

Section 4

RESOURCES FOR DAILY LIVING

WHO CAN HELP YOU

Through the Lois Insolia ALS Clinic you will have access to occupational therapists, physical therapists, orthotists, and wheelchair specialists. 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 at the ALS Center 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 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 patient needs to 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 assist a person with ALS safely. 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. No one changes the method of performing a task unless it can no longer be done as it was in the past. The change also depends on how easy it is to accomplish the task when performing the new method. It has to be easier the first or second time it is attempted. 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 will fit your specific problem or situation. Check with your ALS clinic staff. 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
- * 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
- * For clothing adaptations, contact Accessible Threads, Janet Kimmel cloth@prodigy.net; Adrians Closet www.adrianscloset.com
800-831-2577

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)
- * Fanny pack for carrying portable phone with you
- * Infant monitor, walkie-talkie, wireless pager 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

- * 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.

For Weakness in Legs

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

- * A straight 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.
- * Forearm crutches act like two canes by giving two-sided support.
- * 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.

Mobile walkers

- * The U-Step Walker is covered by Medicare with a prescription and a letter of medical necessity. It has a seat and carrying basket. It is a good choice for tall people with severely limited hand strength, or moderate to severe leg muscle stiffness. It has a push bar for patients with weak hand grasp, and hand brakes. It locks when you release the push bar and hand brakes. It folds for transporting in a car. The walker can be purchased and then reimbursed through your insurance carrier or Medicare. A prescription and a letter of medical necessity are needed for reimbursement. The walker can be obtained from InStep Mobility, 8040 N. Ridgeway Ave., Skokie, IL 60076, 847-676-1275.

- * The Nova-Deluxe Wheeled Walker is covered by insurance and requires a prescription and a letter of medical necessity. It is a good choice for persons with leg weakness, stiffness, or poor walking endurance. This walker can be obtained through most durable medical equipment (DME) companies. The manufacturer is Snug Seat, 12801 E. Independence Blvd., Stallings, NC 28105, 800-336-7684 or it can be purchased at Walgreen's Home Medical stores.
- * Other rolling walkers are also available. Considerations in making a selection 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 and some have Velcro. 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. It is available from North Health Products, Inc. P.O.Box 187, Lake Forest, IL 60045, 800-672-3279.
- * The Easy Pivot Lift is a mechanical patient lifter. The local contact is 630-961-7388, the manufacturer is Rand-Scot Inc., 800-467-7967. This lift tilts the person forward to make dressing and toileting easier when the person cannot stand. Call for a demonstration to make sure the patient is comfortable in it and that the caregiver can operate it in the home.
- * The Lyko Sabena Ilee is a power patient lift that stands a patient before transfer. This lift can be purchased through insurance with a prescription and a letter of medical necessity.

- * For information on hydraulic and power patient 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.

Aids for swelling in lower extremities

- * TED hose are used to reduce mild swelling in feet, ankles, and legs; to promote circulation; to reduce risk of blood clots. Available by prescription from your physician 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 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. Available from Walgreens, Fitzsimmons, Apria Healthcare, and Sammons/Preston catalog.
- * 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. Brands include Activeaide, Invacare, Aqua-Tec, and Clean Shower. Check availability from Fitzsimmons Surgical Supply, Metro Rehab, Apria Healthcare, Rehab Tech, or your DME vendor. Models vary in price from \$1000 to \$3000.
- * Padded bath benches are set up across the side of the tub. They cannot be used with tubs that have sliding glass doors. 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 from Sammons/Preston catalog for about \$150. Tub Slide Shower Chair from RD Equipment, 508-362-7498, is about \$2500.
- * 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 standard walker with no wheels can be used in the shower stall to aid stability.
- * 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 help the patient clean his or her 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.

Catalogs

- * Harriet Carter Catalog www.harrietcarter.com
- * Help At Home 800-225-2610
www.alimed.com
- * MOMS/Mail Order Medical Supply 800-232-7443
www.momsup.com
- * Northcoast Medical, Inc. 800-821-9319
www.ncmedical.com
- * QUEST Magazine: Muscular Dystrophy Association:
520-529-2000
www.mdaua.org
- * Sammons/Preston Inc. 800-323-5547
www.sammonspreston.com
Fax: 800-547-4333
- * SKYMALL Magazine 800-SKYMALL
www.skymall.com
- * Smith Nephew Rehabilitation Products 800-558-8633
www.smith-nephew.com

Chicago Area Suppliers of Durable Medical Equipment (DME)

- * Walgreens Home Medical, various locations 630-617-9030

For those PALS seen at the Lois Insolia ALS Center, call Jennifer Armstrong, BSN, Clinical Nurse Coordinator (CNC) for assistance with ordering equipment. You may be able to get special pricing when ordering through the CNC with Walgreens. Registering with the Muscular Dystrophy Association (MDA) may also qualify PALS for other equipment loan programs. Check with your CNC for MDA office information.

