

LIVING WITH ALS

Functioning When Your Mobility Is Affected



Cover: *The Wheelchair Race* by Jean Watson.
The artwork on the covers of the *Living With ALS* Manuals was created by individuals with ALS or their family members.

Message from the Artist

“Soon I’ll be 70. WOW!! When I was in my 20s and 30s, I could never imagine being 70. Life is slower and has limits imposed by ALS. Almost 12 years have passed since my diagnosis, but this does not impose limits to my enjoyment of the fullness of each and every day. The positives of life will always outweigh any negative, and, besides, you never lose the power of remembering the experiences you have lived and loved.

I call this painting “The Wheelchair Race” because my son is a marathon runner, and I have gone to many of his races. Naturally, I am interested in the passion and the heart shown by wheelchair participants, particularly now.”

JEAN WATSON
Artist
Person living with ALS

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Manual 4

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A note to the reader: The ALS Association has developed the *Living With ALS* manuals for informational and educational purposes only. The information contained in these manuals is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.

LIVING WITH ALS
Functioning When
Your Mobility is Affected

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Introduction

G

etting up out of a chair, going downstairs, walking to the corner store, and carrying groceries are some typical daily activities.

Many people are unaware of how much simple pleasure they get from these changes of scenery or from the independence of being mobile. Living with ALS causes you to pay attention to and come up with ways to maintain your everyday activities.

Physical and Occupational Therapy

A

s your ability to function changes, you can meet the challenges of maximizing your mobility, independence, safety, and comfort with the help of **physical therapy/therapist (PT)** and **occupational therapy/therapist (OT)**. PT is rehabilitation concerned with restoring function and preventing disability by using exercise, heat, ice, electricity, ultraviolet radiation, and massage. OT is the use of work, self-care, and play activities to increase independent function, enhance development, and minimize disability.

Specifically, PTs assist you with meeting the challenges of safe walking, transfers from one position to another, prevention of injury, exercising, and pain treatment, as well as education for you and your family regarding these issues. OTs specialize in making recommendations to adapt your **activities of daily living (ADL)** such as combing hair, brushing teeth, writing, and so on. They can suggest equipment to make some of these tasks easier or help you to adapt your home environment in order to maintain your functional independence. By making home visits, both PTs and OTs can measure you for a wheelchair and suggest other adaptations for your home environment.

In order to design an appropriate program for adapting the needs of a physically disabled person, an OT or a PT must have: 1) creativity, 2) a comprehensive background working with the disability, 3) knowledge of funding resources, and 4) awareness of all products available, as well as the ability to customize them and provide training in their use.

Bone, Muscle, and Joint Problems

P

art of maximizing your function and comfort lies in preventing or minimizing joint discomfort and addressing any painful areas quickly; thus, your first priority is to get help from your doctor(s) and therapist(s) as early as possible. As you know, ALS is primarily associated with weakness, not pain.

Yet, changes in muscle strength, and therefore your ability to fully use your joints and maintain your usual posture, can lead to secondary joint and muscle aches. For example, if you find walking so difficult that you spend much more of your day sitting than ever before, you may find that your neck and upper or lower back ache a little, or that your feet get cold and “puffy.” Persons with shoulder weakness, if not advised about prevention, can get a very painful condition called **adhesive capsulitis** (frozen shoulder). Sometimes, hand weakness can lead to mild knuckle and wrist aches or swelling. You do not have to put up with these problems; they can be prevented and/or managed.

SITTING

Sitting in a chair, on a soft couch, or in bed with your lower back “slumped,” the upper back “rounded out,” and your head tilted forward is enough strain to give the healthiest person a headache or backache. This strain is even greater when you are not able to change positions frequently or walk for very long. If you can stand safely, do not sit for more than an hour without getting up; simply standing and shifting your weight back and forth from right to left for a minute or so helps. If you are able to walk safely, frequent, short strolls around the house can reduce your sitting time.

Supporting the small of your lower back with a pillow (a **lumbar roll**) is critical to decreasing the likelihood that you will get neck or upper- or lower-back strain from prolonged sitting. When you are seated, try not to raise your knees up higher than your hips because this position tends to flatten or slump the lower back. Either use a different chair, or place another cushion under you so that the knees are level with or slightly lower than the hips. Avoid chairs that have “sling” seats. These tips are particularly important if you have any neck or back weakness from ALS.

If your feet get puffy, it may be helpful to prop them up (elevate) sometimes or get a prescription from your physician for support stockings. The swelling is most often related to decreased foot/leg strength, because the muscles are not adequately pumping fluids back up toward the trunk of your body.

EXERCISE

Whether you were just diagnosed with ALS or you have had it for a while and have restricted mobility, exercise is beneficial to you. Remember, though, that there are many kinds of exercise, and although strengthening may not be appropriate for the weakest muscles – or not recommended at all for some people with ALS, stretching is beneficial at every stage.

Strengthening, unlike stretching, involves a repetitive movement which is often done until the muscle fatigues a little; **stretching** is most often a slow activity that is done to preserve or increase flexibility. One of the most frequent and pressing questions asked is, “Can I strengthen my muscles?” There is no consensus among health care providers regarding the effectiveness of strengthening exercises in ALS. However, what is known is that strengthening does not change the rate of the progression of weakness.

Caution: Do not attempt any exercise program until consulting with your doctor and a PT; this warning is particularly important for people with underlying cardiac conditions or other medical problems.

Please consider the following guidelines before initiating strengthening exercises:

- First, weak muscles that get fatigued with daily activities and are barely able to lift a limb against gravity should not be pushed by strengthening. For example, if you are unable to lift your right arm overhead but your left one is strong, then the treatment will differ for each arm. With the right arm, it would be advisable to do stretches but not repetitive weightlifting. Such a weak muscle is most likely functioning at its peak with simple motions; to force weightlifting could be harmful.

