

LIVING WITH ALS
RESOURCE GUIDE



Functioning When Mobility is Affected by ALS



FUNCTIONING WHEN MOBILITY IS AFFECTED BY ALS

*Nanette C. Joyce, DO
University of California, Davis School of Medicine
and
Charlotte Chatto, PT, PhD
Augusta University ALS Center*



A note to the reader: The ALS Association has developed the Living with ALS resource guides for informational and educational purposes only. The information contained in these guides 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.

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INTRODUCTION

ALS is a disease of the motor neurons: those that make up the chain of nerve cells starting from the brain, that travel through the spinal cord (**Upper Motor Neurons—UMNs**), and ending with nerve cells that project from the spinal cord to the muscles (**Lower Motor Neurons—LMNs**). The LMNs provide signals for muscle contraction and move our bodies through space, as we demand. Defining this distinction between the types of motor neurons is important when discussing mobility and ALS because the loss of UMN or LMN will cause unique corresponding symptoms and related mobility impairments. Although various changes in mobility will occur and the challenge of everyday movements will increase over time, there are many types of equipment and devices that can be used to help maintain independence for as long as possible. For example, one person with ALS described his experience in the following way:

“ALS is a disease of daily discovery... each day I awaken to discover those things I can’t do today that I could do yesterday.”

But, this individual approached each day creatively, adjusting his technique and tools so that he could continue to participate in the activities that he loved. He loved to fish. When he lost the function of one of his hands, he fashioned a fishing pole that did not need both hands to control. When he could no longer stand, he used his power wheelchair to go to the docks. When he could no longer hold his pole, he attached it to his wheelchair. His spirit for pursuing what he loved could not be taken away from him. He spent his time focused on maintaining a life filled with meaning and joy.

What we will cover in this resource guide:

- UMN Versus LMN symptoms and impairments
- Taking a proactive approach
- Team members required to address constant decline in mobility
- Energy conservation
- Activities and aids for daily living
- Exercise, flexibility, and stretching
- Durable medical equipment and assistive devices
- Home adaptations

UPPER MOTOR NEURON (UMN) VERSUS LOWER MOTOR NEURON (LMN) PREDOMINANCE

People with UMN predominant ALS develop stiffness in their muscles, also known as spasticity. Spasticity is defined as an increased tension in the muscle that depends on how fast the muscle is stretched; the faster a muscle is stretched the greater the involuntary resistance in the muscle becomes. This is due to an imbalance in the signals that influence the spinal cord and control the muscles’ responses to being stretched. In healthy individuals, coordinated movements require some muscles to contract while others relax. In spasticity,

this coordination is impaired. People with spasticity lose fluid, coordinated mobility of the limbs. Imagine, for instance, driving a car while applying both the gas pedal and the brakes. As you press faster and harder on the gas you also press faster and harder on the brakes. Strangely, you do not know which action, stopping or going, will prevail. Driving under these circumstances could be jerky, unpredictable, and unsafe.

When you have a spastic muscle from UMN disease, your response to environmental disturbances is impaired by your inability to respond with rapid, instinctual responses. For example, a person with spastic leg muscles will walk with a stiff, jerky, and dis-coordinated gait pattern. If during an afternoon stroll this person catches their toe on a crack in the sidewalk and stumbles, they will instinctively attempt to right themselves but will instead respond with spastic stiffening of their legs and likely fall. If their upper limb muscles are also spastic, they will not be able to coordinate the protective response of reaching their arms out to slow their contact with the ground and protect their head from injury.

On the other hand, those with LMN predominant ALS have muscle weakness at the core of their mobility impairment. Lower motor neuron loss causes muscles to weaken and shrink, becoming smaller and less powerful, until they are no longer able to signal muscle contraction. Progressive LMN loss in ALS eventually results in paralysis of all skeletal muscles of the body.

To meet the clinical diagnostic criteria for ALS, a person will necessarily have evidence of both UMN and LMN abnormalities. ALS, however, is quite varied from person to person. Each person presents with a unique pattern of signs and symptoms, and a combination of spasticity, muscle atrophy, and weakness. Addressing your ongoing mobility needs requires frequent assessments and is best handled in collaboration with your care team, who are willing to be endlessly creative in their approach to problem-solving. Table 1 lists some primary reasons why mobility might be affected.

Table 1: Primary Reason Why Mobility Might Be Affected

Muscle weakness in limb(s)
Paralysis occurs in some muscles, while other muscles may be weak or not affected
Spasticity (involuntary spasms and stiffness in muscles)
Painful muscle cramping
Loss of range of motion and flexibility, especially in the shoulders, hands, and ankles

BEING PROACTIVE

One of the things that is pressed upon you at ALS support group is to always stay ahead of the curve when making decisions. You don't want to make decisions after you need something; instead, make these in advance so that you are not caught off guard. This comes from folks who know and who've been there.

