



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Adaptive Equipment

Adaptive Equipment Overview-73

Mobility-74

Transfers-78

Environment-80

Eating-82

Hygiene-84

Sleeping-87

Swelling (Edema)-88

Augmentative and Alternative Communication-89

Breathing-91



Adaptive Equipment Overview

Adaptive equipment or assistive technology can greatly improve the quality of life of an ALS patient. Indeed, adaptive equipment can significantly extend the lifespan of an ALS patient, if he or she chooses to take advantage of available technology. The assistive technology field has exploded with growth in recent years allowing ALS patients many more options. Exciting new technologies are continuously being developed and existing adaptive equipment is always being improved and refined. To view some pieces of equipment or to get more information about adaptive equipment visit <http://neurology.ucsf.edu/brain/pdf/ALSManual.pdf> This manual is presented by the University of California at San Francisco ALS Center. It has useful information about equipment used by ALS patients.

Important: One thing to always remember is to investigate and try to obtain adaptive equipment before you really need it. There is no way to know how quickly your body is going to change, and you don't want to have to endure the frustration and aggravation of not having the equipment there when you absolutely have to have it. Keep in mind that it is not uncommon for insurance approval and supplier lead time to result in a delay of weeks and even months in getting equipment. Typically the more specialized or expensive the equipment is, the longer it will take to get. This is not to say that you should rush out and get every piece of adaptive equipment you can think of as soon as you are diagnosed. Rather, keep a close eye on your ALS "progression" and think ahead to your future needs.

Most health insurance, including Medicare and Medicaid, will cover most of the cost of adaptive equipment as durable medical equipment (DME). Coverage at 80 percent with an annual out of pocket limit is common. Other options for funding the cost of adaptive equipment include Michigan Rehab Services at (800) 605-6722 or www.michigan.gov/mdcd for those still employed. Programs that loan equipment are ALS of Michigan, Inc. Other programs to check with are the Rotary, Kiwanis, Elks, and Lions Clubs. Local suppliers, support groups, hospitals, and churches are good places to ask about local programs. Another alternative is purchasing used equipment either from a local supplier or through the classified ads in local newspapers.

There are a couple of suppliers that offer extensive catalogs of adaptive equipment. It is a good idea to get a couple and learn what is available. Most offer these catalogs at no charge. Some popular suppliers are:

Best Buy Healthcare

(800)603-7366

www.BestBuyhealthcare.com

Sammons Preston

(800)323-5547

www.sammonspreston.com

Mobility

Many ALS patients will begin to have difficulty walking. Loss of balance due to foot-drop, muscle atrophy, and spasticity can make walking extremely difficult and dangerous. A typical progression in mobility aids is: ankle-foot orthosis (AFO), then cane, then walker, then manual wheelchair, then power wheelchair and handicap accessible van. While most ALS patients will understandably resist the use of a mobility aid for as long as possible, it is important that they accept that they are going to get weaker and that mobility equipment can help them maintain independence, conserve energy and most importantly, avoid the perils of a serious fall and related injury. This last point cannot be over emphasized. Catfish Hunter, the famous baseball player who was stricken with ALS, died relatively soon after diagnosis as a result of a head injury sustained as a result of a serious fall. Living with ALS is challenging enough without the added burden and pain of injury.

Ankle Foot Orthosis (AFO)

One common mobility symptom resulting from ALS is the inability to hold the toe of one or both feet up while walking. This is commonly referred to as foot-drop and results in the patient having to lift the foot more than normal while walking to avoid tripping. Correcting foot-drop with a lightweight ankle-foot orthosis can be helpful to minimize falls and maintain endurance.

AFO's are made of lightweight plastic and are available in a variety of types, styles and cost ranges. The simplest and least expensive is the off the shelf, catalog variety. These are a one-piece unit, which come in a variety of sizes. The best and most expensive are custom made devices, which incorporate a spring-loaded hinge at the ankle. Unfortunately, as with most things, you get what you pay for. The catalog variety tends to be less functional and much less comfortable due its one piece, one size fits all design.

Canes

There are basically two styles of cane available, the standard cane and the quad cane. The standard cane has a single tip while the quad cane has a rectangular four tip base for improved stability. The quad cane is typically considerably heavier and can actually be more awkward making it less stable depending on patient balance and strength. Newer model quad canes are designed using lightweight plastic making them lighter and allowing slight flex which provides some self-leveling. Which style works best for an individual patient will vary depending on condition and can only be adequately determined by having the patient try each style.