- Second, a muscle operating at full strength normally accomplishes its routine activities by using a very small percentage of its total capacity. For example, if your healthy arm normally can lift a maximum of 40 pounds, and the heaviest item you pick up rarely exceeds 10, then you are only using up to 25% of your muscle's total strength. For this limb, strengthening exercises would be fine.

- Third, the precautions for strengthening exercises are that if you feel weaker afterward, *or* if you notice fatigue that lasts a long time, then you have done too much. Always “listen” to your body and cut back when necessary. If you have arm weakness but do not notice any leg symptoms, you can walk, ride a bike, and do a number of different activities to improve body circulation and strength. Additional benefits of exercise also include mood elevation and improved sleep patterns.

- Fourth, if you experience mild-to-moderate weakness in all of your limbs, yet want to feel uplifted and increase your comfort, a program of low-level range-of-motion exercises in a warm pool may be helpful. **Pool therapy** offers the benefits of **buoyancy** (the power of supporting a body so that it floats), because the water assists you with your workout and therefore requires less effort. Walking is also easier when you are in a pool; you get the benefit of being upright and weight bearing without the worry of falling. You also get the healthy pressure on joints that comes with walking, without the safety concerns that might usually be present.

FLEXIBILITY

In healthy muscles and joints there is a balance of strength and tension, and the joint moves in a variety of ways throughout the day. With ALS, the natural balance of muscle tension around the joints may be offset by weakness of one or more of the muscles. This imbalance can make the muscles and tendons get tight. For example, with ankle weakness that causes your foot to hang down when you are trying to walk (**foot drop**), the muscles on the front of the lower leg are weaker than the calf muscle; the ankle area (**Achilles tendon**) tightens, which can interfere with endurance and safety in walking.

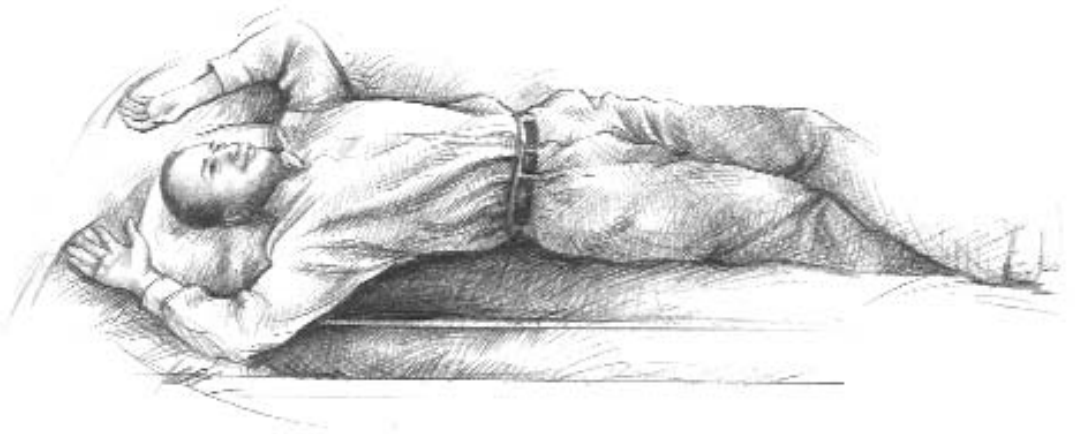
Additionally, movement and pressure are essential for **cartilage** (connective tissue) and joint health. Irregular layers of collagen build up when the joints are immobilized, which is similar to scar tissue in the joint. Often, the most painful joint restriction is frozen shoulder which can be prevented. By maintaining your flexibility, you can take an active role in maximizing your function and comfort. If you are not able to do the stretches yourself (**active stretches**), then a caregiver can be trained to help (**passive stretches**).

There are many types of stretches which can be done on a daily basis to help maintain your flexibility. Four examples of **shoulder flexion** are illustrated on the following two pages (Fig. 1). Stretching can help with the mobility problems that occur in your shoulder area. Hold the stretched position to a point where *you feel a beginning stretch*, not where you feel pain. For more information about additional stretching exercises, please consult with your PT.

FIGURE I

Four examples of shoulder flexion exercises





PRIORITIZING

While most people lead busy lives filled with work, family, friends, and hobbies, some have never made exercise an important part of their lifestyle; however, a diagnosis of ALS might make exercise more of a priority. A strengthening program does not have to become part of your routine, but get accustomed to doing a few stretches every day based on your needs and symptoms. If you have any shoulder weakness, perform the easy shoulder flexion stretch with arms overhead for two minutes in bed, morning and evening, to prevent the painful complication of frozen shoulder. If you begin to note shoulder pain, then your therapist can teach you an “external rotation” stretch and recommend whether or not additional treatment is needed.

You can prioritize a home program based on how effective various stretches are for the prevention or treatment of pain, and how well they maximize the functions most important to you. For example, a person with very weak legs, strong arms, mild-to-moderate neck pain, and an accommodating caregiver (with ample time and strength) will have different priorities than one with **bulbar symptoms** (affecting speech, swallowing, breathing, and saliva control) who walks one mile daily and adds a calf-and-thigh stretch to this routine.

In addition to stretches of the neck, shoulders, and hands, and the range-of-motion exercises for all the major joints, the person with limited mobility must pay attention to proper sitting support and the use of a lumbar roll. If you consult a PT for a home program, be sure to communicate how you would like it prioritized and how much time you can devote to it realistically.

Equipment

A

lthough you will have progressive muscle weakness with ALS, fortunately there are numerous pieces of equipment and other aids that will help maintain your quality of life. This equipment also can provide tremendous assistance and additional support for your caregivers.