Cheryl Timmons, caregiver

(Contributed by The ALS Association Greater Sacramento Chapter)

While the details of each person's story will be unique, there are more similarities than differences from one person with ALS to another. Experts who focus their practices on caring for people with ALS develop a deep understanding of how ALS symptoms spread and change. In this way, they are able to predict and anticipate the mobility and Activities of Daily Living (ADL) needs prior to major transitions, thereby avoiding crises. For instance, if your legs become weak, you will begin to have difficulty standing up from a low-seated position. Instead of waiting until you are unable to stand from the toilet (which are most often low in height) and require a visit from the emergency response crew to transfer you, the perceptive practitioner will have anticipated this problem and provided the recommendation in advance to obtain an elevated toilet seat with handrails to enable transfers on and off the toilet.

One of the goals of the ALS rehabilitation team is to help each individual remain as independent as possible for as long as possible. Just as a construction crew is more capable of completing a job when they have the right tools, you can remain more functional and have prolonged independence if you have the right tools, provided at the right time, to help with declining function.

Ultimately, you have a choice as to whether you will approach your care in a proactive or reactive manner. **Taking a proactive approach provides everyone involved in your care extra time for problem-solving and can help you avoid the stress of being stuck without options, struggling to get by when you have suddenly lost an ability.** It's best if you ask your treatment team to provide recommendations for equipment in advance of your need. Obtaining what they recommend and putting it away for the day it is needed can help you feel assured you are prepared. Getting the appropriate piece of equipment can relieve stress. People often delight in their newly found freedom when they receive a power wheelchair and realize they are able to resume community activities that were given up due to intolerable fatigue or difficulty walking with fear of falling. Remember that tools are used in every trade to improve the ability of the people doing the work. ALS should be no different.

YOUR MOBILITY TEAM: PHYSICAL AND OCCUPATIONAL THERAPISTS

The ALS rehabilitation team includes both **physical and occupational therapists**. The roles of the physical and occupational therapist are to address mobility problems including muscle weakness, spasticity, and contractures that cause impairments affecting a person's ability to walk, to perform transfers such as moving from a reclined to a seated position or a seated to a standing position, and to improve abilities to dress, bathe, groom, and feed themselves. These therapists provide recommendations and treatment to improve function either by initiating corrective one-on-one therapy or by recommending and teaching how to use assistive devices. They design and teach focused range of motion exercises, and ensure that individuals with ALS and their caregivers have the skill to perform these independently in the home or community setting.

Who to See for What

The ALS **Physical Therapist (PT)** focuses on **gross motor activities such as walking, sitting balance, and lower limb range of motion, strength, and balance**. They provide recommendations for braces, canes, walkers, standers, scooters, and wheelchairs (**Figure 1**).