Walkers

When a cane does not provide enough support and the risk of falling becomes more frequent, it is time to upgrade to a walker. There many styles and designs of walkers. The standard walker has wheels in front, grippers for hard surfaces or glides for carpets in the back and typically folds up for travel. More elaborate walkers are available with features such as larger wheels, three or four wheel designs, hand brakes, baskets for carrying items and fold down seats. Most tend to be larger and heavier than the standard walker but typically fold up for transport.



Manual Wheelchairs

If walking becomes more precarious and exhausting, it is usually a good idea to obtain a manual wheelchair to use for longer outings. This wheelchair can also be utilized long term as a backup to a power wheelchair. Manual wheelchairs, like power wheelchairs, are optimally custom fitted for the individual patient. Important features include lightweight folding construction, removable wheels, removable flip up footrests, removable or flip up armrests and a comfortable seat. Depending on factors including cost, availability and how much the wheelchair will be used, the ALS patient may want to purchase or borrow a used wheelchair even though it will not be custom fitted or have all features desired. ALS of Michigan, Inc. operates a loaner closet of medical equipment including wheelchairs available for loan to ALS patients.

Scooters

While scooters are an option for the ALS patient, they are typically useful for a relatively short period of time and for some power wheelchairs may be more appropriate. For this reason, it is advisable to talk with your physical therapist and neurologist to determine what is best for you to use. It is very important to know what your insurance covers before purchasing any equipment such as a scooter.

Power Wheelchairs

As the disease progresses many ALS patients will eventually need a power wheelchair. There are a large variety of power wheelchair designs and options available with costs ranging from several thousand dollars to upwards of twenty thousand dollars. While a low cost wheelchair will probably suffice early on it will quickly become inadequate as the disease progresses. A suitable wheelchair will typically cost at least \$10,000 and once features and options which will be required to meet the long term needs of the ALS patient are added will commonly cost in excess of \$20,000. Insurance companies are very hesitant to approve such expensive equipment and will commonly fight for the purchase of less expensive (and less adequate) equipment. You will likely be required to justify the medical necessity for the wheelchair and options and features you need. For this reason, it is important to have your wheelchair prescription prepared by a physical therapist who understands ALS and can specify and justify your requirements in detail. Options and features the ALS patient should consider are as follows:

1. **Measurement.** The ALS patient should be measured carefully to ensure proper construction of the wheelchair to fit the patient. Remember, the wheelchair will be custom made for you and you have one chance to get it right. Once manufactured, critical dimensions can't typically be changed and you will have to live with the results, right or wrong.
2. **Drive options.** Power wheelchairs are available in rear wheel, front wheel and mid wheel drive. While all three methods have their advantages and disadvantages, front wheel drive typically offers the greatest maneuverability.



3. Controls. Most power wheelchairs come with a joystick control, which can be mounted on either side. If your left handed, make sure your physical therapist knows it and specifies the proper mounting of the control. It is important that the joystick pivot to the side to allow you to pull up closely to tables. Joystick controls are adequate initially but you should make sure the knob can be removed and replaced with other options when the knob becomes difficult to hold. You should also make sure the wheelchair can accommodate future control modification such as sip and puff or head controls. An attendant control (a second joystick mounted on the back of the wheelchair) is also useful in allowing a caregiver to maneuver the wheelchair.
4. Tilt. This feature allows the entire seat assembly to tip backwards. This feature allows the wheelchair to be tilted all the way forward to sit at tables and transfer. Otherwise it can be tilted back slightly to elevate the footrests so they clear ramps, thresholds, van lockdowns, etc. and because it is a more comfortable riding position. You can also tilt back more to go down steep slopes so you don't feel like you're going to slide out. Lastly, tilting allows you to shift your weight helping to prevent pressure sores and elevate your feet and legs, which helps to prevent edema (swelling).
5. Recline. This feature allows the seat back to tip backwards allowing you to bend at the waist. Reclining allows you to relax and/or sleep while in your wheelchair.
6. Foot Pegs (Foot Rests). Power elevating foot pegs allow the feet to be elevated which helps to prevent edema (swelling). This feature also allows the feet to be pulled back from the normal position to enable you to move closer to tables which have legs that interfere with your feet.
7. Lift. This feature enables the entire seat assembly to go up and down, typically from 12 to 16 inches. This is a critical feature that you will use constantly. This feature is invaluable in helping the ALS patient stand up when this becomes difficult. By elevating the seat you will be able to slide off the front or side of the seat into essentially a standing position. The lift feature will also be utilized regularly when transferring since it allows you to adjust the height of the seat either slightly higher or lower than the surface to which you are transferring. It also enables you to sit at tall tables or counters and to reach up to grab or see things.
8. Leg/Trunk Support. It is important that the wheelchair accommodate a variety of leg and trunk support methods. As ALS progresses it is common for the patient to begin having difficulty keeping their legs from flopping apart and falling off the sides the seat. This is typically addressed by installing support pads either on the foot pegs to support the calves or more commonly on the seat to support the thighs. As the upper body becomes weaker the wheelchair should accommodate support pads on the sides of the chest in addition to a second seat belt to go around the chest. Finally, it is important that all support pads be easily removable or easy to flip out of the way.
9. Arm Rests. The armrests need to flip up out of the way to enable transfers. As arms become weaker the standard armrests are typically replaced by armrests with troughs and padded palm rests.
10. Headrest. A cushioned, adjustable headrest, which is easily removable, is essential.