Just as exercises can help you maximize your body's function and your safety, so can various braces and equipment. If you limit your walking because of fatigue, you may choose to participate in more family activities when you get a walker with wheels, brakes, and a seat. This piece of equipment allows you to remain as involved as possible with family, friends, and hobbies. Should you develop foot drop, you must lift your leg higher to avoid tripping, using the thigh muscles in place of lower-leg and foot muscles. This movement takes more energy, since it uses large muscles to do the job of small muscles, and because you must pay attention to each step to avoid "catching" a toe. An **orthosis** or **brace** helps keep the forefoot up and therefore promotes safety and endurance.

If you are worried that braces will increase weakness and thus wish to avoid them, this concern is not the case for ALS patients. Usually, a brace or piece of equipment is recommended because some of the muscles are so weak that they are unable to keep up with the demands of functional activities. Such muscles are already over-fatigued. Not wearing a brace may further decrease their limited effectiveness. The following sections cover the equipment available to assist with and enhance your mobility.

WALKING AIDS

Canes

- **Single-point** (a straight cane with a handle): This type of cane is useful if you need some help with balance and have enough hand strength to grip it. If one or both of your legs are weak, then hold the cane in the hand *opposite* the weakest leg.
- **Four-point** (a cane with four prongs at the bottom): It is like a regular cane, except that there are four prongs with rubber tips that touch the ground. It can be awkward to handle and is not frequently used for patients with ALS.
- **Canadian (Lofstrand) crutches**: While similar to regular crutches, they are not positioned under your arms but have a section that grips the forearm, along with a hand grip. They give additional support because you can bear some weight on your forearm as well as your hand. One or two can be used to help with balance and endurance. They are more successfully used when there is a great deal of **spasticity** (stiffness).

Walkers

Walkers provide the most assistance with balance and endurance among all the walking aids. Standard-issue, inexpensive hospital walkers are not the best choice for most ALS patients – unless the cost of other models is too high or you are limited to very short distances. Tripod walkers are generally not recommended.

The most ideal walker is a large-wheeled (swivel), all-terrain model with brakes and a seat. Hand brakes are appropriate if you have sufficient grip strength; push-down brakes that engage when you lean down on the walker are better for individuals with weak hands. Lightweight models are often best, unless you have a lot of spasticity but good strength; in this case, a heavier model may work well. Try different walkers and get input from your therapist.

The following walkers are currently available:

- **Pickup walker:** a four-legged walker without wheels.
- **Two-wheeled, non-swivel:** a four-legged walker with two front wheels that do not swivel.
- **Two-wheeled, swivel:** a four-legged walker with front swiveling wheels for easy turning.
- **Two-wheeled with brakes:** a four-legged walker with front wheels (swivel or non-swivel) and with either front or rear pushdown brakes, for those with hand weakness.
- **Four-wheeled with brakes** (hand or push-down): a four-legged walker with front swiveling wheels and brakes that are either grip-style or push-down; it is often the most appropriate walker for a person with ALS and can come with a seat for taking a break.
- **Tripod:** a three-wheeled walker with a front swiveling wheel and brakes.

Braces (Orthosis)

The most commonly recommended braces for people with ALS include an **ankle-foot orthosis (AFO)**, **cervical (neck) collar**, **low-back brace**, and **resting hand splint**. Braces are used when muscles around a joint are not able to support that joint adequately, thereby maintaining function and comfort.

Braces should not hurt or make your condition worse, but do not give up if your first experience is uncomfortable or awkward. Work with your **orthotist** (a professional skilled in providing mechanical appliances for orthopaedic use) or PT to revise your brace until it can be worn comfortably. If your health care providers are not familiar with an orthotist, the rehabilitation department at your local hospital or ALS Association chapter may have a recommendation.

- **Ankle-foot orthosis (AFO):** When you have foot drop or when spasticity pulls your foot down, an AFO can increase safety and endurance (Fig. 2). A manufacturer's ready-made AFO may be appropriate, if your knees and thigh muscles (quadriceps) are strong enough not to buckle, and you do not have a lot of spasticity. A thin, ready-made, or hinged AFO will not help you keep your knee straight, nor will it resist knee buckling, so a custom-made brace might be suitable.

Maintain your ankle range of motion by stretching your Achilles tendon. If your Achilles tendon does become tight, your orthotist can still make a brace; however, by then, it will only accommodate your **best corrected position**, which means that ankle tightness will limit the effectiveness of the brace. Limited ankle range of motion tends to throw your weight back and affects your overall balance.

FIGURE 2
Ankle-foot orthosis



- **Cervical (neck) collars:** The level of weakness determines what kind of neck brace you require. You may have enough neck strength in the morning to hold up your head, but as the day progresses, it becomes more difficult; a soft collar could be used as needed. If your neck weakness is moderate or marked, challenging you to keep your head in a comfortable position, you probably need a firmer brace.

It is almost impossible to find a hard collar that is both adequately supportive and comfortable, since your head is heavy. If you prop its weight mostly on a chin support, for example, the skin and jaw pressure may be too much. Your orthotist or PT should help you select a brace that is best for you. When you take off the brace, do neck stretches with a caregiver's assistance.

- **Low-back brace:** If your abdominal and back weakness forces your pelvis forward and your back to slump when you walk, a soft, low-back brace (**abdominal binder**) may help. Although it will not correct the problem, it may decrease lower-back soreness and fatigue with walking. Rigid back braces may throw off your balance and be uncomfortable.
- **Resting hand splint:** With hand and forearm weakness, sometimes the muscles going into the fingertips can get tight. You can do stretches or wear hand splints (at night usually) that keep your fingers and wrists slightly extended. Using two hand splints might limit your mobility, so consult with your PT or OT to discuss these types as well as to evaluate their cost/benefit.

