

**OT/PT GUIDELINES:**

1. **EXERCISE:** There is a large debate about exercise with ALS, and many patients are told not to exercise. However, appropriate/moderate exercise can be very beneficial for ALS patients for the following reasons: to prevent joint stiffness and maintain joint mobility for easier performance of functional tasks, to prevent/slow muscle atrophy because of disease and to keep muscle tissue that is not affected by ALS healthy and strong. When instructing patients about activity please keep the following things in mind. They should not perform exercise to the point of severe fatigue. Exercises should be low impact and non-stressful. They should not feel sore or tired from exercises done the day before. Exercises such as swimming, biking and walking as well as stretching and range of motion exercises, especially at the shoulders are great choices. They should be reminded to save energy for important daily activities, take short rest periods throughout the day and space activities over several hours. They could also be informed that it is not uncommon to see ups and downs in strength as motor neurons die. Most importantly, it is important to keep in mind that exercise will **not increase muscle strength in ALS patients, but will help with mobility, stiffness and keeping a healthy body and mind.**
  
2. **ADLs** – Think about the future when you are talking about ADLs, and stay ahead of the game. Consider the possibility of **total dependence** when recommending equipment. Instead of recommending a shower chair for bathing, go ahead and get a transfer tub bench. **Also, recommend pieces of equipment earlier than you might otherwise do so.** Common sense is crucial (i.e., don't give a sock aide to someone with severe hand weakness, because he/she won't be able to load the sock in the first place). Think low tech (i.e., get a voice activated light switch from the hardware store for under \$20 or use a fishing line loop as a zipper pull). Mobile arm supports, environmental control units, (Electronic Aids to Daily Living or EADL's), communication devices (AAC aids and strategies), home modification and accessibility are all possible issues to be faced by you (the therapist) when delivering care to someone with ALS. **Please consider consulting one of the McMaster Clinic AAC and EADL team members to discuss options and funding opportunities.**
  
3. **MOBILITY:** ALS is progressive so you will need to assess the patient on an ONGOING basis to keep up with all the physical changes and to be in a position of making decisions **proactively rather than reactively.** Some simple suggestions include: a walker with a seat, basket and wider wheels, which will be more useful as the person progresses with weakness. These types of walkers have better stability in the grass and uneven terrain. For wheelchairs, **it is important to think long term.** Think long and hard before ordering a manual chair. This can be a quickly progressing disease, and so it is very important to carefully consider all mobility options when deciding how to use ADP funding. The patient only gets one wheelchair every 5 years, so it really needs to serve him/her for the duration of their disease. Ordering a manual wheelchair before checking the ALS Society loan cupboard would not be a good decision. In addition, only order a power wheelchair once ALL FUTURE needs have been considered including, tilt, recline, pressure relief cushion, upgradeable electronics, head rest, supportive back, lateral balance support, communication device mounts, and vent tray. Home modifications and accessibility are things that will need to be assessed on an ongoing basis to ensure mobility changes can be accommodated. Possible modifications associated with accessibility into a home, bathrooms, bedrooms etc....take a lot of planning and negotiating. Modified vans that are wheelchair accessible are expensive and also take time to arrange. Funding from government agencies and March of Dimes take a lot of time to process and are NOT retroactive. **SO PLEASE ENSURE** patients and families get the information they need to make **educated decisions in an appropriately and timely fashion.** Decisions about moving, getting a power wheelchair or accessible van and/or making modifications to the home (even refusing service) are the patients to make. **Our job is to simply ensure we have given patients and families ALL the information they need to make decisions in a TIMELY fashion.**

For more information please contact: The ALS CLINIC at McMaster University Medical Center at  
 905 521 2100 extension 76870 OR The ALS Society Regional Manager at  
 289-313-0619, AND refer to [www.alsont.ca](http://www.alsont.ca) (under "our services" you will find information  
 about the equipment program, a useful manual and resource guide).