11. Charger. A built in battery charger is very convenient but not essential.
12. Vent Tray. The wheelchair should be able to accommodate a vent tray and an additional battery. If these options can be added later, it is not necessary that they be included upon initial delivery unless they will be required in the near future.
13. Seating. Good seating is extremely important not only for patient comfort but to protect against pressure sores. While the standard seat which comes with most wheelchairs is adequate if the patient is not using the chair continuously, as the disease progresses and the patient spends long periods of time in the wheelchair, a better quality seat cushion will be required. There are a multitude of seating options available including foam, air and gel with the Roho and Jay2 being the most popular. Because of the variety available and the individual nature of decision, it is a good idea to consult a physical therapist and demo several options before buying.

Vans

The use of a power wheelchair requires the purchase of some sort of handicap accessible van. The two common options are a minivan with a ramp or a full size van with a lift. There are a number of companies that modify minivans by lowering the floor and adding a ramp that either folds down or slides in under the floor. The ramp is a much more convenient, though more costly option than the lifts typically installed in full size vans. However, the cost of a minivan is typically lower than that of a full size van and they are smaller and therefore easier to drive and less costly to operate due to better fuel economy. Most vans have a power lockdown installed to secure the wheelchair. These are much less hassle and much faster to use than manual tie down straps. You just drive in and the power lockdown clamps onto a bolt installed on the bottom of your wheelchair. To exit you flip a switch which releases the lockdown and you simply back out and leave.

These vans are usually sold through companies that specialize in handicap vans rather than through regular dealerships. Prices for new vans include handicap discounts offered by major auto manufacturers such as Chrysler, Ford and GM. Unfortunately, health insurance does not cover the cost of these vans or any of the handicap modifications, as they do not consider it a medical necessity. However, the cost of any handicap conversions is tax deductible. For ALS patients who are still working, the state government offers funding assistance through the Michigan Rehab Services 1-(800) 605-6722 or www.michigan.gov/mdcd. For veterans, funding may be available through the Department of Veterans Affairs.

Modifications to enable the ALS patient to continue driving for as long as possible are also available. These modifications facilitate driving from the standard driver's seat after transferring from the wheelchair or driving directly from the wheelchair in the driver's position. It is not uncommon to install lockdowns in both the driver and passenger positions. This accommodates a wheelchair in either position or a standard seat can be rolled in and locked into place over either lockdown. Other common vehicle modifications include low effort or zero effort steering, hand controls for operating the gas and brake, and touch pad controls for starting, shifting and operating accessories.



Transfers

Transfer Boards

When an ALS patient has difficulty standing, but can still maintain balance while sitting, a transfer board is recommended. A transfer board enables the person to slide smoothly from bed to wheelchair, wheelchair to shower chair, etc. Transfer boards come in several styles from simple wood or plastic boards to more elaborate options like the BeasyTrans "S" shaped plastic unit with sliding disk. The most common is the plain polished wooden board. These are made of a hardwood such as 3/4 inch thick Maple with tapered ends, are normally 8 inches wide and available in various lengths with 30 inches being the most usable. They are available with hand cutouts, which while handy present a good place for the patient to get stuck during transfers. While simple, these transfer boards have the advantage of being inexpensive enabling the purchase of several boards for use in different locations.

Gait Belts

A gait belt is a specialized belt with hand straps for the caregiver to grasp while assisting an individual during transfers or walking. This belt fits snugly around the moving individual's waist.

Lifts

When a person with ALS can no longer stand or support himself in a sitting position, a patient lift becomes necessary for transfers. The most common type is usually referred to as a Hoyer lift, although Hoyer is actually a brand name. This type of lift typically consists of a horizontal arm attached to a vertical post that is mounted on a "U" shaped base with heavy-duty casters. A sling, which is placed under the patient, is attached to the end of the horizontal bar and the caregiver pumps a hydraulic lift on the unit causing the patient to be lifted upward in the sitting position. The patient can then be easily transferred to wheelchair, shower, reclining chair, etc. To use this type of lift you need a bed that is lifted at least 4-6" off the ground so that the base of the lift can fit under it.

