

From SCOOTER to Head Array

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MEETING THE SHORT-TERM AND LONG-TERM NEEDS OF OUR CLIENTS WITH ALS

AMYOTROPHIC LATERAL SCLEROSIS, ALS, commonly known as Lou Gehrig's disease, is a progressive degeneration of motor neurons. This degenerative neuromuscular disease manifests with varied clinical presentations making determination of CRT (Complex Rehabilitation Technology) needs challenging. As an ATP for ATG Rehab, volunteer with the CT ALS chapter, and someone who primarily specializes in neuromuscular diseases, I am faced with this challenge on a regular basis. The evaluation process of a client with ALS must be completed quickly to determine their CRT needs given the rapid progression of the disease and is the first step in initiating ATG's accelerated delivery program for people living with ALS. In succinct fashion, the short- and long-term goals of the client need to be considered, as well as funding, evaluation, and the delivery and fitting process.

The determination of CRT varies based on the progressiveness of the individual's disease, and though rare, it can vary from a walker or manual wheelchair, to more commonly a complex power wheelchair. The short-term needs of a client are primarily mobility, which is determined during their visits with their physicians. These needs are then met through a CRT supplier, usually with a prescription. In consideration of the long-term needs of a client, the focus becomes specialized with goals of maintaining their independent mobility, comfort, breathing and gravity-assisted posture. In my experience, the clients are seen by the multidisciplinary team at the neuromuscular specialty clinic in my region. This team consists of a PT, OT, SLP, RT, neurologist, social worker, nurse and dietician, which provide a very comprehensive evaluation. After the team determines the client's need for specialized seating and mobility and I receive the referral, my team then determines the insurance funding for the appropriate equipment needed and leaps into action. This is a crucial part of the process and to encounter minimal delays, our ATP-dedicated funding coordinators must have exceptional skill and talent in this area.

Next, I conduct the evaluation of the client with the therapist to determine the client's long-term goals for seating and mobility. Whenever possible, we conduct this right after the evaluation by the entire team as an additional time saver. These goals are determined through interview, physical assessment by the therapist, trialing of different equipment and lastly a home

evaluation to ensure optimal accessibility and functioning in their environment. During this process, it is crucial to take into consideration the ability for the wheelchair to change and adapt as the client's disease progresses. For example, adding a power recline to assist with breathing, and the ability to change drive controls when appropriate will give them the ability to access their environment with increased independence.

Though a rare occurrence, there are times when a client is diagnosed very early in the progression of ALS and has experienced minimal symptoms at the time of the evaluation. Often when they assume there is more time, the progression will be slower than what they are being told, and they can utilize a scooter for mobility. These individuals typically are very resistant to the idea of a power wheelchair and the process requires a great deal of tactful, honest education about what to expect from the disease and its rapid advances. These are often emotionally-charged conversations, but remaining steadfast to the appropriate course of action and limits to funding, especially as it relates to the progression timeline, is critical to paint an effective picture for the client. It's very challenging when the client is in the initial phases of coming to terms with this devastating illness. In their minds, they were just riding bikes with their kids or coaching the T-ball team, and suddenly a bunch of very concerned people are having them pick out colors for their power wheelchair; it's a tremendous amount to handle, for anyone. As difficult as it can be, it is essential to creating positive outcomes for the client.

Often we will trial more than one type of product to ensure everyone is satisfied with the decision. Almost exclusively we are deciding between mid-wheel and front-wheel drive power bases and essentially that boils down to Quantum Rehab or Permobil. Often we will select a Tru-Comfort plus or Corpus for the back support as they have a sleek mainstream look to them, while providing good support and comfort.

Product selection can be challenging and is always individual specific based on their presentation. This is especially true when selecting the seat cushion, as we often deploy the use of a pressure mapping system to ensure the product we are selecting is providing good readings for the individual. Drive controls are almost always started with an expandable joystick, and as the

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client functionally progresses beyond the use of a joystick, we almost always utilize a proportional input device, such as the ASL or HMC mini-joystick as a first choice.

The last step in the accelerated process is the delivery and fitting of the wheelchair. This can be an ongoing step due to the client's changing needs, and one that we focus on conducting in a very timely manner. It is important to make sure all the goals of the client are met at the time of delivery, to ensure the client is comfortable, and can safely operate the wheelchair in his or her environment.

All of this technology can be overwhelming for the client and family/caregivers, so complete education for everyone is a must. When a wheelchair is delivered and has multiple power functions – power leg rests, tilt, recline and specialty controls – it is imperative to conduct thorough patient and caregiver training of these features. Often, this will require more than one session and sometimes may require leaving simple reminder cards for the family.

Meeting the short- and long-term needs of a client with ALS needs to be an accelerated process from evaluation to delivery due to the rapid progression of the disease. This process must ensure the client will have maximum independence with mobility, optimal comfort, maintain good skin integrity, and the ability to access environmental controls with the least amount of change from the initial start of the evaluation. When an individual is diagnosed with ALS, time is one of the most critical factors working against them. My company and I have developed a process to maximize efficiency and accelerate solution implementation.

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