- * Apria Healthcare, Burr Ridge 630-920-0044
- * Fitzsimmons Surgical Supply, Berwyn 708-795-6300
- * Metro Rehab Services, Worth 708-361-7060
- * Mobility Systems, Hickory Hills 708-599-3500
- * Rehab Tech, Naperville 630-420-8585

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, Osco, Dominick's, or Jewel. The collar may restrict swallowing if too snug. It is not covered by insurance.
- * A plastizote collar is a 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. A prescription from your doctor and a fitting by an orthotist are required.
- * 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 handsplint, 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 preformed, 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 Dominicks. Sammons/Preston wrist braces; Neutral position WHO, and TheraPlus hand positioners are available from Sammons/Preston.
- * 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 Sammons/Preston.
- * 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. 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 useful 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

NW, 233 E. Erie, Ste 200, Chicago	312-787-4400
Rush, 1725 W. Harrison, #960, Chicago	312-563-2795
2434 W. Peterson, Chicago	773-878-2445
U of C, 5659 S. Cottage Grove, Chicago	773-493-2445
1250 N. Mill St. #106, Naperville	630-637-9540
125 E. Lake Cook Road, Buffalo Grove	847-459-9006

Scheck & Siress

Rush, 1725 W. Harrison, #829, Chicago	312-942-2011
2551 N. Clark, Ste 200, Chicago	773-472-3663
U of I, 1740 W. Taylor, Rm C100, Chicago	312-996-6450
617 E. Golf Road, Ste 108, Arl. Heights	847-437-3929
1551 Bond St., Ste 111, Naperville	630-637-4638
One S. 376 Summit Ave., Ct E, Oakbrook Terrace	630-424-0392
1145 Madison Street, Oak Park	708-383-2257
10411 S. Roberts Road, Palos Hills	708-599-8336
6629 W. Lincoln Hwy Rte. 30 Suite 1, Schererville, IN	219-864-9501

Rehabilitation Institute of Chicago (RIC)

345 E. Superior, Room 1764, Chicago 312-238-2810

HOSPITAL BEDS, MATTRESSES, AND LIFTS

Hospital beds and appropriate mattresses can help in positioning the patient and in preventing such pressure-related problems as bedsores. All hospital beds require a prescription and a letter of medical necessity from your physician.

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 or gel-foam mattress or pad provides maximum pressure relief. It is heavy once in place, and needs a prescription and letter of medical necessity. Temperfoam products are also available from Brookstone stores.
 - * 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. The mattress can be rented from a durable medical equipment company for about \$700 per month. Purchase price is about \$12,000. A prescription and a letter of medical necessity are needed.

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 patient 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 patient before transferring him to a wheelchair.
- * Ceiling track patient lifts use electric power.

WHEELCHAIRS

Determining what kind of wheelchair is appropriate for a particular person depends on the patient'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. A manual wheelchair, needed for transportation and safety is usually priced between \$200 and \$2000. A power wheelchair, needed for independence and weight-shifting is usually priced between \$6,000 and \$25,000. The Muscular Dystrophy Association can apply \$2,000 toward a wheelchair for patients who are registered with them and who are seen in their clinics. Call your local Muscular Dystrophy Association office. Medicare will cover a manual or a power wheelchair.

However, once a manual wheelchair has been paid for, 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 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.
- * 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.

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| * New Ability Inc. | 708-345-3939 |
| * Midwest Mobility | 800-809-3738 |

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. A decision to move 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.

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|---|--------------|
| * Extended Home Living Services, Inc. | 847-215-9490 |
| * ADC Services, Inc./Construction | 630-628-6909 |
| * Access Specialists, Inc./Evaluation | 630-628-6909 |
| * ADC Professional Handyman Service | 630-628-6909 |
| * Mobility Systems mobilityaccess@aol | 708-599-3500 |

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.

- * "How to Build Ramps for Home Accessibility" from www.dragnet.org or purchased for \$15 from the Metropolitan Center for Independent Living, 1600 University Ave. West, Suite 16, St. Paul, MN 55104-3825, 615-646-8342, companion video is \$20.
- * DME Access 800-892-7400
- * Constructs new ramps, wood or metal, for homes.
- * HandiRamps, Inc. 800-876-7267
- * Constructs aluminum and galvanized steel ramps and concrete decks for homes and businesses.
- * Mobility Systems 708-599-3500
- * Constructs new aluminum ramps for homes and businesses
- * Sammons/Preston Catalog 800-323-5547
- * Has portable aluminum ramps. www.sammonspreston.com
- * AM Ramp 800-649-5215
- * Provides affordable ramps for rent or purchase
- * 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 bilevel and trilevel homes and allow use of two levels without major renovation to the home. Assessment of construction requirements must be made by the installer.

- * Omry Rehab and Medical Products carry Cheney Lifts 888-228-4543
- * Mobility Systems 708-599-3500
- * Installs new porch lifts for homes and businesses.

Stair Lifts

Stair lifts can be rented or purchased. Straight stairs and curved stairs can be fitted with the appropriate models. 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.

- * American Access Systems 800-688-0741
Installs new and used stair lifts, rental and sale, for homes and businesses.
- * Bruno Independent Living Aids, Inc. 800-882-8183
www.bruno.com
- * Mobility Systems 708-599-3500
Installs new stair lifts for homes and businesses.
- * Stannah Stair lift 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 800-724-5305
www.surehands.com
- * Barrier Free Lifts 800-582-8732
www.bfl-inc.com
- * Moving Solutions 800-228-7980
- * Mobility Systems 708-599-3500
- * Waverly Glen System, Ltd. 800-265-0677
www.waverlyglen.com

Elevators

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

- * American Access System 800-688-0741
- * National Wheel-O-Vator Co. 800-551-9095
- * Mobility Access 708-599-3500

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

800-727-9907

www.best-bath.com