Hoyer's are not good for bathtub transfers because they cannot get that close to the tub and they are too large to fit into most bathrooms. Wall mount versions, which can be mounted on the wall next to the tub, are available. Models with battery operated, rather than manually operated, hydraulic lift cylinders are also available. Insurance will generally pay for a manual Hoyer lift. They are also commonly available on the used equipment market, from ALS of Michigan and from local MDA loaner closets.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Another lift option is the ceiling mounted lift system. This is a battery powered lift system, which operates from a track that is installed on ceiling and uses the same type of sling as the Hoyer lift. Ceiling track can be relatively short or can be elaborate extending throughout several rooms. These have the advantage of being battery powered, don't take up much room and moving the patient is much easier and safer, especially when compared to trying to roll a Hoyer lift on carpeted floors. While convenient and easy to use, ceiling mounted lifts are also considerably more expensive than Hoyer lifts and insurance rarely authorizes coverage for this type of system.

As mentioned, both Hoyer and ceiling mounted lift systems utilize a sling for lifting the patient. It is important to make sure the type of sling selected provides adequate head and neck support. The newer 4-point style of sling features an open bottom, which makes it easy to put on when you are sitting in a bed or wheelchair without having to pick you up. The sling isn't stuck under the patient, can be easily removed and the open bottom enables toileting.



Environment

As ALS progresses and hands, arms and legs become weaker, environmental access and control become more of a challenge. Opening doors, negotiating stairs and operating stereo and television equipment are examples of common problems that adaptive equipment can help address. Insurance typically will not cover environmental access modifications and control equipment. For ALS patients who are still working, the state government offers funding assistance for environmental access through Michigan Rehab Services. For veterans, funding for environmental access may be available through the Department of Veterans Affairs.

Ramps

Getting into the house can become a challenge especially once the ALS patient begins having trouble climbing stairs or using a wheelchair. Even a single step can prevent access. The most common solution to negotiating entry steps is the construction of a ramp. While ADA requirements specify that a ramp can't have more than a 1:12 slope (1 foot up for every 12 of length) ramps of twice that slope and are commonly built and work fine. Ramps should be a minimum of 36 inches wide and should have a wheel stop along both edges. Depending on the height and whether the patient is walking or using a wheelchair, a handrail on one or both sides may be appropriate. Intermediate landings should be built wherever the ramp makes a turn and a top landing should be built to allow a flat place to stop while opening the door. Most ramps are constructed of wood using post and beam construction similar to that typically used for outdoor decks. The ramp surface is typically 2x6 lumber laid perpendicular to the direction of travel. The Metropolitan Center for Independent Living (MCIL) in St. Paul, Minnesota has excellent ramp construction manuals and videos available for purchase. The manual is also available for free online. Contact information is as follows:

Metropolitan Center for Independent Living, (651) 603-2029
1600 University Ave., St. Paul, MN 55104-3825
Website: <http://www.wheelchairramp.org/>, Email: MCIL2@aol.com

Portable Ramps

Another type of ramp that many ALS patients find handy is the folding portable aluminum ramp. These often allow access to the homes of friends and family. These ramps are typically 30 inches wide by 5 or 6 feet long and fold up to be 8 inches by 16 inches by 36 to 40 inches. Most have a handy carrying handle.

Lifts

Platform lifts can provide access when ramps are not feasible. These lifts are available in vertical and inclined versions, can be installed inside or outside and can provide vertical lifts of up to 12 feet.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Doors

As hands and arms become weaker, opening doors can become a problem. Door width may also present problems for wheelchairs. One of the simplest ways to make doors easier to open is to install lever style handles. Many medical suppliers also sell doorknob turners which convert round knobs to lever handles. Another option is the installation of an automatic door opener. These are extremely handy for wheelchair users and are readily available for both standard doors and sliding glass patio doors. For doors that are too narrow to provide adequate wheelchair clearance, some relief can be obtained by installing offset hinges which typically increase clearance by about two inches.

Environmental Control

Controlling stereo and television equipment, turning lights on and off, adjusting the heat and opening blinds are just a few of the things around the house that become difficult as hands and arms become weaker. Environmental control will be able to help in these situations.