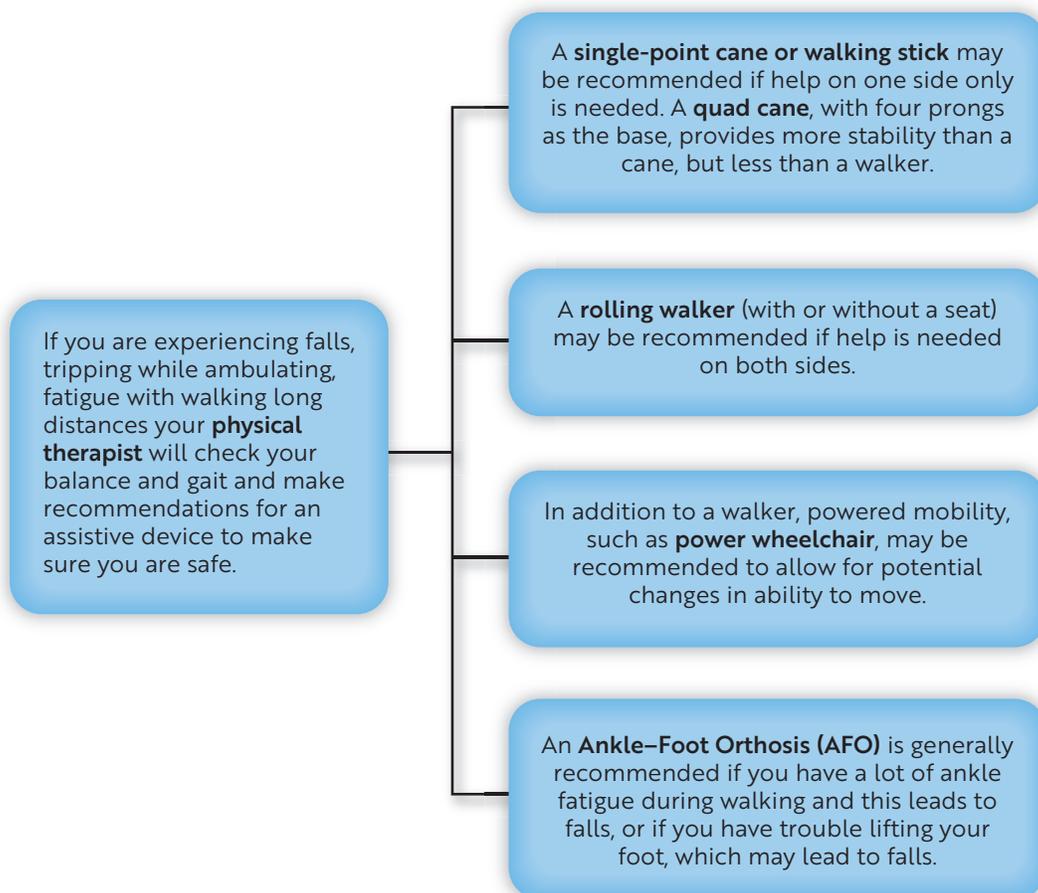


Figure 1: Physical therapist recommendations for increased mobility.

The ALS **Occupational Therapist (OT)** provides assessment and treatment for the skills needed to perform activities of daily living. They focus on their client's ability to transfer, dress, bathe, groom, toilet, and feed themselves. They assess upper limb range of motion and strength and provide recommendations for upper limb and neck bracing. In addition, they perform home safety evaluations and also are able to perform wheelchair assessments. Together, the PT and OT help families negotiate the transition of their loved one from independence to dependence, providing caregiver training, teaching transfer techniques, and offering recommendations for durable medical equipment and assistive devices. In addition to interacting with therapists, you may also need the services of an **orthotist, who fabricates, fits, and maintains braces (Figure 2)**; and a **durable medical equipment provider, who provides and maintains wheelchairs, transfer equipment, bath equipment, and hospital beds.**



Figure 2: Example of bracing options to stabilize the wrist and head.

CONSERVATION OF ENERGY

As the disease progresses in ALS, **individuals often struggle with the feeling of fatigue**. Using your energy for those activities that matter most and applying energy conservation techniques for other tasks can be a helpful strategy for maintaining a schedule that is not too tiring. Both PTs and OTs are trained to provide recommendations and teach energy **conservation techniques**.

The following are a few examples of conservation strategies:

■ **Rearrange your environment:**

1. Unclutter rooms and have furniture arranged to improve access.
2. Reduce the need to go up and down stairs by moving a bedroom to the main floor used for daily living.
3. Keep regularly used items in easily accessible places.
4. Replace heavy items with lighter weight versions (e.g., plastic plates and cups as opposed to stoneware and glass).

■ **Eliminate unnecessary activities and prioritize:**

1. Eliminate activities that are not important for you to do and delegate those that are important to family and friends.
2. If possible, consider hiring help for completion of chores around the house.
3. Sit rather than stand while performing tasks.
4. Use a rolling walker with a seat or a wheelchair with a tray to help carry objects through the house.

■ **Plan ahead:**

1. Plan enough time for activities to reduce the extra energy demand required when rushing.
2. Schedule rest breaks in the middle of planned activities.
3. Call ahead to make sure that everything you will need is available when shopping, etc.
4. Have meals made ahead and packaged into easy-to-prepare servings.

There are many other ways to conserve energy. A creative PT or OT can help you look for ways to modify your home and activities to reduce fatigue. Attending support groups or participating in online conversations with other people living with ALS is another rich resource for solving mobility challenges.

Here are some ways you can **plan and prioritize**:

- If you know that you are going to have to walk a long distance, plan for plenty of time and rest breaks.
- If you can sit to take a shower, instead of stand, make sure you have a bathtub seat.
- If you are going to prepare a meal, make sure you get all of the items you need before you begin.

- Think of ways that you can slide, push, or pull items, rather than carry them.
- If you have more energy in the morning, do those activities that are most important to you at that time.

ACTIVITIES AND AIDS FOR DAILY LIVING

There is a long list of Durable Medical Equipment (DME) and assistive devices that are potentially helpful. The goals for using DME and assistive devices are to improve function, prolong independence, and maximize safe caregiving once a person has transitioned to dependence. Activities of daily living include dressing, bathing, grooming, toileting, bed mobility, transfers, and feeding oneself. Each person's needs differ depending on the extent and location of their weakness. For example, if your arms are weak and lifting your hand to your face becomes challenging, elevating the arm above the waist by resting the elbow on a table, tray, or other elevated surface will improve arm function for eating, brushing teeth, or grooming as you eliminate much of the work done against gravity. Consulting with your OT on a regular basis and exploring online or catalog resources can provide options for commonly encountered problems.

