

# SEATING CONSIDERATIONS FOR INDIVIDUALS WITH ALS

Whether an individual is newly diagnosed with Amyotrophic lateral sclerosis (ALS) or has lived with it for some time, many aspects of everyday life and care must be considered. Unfortunately, with so many complications surrounding this condition – from medical to emotional – decisions regarding a seating system and mobility device often get put off for long periods of time, especially when the client can still ambulate.

## early intervention is key

Clients with ALS have often had a wheelchair for some time, but may not be using this if they are still able to ambulate at all. When a client starts having problems with his or her mobility, the physician, nurse or therapist may insist the client start using a wheelchair for safe, effective and efficient mobility throughout everyday environments.

Anyone who works in the health care field and has experience with someone who has been diagnosed with ALS knows practitioners don't have time to put off making important decisions. The average lifespan of someone with ALS is three to five years. Based on this time frame,

early intervention, with tremendous forethought toward the future, is critical to making appropriate seating and mobility recommendations.

In the early stages of this disease, it is not unusual to see clients use a lift chair instead of a power wheelchair. Lift chairs may provide the individual with the ability to get out of the chair and up onto their feet, but are not appropriate as a primary seating configuration for the person with ALS. Lift

chairs can be used for short periods of time while engaged in an activity, such as watching TV, but do not provide adequate postural support. The client often collapses into a posterior pelvic tilt which results in a kyphotic trunk posture and forward head position with neck extension (see Figure 1). This posture is often the result of an over long seat depth. Once this kyphotic posture becomes prevalent and it is very difficult to reduce. This isn't to say lift chairs can't serve as a functional tool, however, they must be properly fit and not be seen as a long-term seating solution.

It is important to provide the person with ALS with a good, supportive seating system in a properly configured mobility base. This base is typically a power wheelchair with power tilt, recline, elevating leg rests and, if funding is available, a power seat elevating system. The seating system needs to provide the postural support required now and in the future as the client's condition progresses.

## pelvic support considerations

Pelvic support is essential throughout the progression of this disease. ALS will obviously progress differently in each individual, so every solution will be unique. Early on, significant postural mobility will be necessary. The ability to move forward, backward and side-to-side on the seat cushion allows for completion of functional tasks, as well as pressure management and comfort. How is this accomplished? First, provide a

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FIGURE 1: POSTERIOR PELVIC TILT IMPACTS THE POSITION OF THE TRUNK AND HEAD.

stable surface underneath the pelvis that allows movement without loss of postural control. This doesn't mean foregoing pressure management, but rather, the seating surface needs to provide both stability and pressure relief. Consider a cushion made of multiple materials or one material that provides both stability and pressure management. Often combinations of materials will provide stability with one material and provide pressure relief with another material, typically under the ischial tuberosities. Second, keep in mind that although the backrest

is important for trunk support, the lower portion of the backrest provides posterior pelvic support as well and may prevent a posterior pelvic tilt. Pelvic stability is optimized when the pelvis is maintained in a neutral position on the seating surface. This is often achieved with a pelvic positioning belt. The pelvic positioning belt needs to allow the pelvis to rock forward for forward leaning activities, but prevent the pelvis from falling into a posterior tilt upon return to upright. This can be achieved with a multitude of pelvic belt angles, but often a 90 degree angle (across the lap) is most effective. Many individuals decide not to use a pelvic belt. This is a personal choice that often leads to poor positioning. Clients may be more receptive to using a pelvic positioning belt that can be easily and independently released and reapplied. Try various pelvic positioning belts and buckles to find what works best for the individual.

### power positioning considerations

With the diagnosis of ALS, power seating including tilt, recline, seat elevation, and elevating leg rests or articulating foot platforms should be considered. This technology has benefits throughout the progression of the disease. Tilt and recline provide repositioning assistance by using gravity and conserving energy. Since most individuals who have ALS fatigue throughout the day, good energy conservation techniques are vital. Perhaps the main benefit of power tilt and recline is pressure management. Optimal pressure redistribution occurs with full tilt and/or recline. This can maintain skin integrity even as weight and body mass are lost. With ALS, power tilt and recline can provide positioning that optimizes respiration. Recline and power elevating leg functions move the hip and knee joints, so they don't get stiff from remaining in the same position for long periods of time. Slight changes in recline or tilt may allow gravity to assist the individual's trunk and head control. Tilt and recline can be used to bring their trunk to a full upright position for a stand-pivot transfer. These are just some of the benefits that power seating can provide.

Typically, as the individual's ability to ambulate decreases, swelling may develop in the lower extremities. Muscles in the legs typically pump fluids out of the legs and back to the core of the body during ambulation. To resolve this issue, power tilt, with or without recline, may be used with elevating leg rests to raise the feet above the level of the heart to allow the blood to flow back to the heart and the core of the body, hence reducing the swelling in the lower extremities.

Power seat elevation is a common funding challenge, regardless of diagnosis. Nevertheless, this can be a major benefit for those with ALS. A power seat elevator provides the ability to elevate the seat for transfers, getting the individual closer to a standing position, or matching the height of the surface to be transferred to. Seat elevation may allow the client's arms to remain level on a surface like a kitchen counter, which can make performing an activity like food preparation or eating more energy efficient and prolong independence. Use of seat elevation also prevents the individual from always having to look up at everyone from a wheelchair sitting

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### SEATING CONSIDERATIONS... (CONTINUED FROM PAGE 49)

height, which itself can be very fatiguing throughout the day. Clearly, the seat elevator can also increase independence in other activities of daily living as well.

## head, neck and upper extremity positioning considerations

Head and neck positioning are among the biggest challenges in seating a client with ALS. As the individual weakens, the ability to control pelvic and trunk positioning is lost, which will significantly impact head control. Head position impacts breathing, swallowing and speech production – all of which all are affected by ALS. The upper extremities, upper trunk, head, neck and accessory muscles for breathing are affected much earlier with Bulbar type ALS. Providing proper positioning early on can lengthen

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FIGURE 2: SLIGHT INTERNAL SHOULDER ROTATION AND ADDUCTION MAY IMPROVE COMFORT.

the time before a more complex headrest is needed. Forehead straps and collars are also available, though significant success with these is rarely seen with ALS. As mentioned previously, use of tilt and recline can also improve trunk and head control by reducing the effects of gravity on posture.

Positioning of the upper extremities also impacts the comfort and positioning of the individual. If the upper extremities are unsupported, the trunk may be pulled into forward flexion. Shoulder subluxations can occur as a result of weak muscles which cannot maintain the integrity of the shoulder girdle. This produces pain in some individuals. Positioning the upper extremities close to the body with some internal shoulder rotation and adduction tends to offer the greatest comfort for individuals with this disease (see Figure 2). This being said, achieving a position of comfort is not always easy and some individuals find that resting their arms in their lap is preferable, though this can compromise the integrity of the shoulder girdle.

## diversity in practice

Every individual with ALS presents differently and even two people with similar abilities are likely to have very different goals. Keep in mind that we want to provide equipment as soon as possible as ALS is a rapidly progressing disease and early intervention is key. Finally, clients with ALS may be losing independence on a daily or weekly basis, and our job is to assist them to be as comfortable, functional and independent for as long as possible. A properly configured seating system and mobility base can provide just that. ➤

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