Eating

ALS patients can have difficulty eating and drinking. Some of this difficulty is related to the weakness of the mouth and swallowing muscles. With chewing and swallowing weakness ALS patients must make changes in their dietary consistency meaning they have to eat softer foods and avoid thin liquids. It is important that you monitor and address chewing and swallowing difficulties to avoid problems with nutrition, choking and aspiration (breathing in food, drink or saliva). It is recommended that upon noticing the first signs of swallowing problems you consult a Speech Pathologist/Therapist to be evaluated and receive instruction in safe swallowing techniques. Other eating related difficulties are a result of weakening hand, arm and shoulder muscles. Many adaptive devices and techniques are available. Consulting an Occupational Therapist trained in assessing a patient's ability and recommending environmental modifications and assistive equipment is typically worthwhile.

Thick-It

Thick-It is an instant food thickener for adding a thicker consistency to foods. It will thicken hot or cold, thin or thick liquids and pureed food to any desired consistency quickly, easily and controllably. Simply add the desired amount while stirring briskly and wait 30 seconds for food to thicken. Depending upon the amount of product you use, you can arrive at nectar, honey or pudding consistencies. Thicken everything from fruit juices to carbonated beverages to milk to drink mixes to tea, coffee, lemonade, broth and pureed vegetables. Thick-It is available through your local pharmacist.

Eating Utensils

Holding conventional utensils can become difficult for the ALS patient due to hand and finger weakness. Common solutions include building up the handles of existing utensils using rubber based cylindrical foam available from medical suppliers. Alternately, utensils with large diameter handles, which are specially weighted and balanced, are available. Good Grips is a brand ALS patients have reportedly had good experience with. A variety of utensils are available and many include a special shaft that allows them to be easily bent for right or left hand use. Special knives are available which enable cutting via a rocking motion and require minimal strength. Elastic straps are also available for those with extremely limited grip.

Dishes

Plates are available with non-skid bottoms and raised edges. These plates are non-breakable and eliminate difficulty with chasing the plate around the table and with pushing food off the edge of the plate. Partitioned plates are also available allowing for separation of different foods. Food guards, which fit onto standard plates to provide a raised edge to push food against, are also available. Cups are available with both single and double handles, which make them easier to lift. They are non-breakable and available with spouted lids, which minimize spillage. It is important to verify that dishes you consider are microwave safe as many are made of melamine and should not be microwaved.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Straws

If lifting a drink becomes difficult, drinking straws become indispensable. Straws are also helpful in enabling you to drink with your chin down which helps prevent choking and aspiration. Straws are readily available in bulk from Costco or restaurant suppliers. Slightly larger diameter straws may be easier to use and clear straws allow you to see what you are drinking as it comes up the straw.

Phone Books

As it becomes more difficult to lift food to your mouth, one simple means to make it easier is to elevate the plate closer to your mouth. It may also help to elevate your arm by putting something under your elbow.

Hygiene

As ALS progresses personal hygiene such as bathing, toileting, shaving and dental care become more difficult. If not addressed there is a common tendency to become lax regarding personal hygiene, which may lead to both social and medical problems. Again, this is an area where consulting an Occupational Therapist trained in assessing a patient's ability and recommending environmental modifications and assistive equipment is typically worthwhile. A primary concern needs to be safety since a significant percentage of serious falls typically occur in the bathroom.

Bathing

Since showers and tubs are wet slippery places, safety is extremely important to avoid the serious injury that can result from even a minor fall. Grab bars should be installed to provide support both inside and outside the tub or shower. Look for grab bars in 16, 32 and 48-inch lengths to facilitate mounting on standard stud spacing. Grab bars that clamp onto the edge of the tub are also available. You should also make sure your tub, shower and bathroom floor have a non-slip surface applied and it is a good idea to replace glass doors with a shower curtain. It is helpful to install a hand held shower unit and many patients find soap on a rope and a shower mitten easier to use than soap and a washcloth.

A shower chair is a good idea as leg strength and balance start to become problematic. Shower chairs are available in a variety of styles. The simplest fits completely inside a tub and is available with or without a back. Bench style units are available which extend outside the tub allowing you to avoid stepping over the edge of the tub. As transfers become more difficult, most ALS patients end up using a combination shower/commode wheelchair. This is simply a wheelchair with a padded seat, which has a hole in the middle it, allowing the patient to be rolled over the toilet and then into a shower. These wheelchairs typically have a padded back, flip up armrests to facilitate transfers, removable footrests and usually have roughly 5-inch front and rear wheels. Their use for showering typically requires a roll-in shower. Roll-in showers are expensive bathroom modifications and are typically constructed of ceramic tile or by installing a fiberglass shower unit designed for handicap use. Unfortunately, health insurance does not cover the cost of home modifications although the cost is tax deductible. For ALS patients who are still working, the state government may offer funding assistance through Michigan Rehab Services. For veterans, funding may be available through the Department of Veterans Affairs

Showering while traveling can often be difficult. Newly constructed or remodeled hotels and motels are required by ADA requirements to offer handicap accessible rooms including roll-in showers. These must be offered at the same nightly rate as similar non-handicap accessible rooms. You should however carefully confirm the handicap accommodations as the definition of handicap accessible varies widely. Another option to consider is foregoing a shower for a sponge bath and either shampooing your hair using a sink or using no-rinse shampoo and conditioners available from beauty supply dealers and pharmacies.