Devices for Eating, Brushing Teeth, Bathing, Grooming, and Dressing

Eating

When the hands become weak, it is easier to hold tools that have wide handles and are lightweight (**Figure 3**). Using plastic or rubber utensils is lighter weight and easier to do than metal utensils and can extend a person's ability to eat independently. As grip strength weakens, holding objects can be made easier by building up the thickness of handles. This can be accomplished simply by using foam tubing that can be cut to size and slipped over the handle, or you can purchase ready-made utensils with widened rubber handles. Once a person loses the ability to grasp but still has the ability to bend their elbow and bring their hand to their face, a universal cuff that slips over the hand and attaches to the needed tool is useful. A universal cuff can be attached to grooming tools as well as utensils.

Brushing Teeth

Electric toothbrushes make brushing teeth easier, as the handles are generally wider than a standard toothbrush and the user does not need to exert as much energy to scrub their teeth. For the person with bulbar dysfunction or those who are dependent for their care, there are suction toothbrushes available that wick away water and saliva as the teeth are cleaned (e.g., Plak-Vac® by Trademark Medical). Electric razors are easier to use to maintain facial hair.



Figure 3: Utensils and tools to assist with eating.

Showering and Bathing

Aides for showering and bathing include grab bars, long handled scrub brushes, hand-held shower heads, sliding tub and shower benches, and rolling shower chairs (**Figure 4**). Shower chairs and sliding tub benches should be purchased with a backrest high enough to support the head and with a seat belt. These features are needed in the later stages of the disease, when there is no longer good head and torso control when sitting.

Dressing

Clasps and closures can become difficult to manage. As fine motor control worsens, buttonhooks and zipper loops can be used to facilitate buttoning buttons and zipping zippers. Other dressing strategies include switching from tailored clothing to loose fitting clothes or clothes made of stretch fabric



Figure 4: Equipment to assist with bathing.

(e.g., Lycra®) with elastic waistbands and loose pullover shirts. Socks can be donned more easily using a sock assist tool. Long-handled shoehorns minimize the work needed to reach down and put on a pair of shoes. Fabric shoe closures (e.g., Velcro®) or magnetic shoe closures (Zubits®), or coiled no-tie shoelaces can make fastening a pair of shoes much easier than having to tie shoelaces (**Figure 5**). For dressing, a quick internet search using the term “adaptive clothing” can provide multiple resources and options for improving the ease of dressing.

Moving Around and Getting in and out of Bed

There are three major aspects of bed mobility that will need to be addressed during the course of the disease: getting in and out of bed, moving in bed, and body positioning while in bed.



Figure 5: Resources for dressing: curly shoelaces, long-handled shoehorn, button assist (top left), sock assist (bottom left) and grab bar (right).

Getting in and out of Bed

To improve the ability to stand from and sit down on the edge of a bed in the early stage of ALS, **risers** can be added to the legs of the bed to bring it to a height that is easier from which to stand. Adding impermanent **adjustable bed rails or a transfer pole** that extends from the floor to ceiling next to the bed can provide a solid purchase for the upper limb to assist with standing. When you are no longer able to get into and out of bed, a **transfer lift system** should be used for safe and easy caregiver supported transfers. Lift systems come in many varieties, powered by hydraulic or electrical means, and can be mobile units or permanent systems that are attached to the ceiling (**Figure 6**). These lifts use a large sling that wraps under and around the person being lifted and hooks to the machine (**Figure 7**). The system then lifts and supports the individual's entire weight, allowing them to be moved easily into a wheelchair, onto a commode, or



Figure 6: A gait belt is used to transfer people from one position to another.

into and out of bed safely. An OT or PT should be asked to provide your family and caregivers with training on how to use the lift system when it is ordered.

Moving in Bed

It is important to be able to move in bed, whether by your own efforts or the efforts of others. A person with normal strength can naturally move throughout the night while sleeping, repetitively repositioning themselves for comfort. As you weaken, moving in bed can become impossible. **For skin health and to avoid pressure-related wounds, a person who is unable to independently adjust their position in bed requires repositioning at least every two hours.** Draw sheets are helpful for repositioning by putting the caregiver at a greater mechanical advantage (**Figure 8**). One option is a two-draw sheet system where a circular piece of material that is slippery is placed on top of the bottom fitted sheet. This provides a surface that has less friction for sliding a person back and forth over the bed. This sheet is then covered with a second unfitted cotton draw sheet.



Figure 7: Hoyer Lifts allow a person to be lifted and transferred with minimal physical effort.



Figure 8: Draw sheet used for repositioning in bed.

The top sheet is used as the pulley that moves the person in the bed. When you use a draw sheet, the top draw sheet should be placed at the person's shoulders and span to below their hips. The draw sheet should be rolled up close to the body of the person who is being moved, creating a handle to grab. Caregivers should always roll the person being moved towards them and use their legs instead of their back for transfers.