WHEELCHAIRS

When is it time to get a wheelchair?

- When you are no longer able to do things and go places. Some people may think that being dependent on a wheelchair implies being disabled. However, the use of this type of assistive device may allow you to be more independent. Remember that there are millions of people in wheelchairs. Even a former President of the United States – Franklin D. Roosevelt – used one.
- When you are often in danger of falling.
- When you are *not* going on outings because you lack strength and endurance. If you get a wheelchair, it does not mean you have to be in it all the time. You can use it just for long-distance mobility, such as going to shopping malls and taking walks with your family. You can even push the chair from behind for stability and sit in it when you are tired.
- Before your falls become routine. Funding could take time, due to insurance, so think ahead. You may ask your local Muscular Dystrophy Association (MDA), ALS Association chapter, or ALS clinic for a loaner while you are planning your own wheelchair needs. If you are still unsure about whether you would benefit from the use of a wheelchair, consult your doctor or PT.

What types of wheelchairs are available?

Your chair must fit correctly and have the appropriate accessories. If you go to an ALS or rehabilitation (rehab) clinic, you can find a trained professional to help you make these decisions. An OT, PT, or rehab specialist should measure as well as weigh you for seat depth, width, and height, back height, and wheel placement.

Be sure to get the wheelchair from a medical equipment supplier who is familiar with ALS and supplies a rehab clinic, not a home care equipment supplier (who may just handle standard/pre-manufactured pieces). A rehab equipment retailer certified with **National Rehab Tech Supplier** has experience with customizing equipment to meet your individual physical size and medical needs.

FIGURE 3
Wheelchair



Manual Wheelchairs

A typical manual wheelchair (Fig. 3) for someone with ALS usually includes the following:

- **Lightweight construction** (non-reclining), making it easier for you to propel with your arms, feet, or both; to begin with, you may wish to *borrow* this type of chair.
- A **high reclining back with a headrest** which allows you to rest and redistribute the pressure to different parts of the body. It also relieves breathing difficulties. There are also manual chairs which have the ability to “tilt” to various degrees (described under *Power Wheelchairs*). These also provide pressure relief and prevent a person from sliding down in the chair. (You probably will not need either of these features initially, but later on your head and trunk may become weak.)
- **Elevating legrests** to allow repositioning and stretching of your legs.
- A **seat cushion** for comfort and support.
- A **back cushion**, also for comfort and support.
- **Adjustable-height armrests** which are removable for transfers.
- **Quick-release rear wheels** for taking the chair apart and placing it in a vehicle for travel.
- **Correct seat height** for transfers to and from the chair and for propelling with your feet.
- **Appropriate wheelchair width** so that the chair will fit through your living area doorways (which should be measured). For more information about this topic, please refer to *Adapting Narrow Doorways* later in this manual.

Power Wheelchairs

If you are unable to move a wheelchair yourself, a power wheelchair may be prescribed. Two important considerations before you purchase one are: 1) your home is wheelchair accessible and 2) the power wheelchair can be taken apart to fit in a vehicle if necessary (it usually is not designed to do so). While **scooters** can be disassembled and are less expensive than power wheelchairs, they are not as durable, reliable, and stable. They also do not accommodate seating and positioning needs, require hand and arm strength, and lack a reclining back and headrest.

Power wheelchairs usually include the following features:

- **Special electronics** which can be expanded as your needs change. For example, if your hand becomes too weak, you may need to change the hand control to a head or chin control, sip and puff (mouth device), or single-switch scanner.
- **Reclining back with head support** with a separate motor and toggle switch that allows you to control the positioning. There are two types that can be combined: *recline* – the back reclines away from the seat, and *tilt* – the seat and back angle are fixed, and the seat tilts back (like a rocking chair). If you do not have the funding for both, the recline type is preferred.
- **Elevating legrests** are usually power-operated if there is a power reclining back.

The features discussed above are the most ideal; however, funding is a critical consideration and will be discussed later. These points/features are generalities, since the final product should be as unique as the individual using it.

Specially adapted vans are also available to accommodate power wheelchairs so that you can continue to travel as you need and want to. Vans equipped with ramps, electric lifts and adjusted height, can be expensive. Used vans are often available and it is important to coordinate the van adaptations that will be necessary based on the particular power wheelchair designed for your individual needs. Remember to assure that the van includes adequate seat belt restraints for you and your chair to prevent injury.

Types of Seating Equipment Used with Wheelchairs

The longer you are sitting in a wheelchair, the more important your seat and back supports become. It is easier to get up and out of a firm, high chair than a soft, low one. The surface heights can be adjusted with the use of one-to-four-inch cushions. If possible, carry a cushion to allow you to sit on a number of different surfaces as well as to help you to stand up independently.

The following are some of the different kinds of cushions that can improve your positioning, increase your comfort, and assist in your standing up:

- **Air cushions:** The **Roho**[®] pressure relief cushion has proven to be the most successful; it has rows of cells that are pumped up with air. Roho[®] makes a lightweight cushion called the “Enhancer” which contours and positions well. This product is good for people who cannot move themselves to redistribute pressure while sitting or who are at risk for **pressure sores** (bedsores) caused by the body’s immobility. Air cushions require maintenance (pumping them up) for proper pressure distribution. If you do not have a caregiver readily available, avoid devices that require maintenance.

- **Gel cushions:** When you sit on this type of cushion, the gel conforms to your thighs and buttocks and spreads the pressure evenly. It is usually for people who cannot move around to provide their own pressure relief. Be aware that the most commonly used gel cushions are heavy, weighing up to eight pounds, and that some types require that the gel inside must be massaged periodically, to keep it evenly distributed.
- **Foam cushions:** Generally lightweight and maintenance-free, they are useful if you can move around in your seat to get some pressure relief. **T-Foam** cushions are firmer and conform more than the standard kind.
- **Cushion Covers:** If a waterproof cover is needed for **incontinence**, (inability to hold urine or stool) use a foam cushion interior. Obtain two covers, if possible, especially if you plan to be sitting all day.