Toileting

Using the toilet can become a frustrating and dangerous activity if proper modifications are not made. One of the first recommended adaptations is either installation of a handicap toilet or a raised toilet seat. A handicap toilet has the advantages of a more normal appearance which guests will not feel uncomfortable using and of being more stable and easier to clean. Unfortunately, it is considered a home modification and therefore is rarely covered by health insurance. Raised toilet seats with arms to help you push off the toilet, can be installed on standard toilets and may be covered by health insurance, one should check before purchasing. Grab bars that can be installed on standard or handicap toilets giving you something on either side of the toilet to help you maintain balance while lowering or pushing yourself up off the toilet are also available. The use of a portable commode or combination commode/shower chair will typically become necessary once using/transferring to the toilet becomes too difficult. One of the most frustrating and embarrassing problems an ALS patient can face is the inability to wipe themselves after using the toilet. While most rely on a caregiver for help, one alternate solution is the use of a bidet. These units, which provide a cleansing warm water wash and air dry, replace the existing toilet seat and can be installed on any toilet. Many of these items are available in the loan closet.

An inexpensive portable plastic urinal can make life a lot easier because you don't have to leave your wheelchair to use it. Urinals are available in both male and female varieties. Male patients commonly use external condom catheters and leg bags once they reach the point of using a wheelchair full time. This typically involves putting on a clear, latex free, self-adhesive external condom catheter on a daily basis. Skin shield wipes, also known as barrier wipes, are typically used on the skin surface before the catheter is put on to insure good adhesion and to provide a layer of protection between urine and the skin. The catheter is connected to a plastic, fabric backed leg bag via clear tubing which is an integral part of the leg bag. The leg bag, which has a valve on the bottom for emptying the contents, is worn on the calf of the leg and held on with a pair of Velcro straps. The leg bag typically holds about 500 ml, which normally allows the patient to urinate twice before it needs to be emptied. The leg bag is rinsed with water when removed and is reused for about 3-4 weeks on average before disposal.

Shaving

When shaving with a razor blade becomes difficult, the easiest and safest solution is the use of a lightweight, rechargeable electric razor.

Dental Care

The action of brushing teeth can become difficult as weakness continues. A lightweight cordless electric toothbrush such as the Braun Oral B can make the chore much easier. Even if you have very limited arm strength, you can usually prop your elbows up either on your wheelchair or on the counter. Then put the toothbrush in your mouth and move your head from side to side as the brush does its work. When you are unable to hold the toothbrush, caregivers usually do a much better job using an electric toothbrush. As swallowing and choking become a problem, one option that is available is a manual toothbrush made to be installed on a suction machine. The handle has a hole in it like a typical suction wand, which when uncovered allows saliva and toothpaste to be suctioned from the mouth. It is also important to maintain regular dental checkups and cleaning appointments



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

and to discuss optimal care with your dentist. Depending on your condition, your dentist may recommend other preventive care such as the use of an antibacterial mouthwash or fluoride rinse.



Sleeping

As ALS progresses, sleeping can become more of an issue. As the patient becomes unable to turn or move, sleeping comfortably in one position for extended periods becomes more challenging and the possibility of pressure sores becomes more likely. As respiratory weakness progresses, proper positioning to make breathing easier also becomes more important. Luckily, adaptive equipment is available which should enable the patient to comfortably sleep even in the advanced stages of ALS.

Hospital Beds

A hospital bed can make a big difference in comfort for ALS patients. These beds have adjustments for raising and lowering both the head and the foot sections. Sleeping with the head raised 10-40 degrees allows for easier breathing. Sleeping with the legs raised slightly will help reduce the common problem of swollen feet. There are three types of hospital beds: manual, semi-automatic, and fully automatic. A semi-automatic model with electrical controls to raise and lower the head and the foot sections is the most appropriate type for an ALS patient. A fully automatic bed, which will also raise and lower the entire bed to facilitate transfers and aid caregivers, is nice but not necessary. Hospital beds should be ordered with half linked side rails that can be raised or lowered as desired. These give the patient something to grab when transferring and turning or repositioning. Insurance companies will usually cover the cost of a semi-automatic hospital bed. In most cases, the beds are provided on a rental basis.

