



ALS Regional Center

ST PETER'S HEALTH PARTNERS

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ALS THERAPY GENERAL INFORMATION

We are pleased that you have come to the ALS Center and look forward to helping you navigate your journey with ALS. We can be a great resource for anything you might have questions about concerning Therapy, Equipment, and Rehabilitation. Just ask, and if we don't know, we can point you in the right direction. Here are a few hints to keep in mind:

❖ **THERAPY:**

We will evaluate you here as often as our Medical Director prescribes, and help to get you set up with other therapies if there is a need identified. Your therapists at the ALS Center can help you to coordinate any therapies that you might already be receiving at home or as an outpatient. Additionally, we may recommend that you begin therapies outside of the ALS Center if you are not already involved in an outpatient or home program. We are not able to treat you for therapeutic goals in the traditional model of weekly visits here at the Center, or see you at home for therapy due to insurance regulations, so you would need to be seen by therapists outside of the ALS Center.

❖ **ALS EQUIPMENT LOAN CLOSET:**

Approximately 3500 pieces of equipment are available at any time for loan. The safety, maintenance and oversight of these are overseen by our Occupational Therapists with support from St. Peter's Hospital. All equipment is loaned **free of charge for as long as you may need it to those who are on program at the ALS Center**. Frequently borrowed equipment includes: Manual and Power Wheelchairs, Patient Lifts, Shower Chairs, and Communication Equipment as well as smaller adaptive equipment to assist in daily living and maintaining one's independence. Please be sure to fill out the ALS Loan Agreements when you are here for your first visit. Completion of these documents (by simply signing them) ensures that you may receive any equipment from the loan closet that is available.

❖ **WHEELED MOBILITY:** Typically, no matter what the diagnosis, Medicare and most other Insurance companies will only pay for ONE wheelchair within a (4-5) year timeframe. This is regardless of whether the chair is manual or power, or a scooter. ***We have found that many times inappropriate equipment is prescribed by those who do not know or understand ALS as a disease process, including Physicians, Occupational and Physical Therapists, and Mobility Suppliers.*** We will be happy to help you in whatever way we can, even if it means simply acting as a knowledge base for the involved clinicians. ***One important thing to understand is that you can refuse delivery of any wheelchair and not sign the papers to acknowledge delivery, if it doesn't seem correct to you for all of your ALS needs and changes.*** However, once you have signed the delivery papers and the chair is left in your home, it is YOURS. The details and the paperwork surrounding a purchase can be daunting. Forethought can be vital to obtaining the appropriate equipment. Utilizing professionals who work with ALS and are familiar with the process of the disease can help to conserve time, finances and frustration.

- ❖ **VETERANS:** We have found that the Veterans Administration will pay for most all Durable Medical Equipment that we recommend. However, they have a process that must be undertaken which includes using their therapists and referral from the ALS Medical Director. Our RN Case Managers and Medical Director initiate the equipment referral to the VA who then will set up your appointment to see a therapist there. Typically you are assigned a Case Manager who helps to coordinate appointments, and all of your care at the VA so use her or him as a resource to help make and coordinate appointments.

- ❖ **ACCESSIBLE VAN PURCHASE:** You may wish to pursue the purchase of an accessible van or undergo modifications to a van you own, in order to accommodate travel with a power wheelchair. We can help to direct you towards notable, knowledgeable dealers who can assist you whether you are pursuing new or used vehicles. Be aware of car dealers without intimate knowledge of ALS, as you may end up with a van that doesn't work well for you. Also please understand that although new vans from dealers can be great, the resale back to the dealers is usually very poor. Used vans are frequently available and work well also, and we can help to advertise van .

- ❖ **HOME RENOVATION:** Our Occupational Therapist is specially trained in both therapeutic interventions and Home Accessibility/Modifications. A typical remodeler may know about some accessibility home building techniques, but they may not necessarily understand how to compensate for changes that can occur with ALS. Additionally, we have an electronic document that may give you access to community resources/building grants, etc. and a Ramp Grant that can assist you in funding the cost of a ramp.

- ❖ **HOME VISIT:**
We find that there are many advantages to seeing our PALS in their home environment: Accessibility issues or needs can be identified, and we can offer suggestions to ease mobility and increase safety in the actual environment in which you live. There are NO conflicts with any Outpatient or Home Care therapeutic interventions you may already be receiving, as your insurance will not be billed for this visit. If this is a priority for you, please discuss with your Nurse Case Manager. Potential Home Visits are reviewed by the ALS Director on a case by case basis.

Most importantly, please understand that simply by helping many PALS over the years, we have developed an expertise in most all things related to therapy and ALS.