Types of Positioning Equipment Used with Wheelchairs

- **Trunk supports** (torso or lateral): They keep you from falling to the side in a wheelchair, which can occur with upper-body weakness.
- **Arm troughs:** Installed on the armrests of the wheelchair and used as an arm cradle, troughs are for people who cannot hold up or move their arms. Persons with swelling in their hands and/or who are at risk for dislocation of the shoulders should make use of them, also. Wheelchair trays (“lap boards”) provide similar relief and support.
- **Headrests:** If you have a reclining or tilt-type wheelchair, you will need to support your head when you recline. A headrest can usually be adapted to other types of wheelchairs, as well.

Transfers

T

RANSFERS WITHOUT EQUIPMENT

The more you and your caregiver know about transfers, the easier it will be for both of you. Using brute strength without good body mechanics to lift and move a person with ALS puts the caregiver at risk of low-back strain and endangers the patient. It is very important for you to have a home or outpatient visit with a PT before you try any of the transfers described below; he/she can help you learn the essential principles regarding body mechanics and the proper techniques involved with transfers. Even under the best circumstances, it is not easy to help someone move. Caregivers should consider an exercise program to keep up their own strength and flexibility, so that they can perform transfers effectively.

Sit-to-stand

When you rise from a seated to a standing position, either on your own or with assistance, the same principles apply. Scoot to the edge of the chair, lean your trunk forward 30-to-40 degrees (taking some of the weight of your trunk and head away from your bottom), and rise. For help in getting up, assume the same position, and your caregiver should squat (bend knees, stick bottom out) facing you and grab your belt or under your buttocks (do *not* pull on caregiver's neck or back); the caregiver then blocks your knee with one of his/her knees in case it buckles, and both of you stand at the same time. Your caregiver should pull your pelvis toward him/her as though you were going to slow dance. If this method becomes too difficult, go to a sitting transfer. Your caregiver should *not* bend from the waist but from the hips and knees.

Standing pivot

After your caregiver assists with sit-to-stand, then he/she should face you, holding your pelvis closely, and pivot 90 degrees without twisting his/her spine. If you can take small steps during the pivot, you can help by shifting your weight to the side while one foot moves, then shifting to the opposite side to move the other foot. With your backside directly in front of the seat you are about to use, your caregiver keeps one of his/her knees in front of your knee in case it buckles. As you are lowered into a sitting position, he/she bends at the hips and knees and aims your bottom toward the back of the chair or all the way onto the bed. It is as though you are both getting into a seated position, but your caregiver should end up in a squat.

Sitting transfer

Position a chair next to the surface to which you are transferring. Ideally, the chair should have no arms, or a wheelchair should have the arm next to the surface removed. Scoot your bottom toward the edge of the chair; your caregiver can help by shifting your weight to one side of your buttocks and pulling the other side of your pelvis/leg toward the edge, then doing the same with the opposite side. While you lean forward, your caregiver squats, and blocks one or both of your knees with his/her own, grabs your belt (or under the buttocks), rocks you forward until your bottom lifts, and then swings your bottom toward the bed or chair. You may find that a swivel disk (like the revolving tray called a lazy Susan) under your feet can help. The caregiver *should not twist his/her spine*, but should end up facing you in a squat position. If this procedure is too difficult, try using a transfer board.

Lying-to-sitting

Whether you are getting up alone or with assistance, the same suggestions apply. Roll to your side facing the edge of the bed that you want to sit on. Your caregiver can help you roll by bending your knee nearest the middle of the bed and then pulling from your pelvis and shoulder to roll you on your side. Once you are on your side, bend your knees so your legs drop at the edge of the bed (the caregiver can assist). Then push with your elbow and hand (or the caregiver can hold your shoulder) and sit up sideways. Reverse the procedure for a “sitting-to-lying” transfer.

Scooting in bed

When you transfer to your bed, always try to place your bottom so that when you lie down, your head will end up in the right spot. If you need to scoot yourself around while lying on your back, bend both of your knees, keep your feet on the bed, and lift your bottom up a little (the caregiver can help by holding down your feet and/or using a towel under your backside); then you or your caregiver can move your bottom in the desired direction. It may take several such moves to find the best position.

Some practice with a PT or OT will enable you and your caregiver to find solutions to challenging transfers. Do not try to attack mobility problems by yourself. Take advantage of the help that home care and rehabilitation services can offer.

TRANSFERS WITH EQUIPMENT

As transferring becomes increasingly difficult, you might need to use equipment. Get assistance from an OT or PT to help you choose and adapt to transfer equipment. The following are some options:

- **Transfer Board:** It helps you move when you have difficulty standing. The board acts as a bridge, with one end put under your bottom, and the other end sitting on the surface you are transferring to. Then you slide across the board to the other surface, usually with your caregiver's assistance. It gets difficult if you are transferring to a surface that is higher, because you are going uphill (and working against gravity).
- **Beasy[®] Transfer Board:** It has a moving circle like a lazy Susan that rotates you. Although initially it is somewhat complicated to learn, it is perhaps the most effective board transfer device.