Mattresses

As PALS become weaker and unable to turn in bed by themselves, a low air loss mattress or alternating pressure mattress becomes essential. Lying in the same position all night long on a conventional mattress is not only very uncomfortable, but can also lead to painful pressure sores. The only way to minimize this discomfort is to have someone reposition the PALS several times a night or use one of these special mattresses. The alternating pressure mattress is a special air mattress, which has many cells, which alternately inflate and deflate slightly. This prevents too much pressure building up in any area of the body. An even better option is the low air loss mattress. This is a high-tech air mattress made of a material that allows air to seep out slowly. An electric pump keeps the mattress inflated. The constant slow air loss keeps the skin from sweating and prevents pressure points. Both the alternating pressure mattress and especially the low air loss mattress are expensive but insurance companies will often provide them for ALS patients. This is because the cost of treating skin breakdown as a result of pressure sores is even more expensive for insurances.



Swelling (Edema)

Swollen feet and legs, due to the lack of muscle action in the legs is a common problem for ALS patients. The feet often get progressively more sensitive, painful and discolored during the day. Although it is probably impossible to prevent swelling entirely, it is very important to minimize it to prevent further complications such as persistent pain, blood clots and ulcers. The simplest methods to reduce swelling are massage and elevating the feet. Compression stockings and compression boots as described below are also helpful.

Compression Stockings

The use of compression stockings is by far the most common first treatment step beyond simply elevating the feet. These elastic stockings help keep the veins from getting distended by simply squeezing the legs and feet a little. Compression stockings vary from over the counter styles, which provide mild compression to high compression styles requiring a doctor's prescription. Compression stockings can be difficult to put on and unless you have strong hands and arms, you will probably need help getting them on. One useful tip to make it easier to put them on is to wear Playtex style rubber gloves.

Compression Boots

Hospitals use what are called compression boots to help minimize edema. These are simply plastic or nylon boots that inflate and deflate to help pump the blood along. One study apparently showed that simple alternating pressure on the soles of the feet greatly improves flow, so some brands of boots simply apply waves of pressure to the bottom of the foot. These boots over sequential compression by dividing the calf boots into four separate sections: toe, ankle, lower calf and upper calf. By inflating these sections sequentially the boots provide a gentle and effective milking style compression motion. With help from your doctor you may be able to get your insurance to cover the cost of this equipment.



Communicating

Perhaps the most frustrating and emotionally painful aspect of ALS is the ability to communicate. The good news is there is an explosion of new technology in the augmentative communication field. New, more sophisticated hardware and software systems are coming out in droves to allow PALS to continue to communicate. High tech solutions are not the only answer. Low tech solutions such as alphabet boards, communication charts, lip reading and the use of Morse Code are a cost-effective, convenient and effective ways to communicate.

Insurance coverage for augmentative communication is normally covered. Medicare considers Augmentative and alternative communication (AAC) devices that generate speech for people with limited vocal ability as durable medical equipment, eligible for coverage by Medicare. Although there are still limitations (laptops probably won't be covered) this is a big step forward since many private insurance carriers base their coverage on Medicare guidelines.

Augmentative communication is an area where consulting a Speech Language Pathologist trained in assessing a patient's ability and recommending assistive equipment is typically worthwhile. This is a fast changing and complex field. Insurance coverage will also typically require an evaluation and recommendation from both a speech language pathologist and physician before considering equipment for coverage.

Communication Charts and Alphabet Boards

In addition to lip reading, communication charts and alphabet boards are common low-tech ways that ALS patients use to communicate. Communication charts are simply charts with numbered lists of commonly used phrases. The patient or character then simply points to a phrase to communicate. An alphabet or letter board is a grid of letters and symbols that one points to in order to communicate.

Speech Synthesis

In the case of bulbar onset, the voice is often one of the first losses experienced by the ALS patient. Many bulbar patients continue to communicate well either by writing, using a keypad device laptop computer. Speech synthesis programs are available for laptop computers to give a voice to what is typed. [E-triloquist](#) is a free Windows based computer program which provides an electronic voice for those who can not speak. It can record, save and play words or phrases as well as performing free-form text to speech synthesis.

Voice Recognition Software

Limb onset ALS patients often lose the ability to use their hands while their voice remains strong resulting in difficulty being able to use the computer. An excellent option to solve problems using a computer keyboard is the use voice recognition programs.



