hinges if there is enough room to set the door behind the door jamb. This will give you about 1 to 2 inches more clearance. Wheelchairs are too wide to go through most bathroom doors. If the bathroom doorway is at least 24 inches to 25 inches wide a rolling shower commode chair can be used. Most shower commode chairs are 21 inches to 22 inches wide, and can be used over the toilet or in the shower and go through most bathroom doors easily.

## Bathrooms

Shower stalls are easier to negotiate than bathtubs. Remodeling is very expensive, but a tiled floor with a recessed drain allows a shower commode chair easy access for patient and caregiver. An oblong shower stall can be modified by adding a wood deck and removable ramp. Glass doors must be removed and replaced with an expandable curtain rod and a shower curtain. Place the curtain rod inside the shower area to prevent the water from dripping outside the shower stall.

- Best Bath System [www.best-bath.com](http://www.best-bath.com) 800 727 9907
- Extended Home Living [www.ehls.com](http://www.ehls.com) 847 215 9490
- Home for Life Advantage, Inc [www.homeforlifeadvantage.com](http://www.homeforlifeadvantage.com) 630 466 2611

## Resources for other Assistive Devices:

<http://www.every90minutes.org/als-technology-guide/>

*Disclaimer: All care has been taken in preparing this document. This information is of a general nature and should be used as a guide only. Always consult your health care team before starting any treatments.*