Patient Lifts (Hoyer Lifts)

Patient lifts, such as the Hoyer lift, make it easy for a small person to lift a large person. Although these lifts may look big and complicated, do not be overwhelmed because they are wonderful tools (Fig. 4). Some general rules to follow when using a patient lift include:

- Before you commit to the lift, make sure you have enough room, such as checking if the device fits through the bathroom doorway.
- Put the sling under you when you are lying down and then roll onto it. An updated version of this lift can be put under you while you are seated in a wheelchair.
- In order to use this type of lift, you need a hospital bed or one that is raised off the ground at least four-to-six inches to allow the base of the lift to go under it.
- Make sure that all hooks to be put on the sling face away from you.
- When you are being lifted, watch all four straps or chains to make sure that they do not catch on anything.
- If you are going to transfer onto a commode (toilet), be sure you are using a sling with a commode opening.
- Have a video taken of the training process, which is a helpful way for you to review how to use the lift properly.
- Patient lifts are not for bathtub transfers because they cannot get close enough to the tub to work correctly; there is a separate unit which can be clamped to the side of the tub for that purpose.

FIGURE 4

The Hoyer lift shown below is an example of many lifts available.



- **Cindy Lifts:** These devices are good for getting from one sitting position to another, as from a chair to a toilet. They will not bring you from a lying-down position up to a chair, nor do they work well if you have poor head control or tight muscles in back of your legs.
- **E-Z Pivot Lift:** It entails no sling and leaves your bottom clear for clothing removal in order to use the toilet.
- **Other Lifts:** Additional types of lifts are available which can be installed for use with pools and hot tubs, but they require permanent installation. Travel lifts are good for chair-to-car transfers.
- **Slings for Lifts:** The sling is the part of the lift that you sit on. Some dacron or mesh slings are best for bathing; others have commode openings, and some are large and have head supports. Most slings are meant to be sat on continuously, although there is a fairly new sling which, by its design, can be put under and removed easily from a person who is seated (see Hoyer lifts).
- **Easy Lift Chairs:** All you have to do is press a button on this large upholstered chair to bring you to a standing position. Some have an optional recline feature. If you get this type of chair, make sure it has arms that rise with the seat in order to stabilize you.

The Last Word

It is inspiring when you realize how much help is available to you – from proper exercise routines and diverse pieces of major equipment, to complex-but-indispensable lifts and simple-but-useful cushions. Your activities of daily living can be enhanced in other significant ways, as described in the next section.

Activities of Daily Living (ADL)

E

ach person living with ALS is unique and has his/her own personal way of dealing with daily concerns. Although your lifestyle needs may be similar to others who have this disease, first and foremost you must evaluate your own situation and challenges.

This section of the manual covers general suggestions and recommendations for adapting your ADL so that you can function more effectively. Talk to your OT and PT, along with the equipment provider you use, so that you can collaborate in evaluating your mobility, ADL, and home adaptation needs. Remember, the OT specializes in ADL, and the PT assists in specific mobility efforts. There are many resources available, so avoid trying to do it all yourself.

MANAGING ADL

These activities usually include cooking, eating, bathing, grooming, dressing, sleeping, cleaning, driving, and, of course, working. It is amazing how much you can do without even thinking about it, especially when all your muscles function properly and making them move takes minimal effort. Living with ALS makes you pay attention to these limitations and look for alternative tools to help you function effectively.

There are all kinds of gadgets/devices available to increase your independence with ADL. You may want to try every item available, or perhaps just a few – or none at all. It is *your* choice. As your physical situation changes, so will your equipment needs; what you require one month may not be appropriate the next.

Moreover, you may choose to use all kinds of dressing and feeding adaptive devices; however, keep in mind how much time and energy are involved versus the outcome. You may simply choose to have someone to assist you instead of using any tools, because then you can spend those hours with family, on a computer, or stretching your muscles.

The following are specific ADL and their associated problems, along with suggested solutions to make you safer, more independent, or both. The purpose of this section is to let you know your options.

Eating

<i>The Problem</i>	<i>Possible Solutions</i>
<i> Holding utensils</i>	<p>Cylindrical foam buildups can be placed over utensil handles to give a larger surface area to grip (you can get them in tubes and cut off the amount you need).</p> <hr/> <p>If you cannot hold anything, but are still able to reach your mouth using your arm muscles, a universal cuff can be effective; it is usually used in conjunction with a plate that has a raised edge (lip).</p>
<i> Not able to get your arm and hand to your mouth because of arm weakness</i>	<p>Some wheelchairs have adjustable armrests on which lap trays may be placed; then the armrests are raised to a height where you can prop your arms to reach your mouth. You may wish to place the plate on a stack of books at the table to get the desired height.</p> <hr/> <p>Mobile arm supports (ball bearing feeders) are usually attached to a wheelchair, although there is a table version available. They provide a trough which allows you to move your arms up and down, and toward and away from your body. This device also can be adapted for typing at a keyboard.</p>
<i> Cutting food</i>	<p>The rocker knife is only effective if one hand is strong enough to hold it (even with a cylindrical buildup); shoulder movements also must allow you to rock the knife in order to cut food without having to use the other hand.</p>
<i> Holding cups</i>	<p>There are special cups with larger handles that make them easier to hold, but a simple solution is to use extra-long straws.</p>

Brushing Your Teeth

The Problem

*Holding a toothbrush
or using dental floss*

Possible Solutions

Use a cylindrical foam buildup around the toothbrush for a firm grip.

Electric toothbrushes are convenient because their handles are wider than regular ones, and they also are easier for caregivers to use.

Floss holders (plastic devices that stretch and hold your floss straight) are very helpful tools in maintaining the health of your mouth.

Taking a Bath/Shower

When showering or bathing, your safety is the primary concern. Bathrooms are slippery when you are wet. Also, be aware that you might be somewhat weaker after a hot shower. In addition, after getting out of the tub or shower you should use a bath mat for maximum safety. Some people also put nonskid strips on their bathroom floors for protection. More information about bathroom safety will be covered in the *Home Adaptations* section of this manual.