Onscreen Keyboards

Once a patient loses both the ability to speak and to use a keyboard, the use of an onscreen keyboard allows the continued use of the computer for communication. These keyboards can operate by clicking on letters with a mouse or input device that provides mouse emulation. Many onscreen keyboards also have a scanning feature to enable operation via a single switch. When using the scanning feature, each time you click the switch, the cursor "scans" through the "keyboard" row-by-row, then column-by-column until your desired selection is reached. Many onscreen keyboards also have word prediction to eliminate the need to type entire words. With word prediction, as you enter letters, the program predicts words that begin with the letters you have entered. When you see your word on the list of predicted words, you select it and the word plus a space is placed in your text.

Mouse Emulation

There are two common alternatives that provide mouse emulation: the head controlled mouse and the eye-controlled mouse. Head controlled mouse systems operate by placing an infrared camera on top of the computer display. This camera tracks a small reflective dot worn on the forehead and moves the computer mouse relative to movement of the users head. Eye controlled mouse systems work in a similar manner to head controlled mouse systems but track the movement of the eye rather than the head. The tracking cameras are either mounted on the computer display or built into a lightweight assembly attached to glasses.

Switches

There are a number of innovative switches on the market, which can help patients communicate even when most muscle function is gone. Switches are which can be operated by virtually any body part. As long as the patient has one muscle he or she can move, an infrared switch can be hooked up to the muscle allowing access to scanning communication software. Very often the eye muscles remain intact even though the rest of an ALS patient's body may be paralyzed. Several systems are available which respond to eye blinks or eye movement.



Breathing

Many ALS patients will have increasing difficulty breathing. Unlike typical patients with respiratory problems, ALS patients rarely have trouble pulling oxygen out of the air they breathe and therefore the use of supplemental oxygen is typically not appropriate. The problem ALS patient's face is simply the inability to move a sufficient amount of air in and out of the lungs due to muscle weakness. While this can result in low blood oxygen levels it also results in an equally dangerous buildup of carbon dioxide in the lungs and blood, which the use supplemental oxygen does not address. The solution to respiratory problems in ALS patients is the use of a bipap unit or ventilator to help move an adequate volume of air in and out of the lungs. It is generally believed that early use of this type of equipment, typically at night, helps slow the loss of respiratory function. It is therefore usually recommended upon the first signs of respiratory distress (difficulty breathing, morning headaches, drowsiness, etc.) or when a patient's breathing capacity falls to between 50 and 75% of normal.

Bipap

BiPap stands for bi-level positive air pressure. It is a machine with two levels of air pressure--higher when you breathe in--lower when you breathe out. A mask fits over your nose, or alternately nasal pillows fit in your nostrils. The machine senses when you are breathing in and pumps additional air into your lungs. Most ALS patients initially use bipap only while sleeping when breathing is more difficult.

Nasal Masks

There are three common styles of masks used for nasal ventilation: the nasal mask, the full-face mask and nasal pillows. The nasal mask covers the entire nose and is held in place by straps connected to headgear. There are a large variety of manufacturers, models and sizes available and comfort varies depending on the individual. Some patients use several masks, rotating between them to avoid repeated pressure on the same area of the skin. Some patients who have trouble keeping their mouth closed may need to use a chinstrap to hold the mouth closed. Full-face masks are also available to alleviate problems due to air leaks from the mouth or congested nasal passages. These masks cover both the nose and the mouth. These are not used frequently because they impair the ability to talk. Nasal pillows are cushioned inserts that fit comfortably inside the nostrils. Nasal pillows, while not as secure as a nasal mask, have the advantage of being more comfortable for many patients. They also have the advantage of easily permitting the patient to wear eyeglasses. Some patients use nasal pillows during the day and a nasal mask while sleeping.

Ventilator

The ventilator is similar to the BiPap machine but differs in one important aspect: it is designed and approved for life support. Primarily this means that these units have a variety of sensors and alarms to monitor proper operation expense, include an internal battery to allow them to work if there is a power failure and are designed to attach easily to an external battery. Ventilators also have more sophisticated controls and adjustments and support both non-invasive ventilation (via masks) and invasive ventilation (via tracheostomy).



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

In-Exsufflator

One problem ALS patient's face as respiratory weakness progresses is the inability to cough. The In-Exsufflator manufactured by [J.H. Emerson](#) is designed to address this problem and as been successfully used in the treatment of numerous ALS patients. The In-Exsufflator (Cough Machine) assists patients in clearing secretions by gradually applying a positive pressure to the airway, then rapidly shifting to a negative pressure.

This rapid shift in pressure, via a facemask, mouthpiece or tracheostomy tube, produces a high expiratory flow rate from the lungs, simulating a cough. Use of the In-Exsufflator is particularly important for patients on non-invasive ventilation, since suctioning is difficult without a tracheostomy tube.