Positioning While in Bed

Pillows, pillows, and more pillows should be available to support comfortable positions. If the person in the bed is on their side they will need to have cushion support under their ribs so they are not lying directly on their shoulder, which can become painful. Pillows should be used to support limbs so they are not dangling. Even while lying on one's back, the immobile person will need pillow support for under their shoulders and arms.

Hospital beds provide a convenient way for positioning. There are fully electric and semi-electric beds. Medicare typically will cover a semi-electric hospital bed. These beds have electric hand controls that allow the head of the bed to be lowered and lifted and the knees of the bed lowered and elevated, by a push of a button. Elevating the head of the bed to 30 degrees helps improve respiratory performance during the night. The semi-electric bed is equipped with a crank to raise and lower the height of the entire bed. The fully electric bed does this with

the electric hand controls. Changing the height of the bed is helpful for both the caregiver and person in the bed, enabling better biomechanics for bedside care. Hospital beds come with standard hospital mattresses, which are not very comfortable for most people. Alternating **air pressure relief overlays or pressure relief mattresses** are usually more comfortable. They reduce the frequency with which a person with ALS needs to be repositioned. These mattresses are continually shifting the pressure applied to the body, thereby reducing the likelihood of developing pressure-related wounds. It can take time to find a mattress that is soft enough for comfort and firm enough to enable bed mobility.

Personal Hygiene Challenges

Do not underestimate the importance of developing a plan to address needs related to personal hygiene and toileting. This can be one of the most distressing problems for you. It is a fact of life that what goes in must come out. Between the ages of two to three years, we take control of this part of life and it remains a private personal issue until we are challenged by our mobility and can no longer meet our own toileting needs. While it is a good strategy to perform timed toileting, scheduling bathroom breaks every four or so hours during the day to prevent accidents, there will always be some randomness to our urges that make our needs somewhat unpredictable. **Of note, it is not a good strategy to avoid drinking fluids to avoid needing to use the bathroom.** This behavior leads to dehydration and constipation, both of which cause discomfort and are problems of their own.

This transition will occur when you have sufficient weakness limiting your ability to get on and off the toilet, or you do not have the upper extremity mobility and coordination to wipe yourself clean (medical term: **perform perineal care**). Accidents may happen if you cannot make it to the bathroom in time. While there are adult diapers for protection when accidents occur, sitting in a wet or soiled diaper for an extended period of time will lead to painful rashes and increase the risk of developing pressure-related sores if habitual.

So what can you do? **Bedside commodes** improve the convenience of toileting by lessening the distance needed to travel through the house to use the toilet. In addition, they remove the transfers required for toileting out of a small bathroom into a wide-open space. Their height can be adjusted and they provide handrails, which improve your ability to stand from a seated position, prolonging the ability to get on and off the toilet without help. Another option is a **rolling shower chair/commode combination** that can be rolled into the bathroom and backed in over the toilet. Again, this equipment removes the dependent transfer out of a small space.

Actual examples of choices made by two persons with ALS:

Example 1. A woman with ALS declared that she would move into a skilled nursing facility as soon as she could no longer clean herself after toileting. She did not want to burden her children with her perineal care. Her weakness began in her upper limbs. Early into her disease she lost the ability to wipe herself clean;

her legs, however, were still very strong and she was able to walk and transfer with ease. She was still considering moving away from her family, the people she loved the most and who brought her the most joy. The OT recommended she consider getting a **bidet**, a tool to help with toileting, which she did. Her distress was relieved and she remained with her family.

Example 2. Another woman with ALS had psychosocial distress when out in public related to toileting challenges. Maintaining an active social life was very important to her; however, she felt deterred by fears of needing to use the restroom in public. That her husband would have to accompany her into a public women's restroom and then transfer her to the toilet in a stall with limited space and of questionable cleanliness was overwhelming. She searched for a solution and decided she wanted to have a suprapubic catheter. A **suprapubic catheter** is a permanent tube inserted through the skin of the lower abdomen into the urinary bladder. The catheter tube connects to a bag that is attached to the leg and collects urine as it drains from the bladder. After a lengthy discussion regarding the cons of having the procedure, she insisted on a referral. She maintained, without question, that it was the best decision she made.

Men have another option that is less permanent: a condom catheter. There are many different styles of catheters but all need to be sized to fit well. A physician will need to provide a prescription for monthly supplies that include the condom, tubing, and a urine collection bag. Baseball season is a popular time of year for requests for condom catheters. In addition, men can use a urinal and avoid having to transfer out of a wheelchair or bed during the night to urinate, as long as they have adequate hand function or a caregiver who provides assistance.

For younger women with ALS, menses can be troublesome. If there is no desire for pregnancy, extended and continuous cycle oral contraceptives that reduce the number of menstrual cycles may be the best solution. This strategy should be discussed with an obstetrician/gynecologist and the benefits weighed against any risks.