<i>The Problem</i>	<i>Possible Solutions</i>
<i>Holding soap and a washcloth</i>	You can put the soap inside of a terry cloth or nylon bath mitt or add liquid soap to a loofa (a washing sponge).
<i>Reaching your feet and back</i>	Use long-handled bath brushes.
<i>Getting in and out of the bathtub</i>	<p>A transfer tub bench, best used in conjunction with a hand-held shower hose, eliminates having to step into the tub; you sit on the bench outside the tub and slide over.</p> <p>A hydraulic bath lift is usually the method of choice if just one person uses the tub; it is not easily installed or removed. The seat swivels for stepping into and out of the tub.</p>
<i>Showering</i>	When showering in a stall, you can use a shower chair (or a roll-in shower chair) with a hand-held shower hose.
<i>Drying Off</i>	Using a terry cloth robe helps absorb moisture without the energy expenditure required in towel drying.

Grooming

The Problem

Brushing and washing hair

Possible Solutions

The best solution is an extended-handle brush or comb with an adjustable angle, or you may choose to have your hair done at a beauty/barber shop.

Nail care

There is a modified nail clipper for people with less hand strength, or you may want to have a manicure and/or pedicure done for you.

If you see a podiatrist, care of the toenails and feet might be covered through your insurance.

A **suction brush** can be used for smoothing and cleaning your nails.

Getting Dressed

You might experience some problems when doing hand and finger tasks, such as buttoning, and reaching, as when you put on garments over your head.

<i>The Problem</i>	<i>Possible Solutions</i>
<i>Doing and undoing buttons</i>	Button hooks, Velcro® closures, and pullover elastic clothes (like sweats) are available. Velcro® is used to close the garment on the inside, but buttons and zippers are sewn on the outside (to make it look normal).
<i>Pulling zippers up and down</i>	You can try zipper pulls , similar to keychain rings, where you can hook one finger in; you also can use a cylinder with a hook on the end to pull and zip up your clothing.
<i>Putting on over-the-head garments</i>	This process is best done lying down, since you are not working against gravity.
<i>Putting on socks and/or stockings</i>	A stocking aid is used to help pull a stocking up your leg.
<i>Tying shoelaces and putting on shoes</i>	Elastic shoelaces can be used, since they stretch when you put on your shoes. They make it easier for you to slip your foot into your shoe, and can be used along with a long-handled shoehorn.
	Shoes can be adapted and enlarged with Velcro® to help them fit and close over braces.

Tips for Caregivers Helping You Get Dressed

If you can no longer dress yourself and someone is helping you, try lying down. A hospital bed is the best place because it allows the height to be changed to aid the caregiver. Also, this position allows the caregiver to roll you over while putting your clothes on you.

MOVING AROUND IN BED

Since bed mobility (moving and turning) is often an area of difficulty, here are some helpful suggestions:

- **Drawsheets.** These thick, flannel-type sheets are placed under you, to be used for rolling you from side to side when you are unable to do so yourself.
- **Mattresses.** There are a number of special air, foam, and gel mattresses available. Utilizing them with pressure pads can be helpful either on a hospital or regular bed. These aids are particularly important in preventing pressure sores and decreasing discomfort.
- **Hospital Beds.** A hospital bed makes it easy for you to change your position by raising and lowering its top or bottom. In addition, altering the height can assist with your personal care and transfers, and raising the head often makes breathing easier. Such a bed does not have to make your room look like a hospital. Some people add their own headboard and certainly their own decorative sheets, comforters, and bedspreads. (You can have rails attached if you need them.)

Standard hospital beds are the same size as twin/single beds; thus, many people push the hospital and single beds together and use a full-size comforter, so that they can continue sleeping with their spouses. There are also double hospital beds available by special order.

The three basic types of hospital beds are:

- **Full Electric.** One button moves the whole bed up and down to change its height; another raises the head/top of the bed; and a third button lifts the foot/bottom. Some electric beds can be adapted with different control switches, if a person cannot operate the standard button control.
- **Semi-electric.** The head and foot of the bed are raised and lowered using the buttons, while the height is adjusted by a **crank** (a bent handle for turning), usually at the foot of the bed.
- **Manual.** All three features are accomplished by turning cranks.

When transferring from a hospital bed to a chair or commode, raise the entire bed so it is higher than the surface you are transferring to; this position allows gravity to assist with the transfer. Reverse the process when you are going from a chair or a commode to the bed, so that the bed is lower than the seat height. This method is best done when you are being assisted.

If you are doing the transfer yourself, it is often easier for you to have the surfaces you are transferring to and from *the same height*. If you are using a transfer board, change the heights to have gravity in your favor.

Home Adaptations

W

hen you moved into your home or apartment, accessibility probably was not a consideration. A wide range of options is available in order to adapt your home – from simple modifications to complete construction renovation. Stairs are probably the biggest problem, and initially banisters and railings are helpful.

Following are some possible solutions for adapting your home to your accessibility needs :

- **Grab Bars.** You can move around more safely if you have something to hold onto. One solution is to buy dresser drawer handles and place them strategically where needed. A long grab bar installed vertically gives you a choice of various heights where you can hold it. If you are installing grab bars in bathroom tile, you need to know where the studs (upright beams in the framing of a wall) are.
- **Guardrails.** There are clamp-on types of guardrails for your bathtub. If you have an old-fashioned tub, you have to specify that fact when you order this type of item. Most everyone who uses the tub can benefit from guardrails, and they are removable.
- **Safety rails** (bars extending from one post to another) which fit on standard toilets are commercially available. Often they are used in conjunction with raised toilet seats (for easier transfers); another option is a bedside commode placed over the toilet, which provides handles and a higher toilet seat.

