

MANAGING MOBILITY

Mobility Issues with ALS

At some point during the course of ALS, most patients will have difficulty with ambulation. Because ALS is expressed differently from person to person, disease progression may happen rapidly (within six months) or take a slower course (over several years). Loss of balance, foot-drop, muscle atrophy, and spasticity can make walking extremely difficult and dangerous. Safety must become a primary concern. Living with ALS is challenging enough without the added burden and pain or injury. Mobility aids can help individuals with ALS maintain independence, conserve energy, and avoid the consequences of falls. Occupational therapists, physical therapists and mobility specialists play a role in determining appropriate options based on an individual's needs. Medicare and most insurance carriers generally cover these expenses; however it is important to review the insurance certificate of coverage.

The Ankle Foot Orthosis (AFO): One common mobility symptom resulting from ALS is the inability to hold the toe of one or both feet up while walking. This is commonly referred to as foot-drop and results in the patient having to lift the foot more than normal while walking to avoid tripping. Correcting foot-drop with a lightweight ankle-foot orthosis can be helpful to minimize falls and maintain endurance. Although these are available off the counter, it is important to get measured properly for safety and independence concerns.

Canes: The standard cane has a single tip while the quad cane has a rectangular four-tip base for improved stability - which style works best for patients will vary depending on the individual's condition and disabilities.

Walkers: come in many styles and designs with features such as: three or four wheels, hand brakes, baskets for carrying items, and fold down seats.

Manual Wheelchairs: can be custom-fitted or are available with standard options. Can be self propelled or pushed by another individual.

Scooters: are typically useful for only a short period of time. It is advisable for ALS patients to skip a scooter and begin using a power wheelchair.

Power Wheelchairs: come in a variety of designs/options. A wheelchair for an ALS patient will typically cost in excess of \$15,000. Justification of medical necessity for the wheelchair and any special features is required. For this reason, it is important to have a wheelchair evaluation done by a physical therapist or mobility specialist who understands ALS and is qualified to submit the necessary insurance paperwork. Optimally, a home assessment is included as part of the evaluation. Consideration should be given to doorways, entryways, and accessibility. It takes four-eight weeks to obtain a power chair, so plan ahead.

Pain Management and Prevention Techniques: Many people believe that ALS patients experience no physical pain as a result of their disease, in truth, individuals with ALS experience varying degrees of pain. The origin of the pain comes from several sources: muscle cramping, spastic muscles, joint pain due to immobility, pain from pressure points, and poor body positioning. It is important to identify the source of the pain in order to treat it effectively. It is also possible to prevent some of the pain associated with ALS with proper medical and therapeutic management. Pain pills can be used in conjunction with some of the management techniques as needed but will not alleviate the source of the pain.

Muscle Cramping: This is quite common in early and middle stages of the disease and can affect any muscles. Muscle cramps can be very painful and are caused by an over contraction of the muscle, probably due to misfiring nerve impulses. They tend to be triggered by overusing the muscles, cold temperatures, and decreased circulation. Once the cramping response is triggered it can last for a period of time. To prevent cramping activities should be paced so as not to overexert muscles. Frequent rest breaks should be taken. It is important to avoid cold temperatures and participate regularly in a light exercise program to improve circulation. Muscle relaxants can be used to help alleviate spasms, but it is essential that patients work with their doctor on the appropriate dose because too much can cause muscle weakness.

Hypertonic or Spastic Muscles

Spasticity is a function of upper motor neuron involvement. Spasticity is defined as increased tone or contractions of muscles causing stiff, awkward, and jerky movements. If a person with spasticity tries to move, is touched, or is positioned in a certain way, an exaggerated motor response can occur. This can take place in the limbs and/or the trunk causing the affected areas to stiffen which can be painful if severe. Proper positioning in bed and in a wheelchair can reduce spastic responses. One drug commonly used for spasms is the prescription drug Baclofen which is very effective in decreasing spasticity. A physical therapist or occupational therapist can offer advice for proper positioning techniques.

Joint Pain and Stiffness: As strength is lost, it may not be possible to move each joint through its complete range of motion on a daily basis. Over time, joints that are immobile result in the shortening of muscles, tendons, and ligaments. This condition causes joint pain and restriction of movement. Pain of this type can be easily prevented by adhering to daily range of motion exercises. Range of motion exercises for all joints of the limbs as well as the neck are very important. Many patients also take daily doses of anti-inflammatory to help relieve joint pain effectively. The shoulder joint can be especially problematic. As shoulder muscles weaken, the shoulder joint can sublux (mildly dislocate) in addition to becoming restricted in motion. The connective tissue around the joint can also become inflamed and a continual cycle of pain can develop. In order to prevent shoulder subluxation and inflammation it is essential that weakened shoulders are supported and properly positioned. Attention should be given to transfer technique. Use of a gait belt is a must. Daily shoulder range of motion exercises can help relieve discomfort. If shoulder pain does develop, deep heat or ice and mobilization techniques along with anti-inflammatory medications can be effective treatment.

Painful Pressure Points: If a person with ALS remains in one position for long periods of time while in bed or sitting in the wheelchair, pain can develop from continual pressure on bony areas such as the hips, heels, and tailbone. Regular repositioning, an alternating pressure pad, and special foot positioners can help prevent the occurrence of pressure points. Special back and seat cushions are other measures that can be used in preventing painful pressure areas while seated in a wheelchair. It is also helpful to use the recline and tilt function on a wheelchair for pressure relief.

Poor Positioning: As muscles weaken special positioning devices may be needed to maintain normal alignment of the body and prevent pain. Hand splints, neck braces, lumbar supports, etc. may be appropriate to accomplish this. Also special positioning devices on your wheelchair like lateral supports and neck rests are also important. An evaluation should be done in order to determine positioning needs and make appropriate recommendation.

Neck Weakness

Many patients with ALS develop neck weakness. An assistive device may be needed to provide proper positioning and support, to relieve strained muscles, and to allow continued performance of desired activities. A popular device used for this purpose is the Headmaster Collar™ (Symmetric Designs Ltd., Salt Spring Island, BC). The Headmaster Collar™ is a lightweight tubular frame collar that gives unrestricted neck support with adequate head support.