EXERCISE, FLEXIBILITY, AND STRETCHING

You may be interested in the role exercise plays in the disease. Can you continue your pre-diagnosis lifestyle? Does exercise have a reparative role with positive effects on endurance and strength?

There is limited scientific evidence regarding the risks and benefits of aerobic and strength training exercise in ALS. Animal studies in mice with ALS have shown that moderate-intensity aerobic-type exercise delayed disease onset and increased survival times in the exercised mice compared to mice that were not exercised (Carreras et al., 2010; Mahoney et al., 2004). On the other hand, high-intensity endurance exercise has been detrimental (Carreras et al., 2010; Kirkinezos et al., 2003; Veldink et al., 2003).

Small clinical studies in people with ALS also support the safety of moderate-intensity exercise. The most recently published study on this subject was a higher quality randomized controlled trial assessing the effects of exercise in ALS

(Lunetta et al., 2015). The study findings were consistent with results of two prior studies of exercise in ALS (Drory, et al., 2001 and Bello-Haas et al., 2007).

All three trials showed less functional decline as measured by the ALS Functional Rating Scale (ALSFRS) in those who participated in a moderate exercise program.

The most recent study showed the greatest benefit in people living with ALS who performed a moderate intensity strength training and cycling program. Ongoing benefit was observed up to 12 months after the initiation of the program. However, none of the three clinical trials demonstrated a prolonged survival benefit.

Based on the available evidence it appears safe for people living with ALS to participate in moderate-intensity exercise. Overexertion, as demonstrated by prolonged fatigue after exercise, muscle pain, or soreness, however, should be avoided (Petrof, 1998). Restorative gentle exercise can be used as a tool to prevent deconditioning, to improve sleep and mood. Aerobic exercise practiced in a community setting (e.g., **accessible pool, adaptive golf, chair yoga, tai chi**) helps provide opportunities for socializing. Stretching and range-of-motion exercises should be started soon after diagnosis as part of a gentle, wellness-oriented, daily routine. Performing simple stretching exercises to target the major joints helps prevent painful and function-limiting contractures, especially at the shoulders. Training by a physical therapist, who will develop an appropriate exercise routine for you, is recommended. The program can be performed independently in the early stages of disease and transitioned to caregiver-assisted, range-of-motion exercise as needed. Linking the range-of-motion program to a dressing schedule, when limbs need to be maneuvered into clothing, is convenient and encourages performance twice daily during morning and night dressing.

DURABLE MEDICAL EQUIPMENT AND ASSISTIVE DEVICES

I could no longer operate my video editing equipment. I was losing my clients one by one. I got very worried that I was going to lose my video post-production business...At that point, my legs and feet were still very strong, and the state wanted to keep every able person working as long as possible. Cheryl contacted the state and after a few days someone from the program called to make an appointment...he showed up at my office with a bag a few days later. He opened the bag and pulled out two rectangular wooden boards. One of the boards contained a controller with a ball and the other contained two switch plates. At first, operating the ball and switches with my feet was slow and difficult, but eventually using the controls got easier and I became faster. I was happy to be working again!

Person with ALS (Contributed by The ALS Association Golden West Chapter)

Medicare covers Durable Medical Equipment (DME) meeting the following criteria: "The equipment must be long-lasting, used for medical reasons, and would not be considered useful to someone who is not sick or injured." DME

is for use in your home and has an expected lifetime of at least three years. **To be covered by Medicare, the equipment needs to be prescribed by a physician.** All people with Medicare Part B have DME benefits. If you have an insurance provider other than Medicare, you will need to review your policy to determine what is covered, the timing of coverage, and how to optimize benefits.

DME that Medicare covers includes, but isn't limited to:

- Air-fluidized beds and other support surfaces (these supplies are only rented)
- Canes (however, white canes for the blind aren't covered)
- Commode chairs
- Hospital beds
- Manual wheelchairs and power mobility devices
- Oxygen equipment and accessories
- Patient lifts
- Bilevel Positive Airway Pressure (BiPAP) or Average Volume Assured Ventilation (AVAP) devices and accessories
- Suction pumps
- Traction equipment
- Walkers

Beds, assisted breathing devices, and other equipment are rented to own. The cost of the equipment is divided over 13 months and once paid, becomes the property of the person living with ALS.

When the loss of independent ambulation occurs, braces, canes, walkers, and wheelchairs should be considered. The transition to and from each of these assistive devices should be monitored in the clinic (**Figure 9**). Braces to stabilize the ankle, called ankle-foot orthoses, are helpful if you have a foot drop. They prevent catching your toe and tripping.