- **Ramps.** If you are building a ramp to adhere to government building codes, the appropriate ratio is one foot of ramp for every inch of rise, which can make a very long ramp; many people do not have the resources or room to ensure conformity to these codes. Remember, however, that you or someone else will be pushing your wheelchair, so the ramp should not be so steep as to be unsafe; the steepness may be minimized by making it zigzag (with short, sharp turns). If you are building a wood ramp outside, do not forget to add nonskid strips.
- **Stair Lifts (Chair Glides).** These chairs are on tracks that run up and down a flight of stairs wide enough to accommodate them. To obtain a stair lift, look in the telephone book under “Elevators” (home type). Most companies will come to your home and give you a free estimate. Since insurance funding for such devices is poor, check with the MDA and local ALS Association chapters which often recycle lifts or may know of a volunteer engineering organization which installs them.
- **Porch Lifts.** They are home elevators which may be used inside or outside along the side of the house.

Adapting Narrow Doorways

The following are some possible solutions for doorways that are not wide enough to let a wheelchair pass through:

- **Accordion hinges** displace the door when you open it and widen the entry by several inches.
- Removing a door also provides extra inches.
- Removing the outer rims on your wheelchair decreases its overall width by approximately 2¹/₂ inches.
- Often a wheelchair will not go through a doorway – particularly the bathroom entry – even if you have tried some of the above solutions. A common remedy is to transfer from your wheelchair to a 21-inch-wide **rolling shower commode** with four small wheels. Most often this assistive device can be rolled directly over the toilet, saving you another transfer. If you have a shower stall with a **lip** (raised edge), try steering and turning the rolling commode over the lip and into the shower.

Other Suggestions for Adapting Your Home

- Lower the rods in your closets so that you can reach the hangers.
- The cabinets under the bathroom and kitchen sinks can be removed so that a wheelchair can fit in those spaces.
- Lower dishes and other common kitchen items to the bottom cabinets for easy access.
- Lazy Susans can be used in cabinets and in the refrigerator to make items easier to reach.
- A rolling cart can be used in the kitchen to transport items from the counter to the table.

HOME RENOVATIONS

Most contractors have some experience with home accessibility. The most common renovations for people with ALS are adding ramps and altering bathrooms. However, because of the potential rapid progression of the disease and the frequent changes in the condition, many people choose to make the simple changes listed above rather than completely renovate their homes. If you are interested in guidelines for home modification and renovation, please request this specific information from your local ALS Association chapter or clinic.

If you are renting an apartment, talk to your landlord about making your living space more accessible. Most property managers are usually cooperative. Taking down glass shower doors and installing grab bars are generally reasonable requests. Do not assume that because you are renting, adaptations are out of the question. If any additional costs are involved, some people split them with their landlords.

INCREASING YOUR SAFETY AT HOME

The following are simple, inexpensive ways to help increase your safety at home:

- Let the Fire Department know you are disabled. In case of a fire or other emergency, the firemen will know there is someone in the home who needs assistance. Many Fire Departments have been helpful in other ways, like assisting a disabled person down the stairs in order to get to a medical appointment.
- Keep a cordless phone handy if you are alone.
- Call your telephone company regarding free services for the disabled, including speaker phones.
- Many hospitals have lifeline-type services where you can press a button and be connected to them instantly. In some states, there are private companies that provide this type of service for a fee. Ask your local ALS Association chapter or rehab clinic for more information.
- If you can walk or are using a walker, remove throw rugs; they can be slippery.
- Use an intercom. The ones for infants are inexpensive and effective. Make sure that if you cannot speak well, you develop two separate sound codes or signals with your family and caregivers – one for a need for assistance and another for an emergency.
- Sliding glass doors in bathtubs make getting in and out, with or without help, very dangerous. If you can have them replaced by a spring-loaded bar with a shower curtain, you will be safer and also increase options of what kind of bath equipment you can use.

The Last Word

All of these suggestions for activities of daily living may seem overwhelming, but each section taken separately as needed will maximize your independence. Your caregivers, family, and friends can assist in narrowing down the choices, but you have the final word. Most important, try to stay safe, comfortable, and as active as possible.

Notes

The following is a list of the topics covered in the *Living With ALS* manuals:

Manual 1

What's It All About?

This manual provides an overview of ALS, what it is, and how it affects your body. It also provides information on what kinds of resources are available to help you deal with ALS more effectively.

Manual 2

Coping with Change

This manual addresses the psychological, emotional, and social issues that you must face when your life is affected by ALS. It provides information on how to cope with the many lifestyle changes and adjustments that occur when you live with ALS.

Manual 3

Managing Your Symptoms and Treatment

This manual discusses the symptoms that affect you when you have ALS and how to treat them. It also covers the most recent breakthroughs in medications and how these treatments can improve the quality and duration of your life.

Manual 4

Functioning When Your Mobility Is Affected

This manual covers the full range of mobility issues that occur with ALS. It specifically discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

Manual 5

Adjusting to Swallowing and Speaking Difficulties

This manual addresses swallowing difficulties and how to maintain a balanced diet with ALS. It also covers how speech can be affected by ALS and the specific techniques and devices available for improving communication.

Manual 6

Adapting to Breathing Changes

This manual explains how normal breathing is affected by ALS. Specifically, it explains how to determine if you have breathing problems and what options are available to assist you as your breathing capacity changes.

The information contained in this manual can be very valuable to people living and dealing with ALS. Please donate this manual to your local library if you no longer need it.

A Reason for Hope



**The Amyotrophic Lateral
Sclerosis Association**

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Telephone: 818/880-9007
FAX: 818/880-9006

Information and Referral: 800/782-4747
www.alsa.org

The ALS Association is the only national not-for-profit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis (often called Lou Gehrig's disease) through research, patient and community services, advocacy, professional education and public awareness.

Member of the National Health Council and Community Health Charities (CHC)