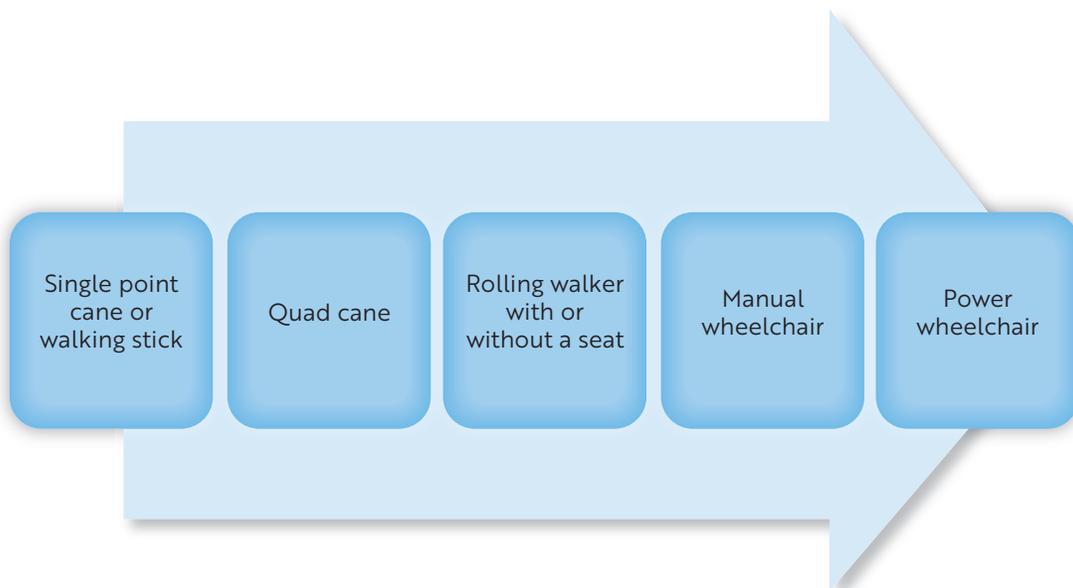


Figure 9: Transitions in assisted devices.

Canes and Walkers. A cane or walker can help prevent falls if prescribed appropriately, or add to the risk of falls if prescribed inappropriately. For example, when you have significant spasticity you may be at greater risk of falls and injuring yourself while using a cane because it does not have adequate stability to provide reliable support. A walker, however, may provide the support needed to continue walking safely. People living with ALS most often do well with a four-wheeled walker with a seat. Hand strength is required to be able to lock the brakes and it should be the type of walker that has enough clearance behind the seat to allow standing within the arms of the wheelchair. **Falls are very common in ALS and every attempt should be made to try to prevent them.** In one study, nearly 2% of people with ALS died prematurely from a fall.

This past week I had to give up using my walker and now fully rely on my “Go Chair.” This causes some mixed feelings since it means giving up a major source of independence, walking. However, using the scooter does provide some freedom that the walker did not. Since I don’t get as tired as I did with the walker, I am not as hesitant to get up and move, I can travel with ease around my house or most important, all over the mall; shoppers, watch out here I come. Either with the walker or the scooter, I have to count the cost, preserve my energy, and realize each step in life is precious.

Susan Catlett (Contributed by The ALS Association Greater Sacramento Chapter)

Wheelchairs. As strength and coordination worsen, hand-held devices will eventually be inadequate to support safe ambulation and a wheelchair will be required. While a slingback manual wheelchair conveniently folds and is easily transported in a car, these wheelchairs do not have good cushion support and are not appropriate for prolonged sitting. It is important to work with a specialist who knows about ALS and can predict what will be needed in a wheelchair for long-term comfort (**Figure 10**).



Figure 10: Transport wheelchair and four-wheeled walker for easier transport.

The most appropriate wheelchairs when living with ALS have complex features such as tilt-in-space and recline that enable repositioning for maintaining skin integrity, comfort, and respiratory health. Many people with ALS spend most of their time in their wheelchairs, so the chairs must be comfortable and facilitate good health. There are tilt-in-space manual wheelchairs and power wheelchairs (Figure 11). The benefit of a power wheelchair is that you can continue to be independent and navigate around the home and community, as well as reposition yourself. However, if there is dementia, a manual wheelchair with tilt-in-space and recline may be the best option, as it will require caregiver participation for use. Medicare typically only covers the purchase of one wheelchair. It is in your best interest to have Medicare help purchase the complex wheelchair, while you borrow or purchase your own light-weight foldable transport chair. Also, a good quality supportive seat cushion is a must to avoid pain and pressure wounds caused by prolonged sitting.



Figure 11: Power wheelchair for easier navigation around the home and community.



Custom Wheelchairs. At the time this resource guide was published, Medicare had recently had a competitive bidding process, awarding specific companies with contracts to provide various DME. The custom wheelchair will be provided by a Medicare-approved DME vendor and your physician's office will know whom you need to contact to obtain the equipment. You will require a face-to-face visit with a physician. They will write the prescription for the wheelchair and place a referral to an OT or other qualified professional who will provide the specifics for the wheelchair to the DME provider. It can take months to receive a custom wheelchair. If ALS progresses faster than anticipated, and a wheelchair is needed before the custom chair is available, contact your local ALS Association chapter to inquire about equipment loan programs that may be able to provide short-term DME solutions.

Transporting a power wheelchair is difficult unless you have access to an adapted van. The adapted van will need a raised top, side, or rear entry, and either a wheelchair lift or ramp for entering and exiting. The van also requires tie downs that lock the wheelchair safely in place and match those on the wheelchair needing to be transported.

HOME ADAPTATIONS

The OT and DME provider are able to perform home safety evaluations. During the evaluation, they will assess the home layout and provide recommendations for making the home more accessible and safe. These recommendations may include advice for minor adaptations or major home remodeling as requested. **Common recommendations include placing grabs bars in the shower or bathtub and ramps for entry to and exit from the home.**

Building a **ramp** requires adequate outside space to meet building code requirements of no more than a 1-inch downslope for every 12 inches of ramp. If there is no bedroom space on the main level of the home, a **stair lift** may provide a temporary method for moving up and down stairs as long as there is

adequate upper body strength. Keep in mind this is a significant investment for only a temporary solution before upper body weakness occurs. Older homes often have **narrow doorways** that are not wide enough for wheelchairs; these **can be widened**. If you have the resources, expanding a small bathroom to allow room enough for a **roll-in shower** and **roll-over toilet** is an investment that will make bathing, grooming, and toileting safer and more convenient. Planning home adaptations is best done early in the disease, so that any changes may be completed prior to when they are absolutely needed.

Lastly, environmental controls are available that enable those who are lacking the independent mobility to turn on and off the lights, televisions, stereos, computers, etc. on their own. Thankfully, there are more options available now than ever before to improve independence.

SUMMARY STATEMENT

ALS is a progressive disease that causes growing mobility impairment and dependence on caregivers. **The good news is there is an ever-expanding number of assistive devices and DME to extend independence and mobility.** Partnering with a PT and OT who specialize in ALS will make for a good team as they can perform serial assessments, make recommendations, and educate you and your caregivers on the use of assistive equipment and mobility devices. The goals of treatment are to improve health, safety, independence, and community access. Moderate intensity exercise and energy conservation techniques can reduce fatigue and improve the energy needed for the activities that are the most important to you and that provide you with the most meaning and joy. It is critical to discuss and plan ahead with your ALS rehabilitation team to allow the goals of treatment and optimal quality of life to be achieved.

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The following is a list of topics covered in the *Living with ALS* resource guides:

Resource Guide 1

What is ALS? An Introductory Resource Guide for Living with ALS

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

Resource Guide 2

After the ALS Diagnosis: Coping with the “New Normal”

This resource guide 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.

Resource Guide 3

Changes in Thinking and Behavior in ALS

This resource guide addresses how thinking and behavior may be affected by ALS and how these changes can impact disease course, symptom management, and decision making.

Resource Guide 4

Living with ALS: Planning and Making Decisions

This resource guide reviews areas where careful planning and decision making will be required and will provide you with resources to help you and your family plan for the future.

Resource Guide 5

Understanding Insurance and Benefits When You Have ALS

This resource guide provides strategies and helpful hints to better navigate health insurance and benefits. While understanding insurance and benefits may feel overwhelming, the guidelines outlined here should help simplify the process for you.

Resource Guide 6

Managing Symptoms of ALS

This resource guide discusses a variety of symptoms that may affect you when you have ALS. As the disease progresses, various functions may become affected and it is helpful to understand potential changes so that you know what to expect and how to manage these new changes and symptoms.



Resource Guide 7

Functioning When Mobility is Affected by ALS

This resource guide covers the range of mobility issues that occur with ALS. It 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.

Resource Guide 8

Adjusting to Swallowing Changes and Nutritional Management in ALS

This resource guide will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

Resource Guide 9

Changes in Speech and Communication Solutions

This resource guide covers how speech can be affected by ALS and explores a variety of techniques, technologies, and devices available for improving communication. By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control of your own.

Resource Guide 10

Adapting to Changes in Breathing When You Have ALS

This resource guide explains how breathing is affected by ALS. Specifically, it will teach you the basics of how the lungs function, the changes that will occur, and how to prepare for the decisions that will need to be made when the lungs need maximal assistance.

Resource Guide 11

Approaching End of Life in ALS

This resource guide examines thoughts and feelings about dying and end of life. Approaching end of life is difficult and support is critical to help sort out feelings, expectations, and plans. By talking to friends, family, professionals, and planning and communicating your wishes, you can help prepare for the best possible end-of-life phase.



1275 K Street NW, Suite 250
Washington, DC 20005
Telephone: 202-407-8580
Fax: 202-464-8869

About The ALS Association

The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

For more information about The ALS Association, visit our website at www.alsa.org.