

Wheelchair needs of the Person with ALS

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The numerous options for wheelchairs seem confusing. Patients with ALS have specific needs and, as opposed to other conditions, they must consider current and future needs in making a selection. Since not every case of ALS is identical they often require input from physicians, therapists, and vendors with some expertise in this disease. The best choice must also take into account the cost and current insurance status. As an occupational therapist in a busy ALS clinic, I think the following recommendations may be helpful and I am providing a link to wheelchair prescription template that can be shared with a physician:

1. Order a powered wheelchair with mid wheel or front wheel drive. This allows it to turn in small spaces and rooms by reducing the turning radius.
2. The chair should also have upgradeable electronics so your wheelchair vendor can add other electronic features later, if you need them. For example, patients who cannot use their hands may need to control the chair with the foot or head.
3. The combined features of power recline and power tilt allow for shifting weight easily and guarantee more independence for changing position. That helps to prevent pressure sores and bloods clot from forming in the leg veins.
4. The progression of ALS can cause a loss of muscle tone in their legs and trunk. Therefore, it is important to choose a wheelchair which provides comfortable back and lumbar support. Tilt and recline along with elevating leg-rests controlled by the electronics of the chair allow a change in position without asking for help.
5. Power elevating leg rests enable the legs to be lifted up easily and to avoid the accumulation of fluid in the legs. Excess fluid accumulation or swollen legs and feet can lead to discomfort or pressure sores. Pressure relieving cushions can also help.
6. 2 to 3 inch flat swing away arm rests can help with getting in and out of the chair. Right handers should use a right side joystick. A removable padded head rest can be used for leaning back or taking a nap.
7. The wheelchair should be vent tray ready or adaptable in case a ventilation machine is ever needed. A half lap tray is another accessory that is helpful for placing supplies that might be needed for a feeding tube. Both of these may involve thinking about the future and are best discussed with a physician or therapist.

8. A power elevating seat eases transfers from the wheelchair to other places. It is also nice to be able to raise the seat elevator up to be at eye level with others. Seat elevators come in handy for reaching counter tops or other elevated structures.

Buying the wheelchair:

A prescription needs to be signed by a physician who can fill out a certificate describing the current medical condition and future needs. This is sent to the insurance company and then the vendor converts the specifications into a specific chair and makes a home visit to evaluate it at home. The home evaluation of the wheelchair is usually part of its cost. Medicare has the expectation that the vendor comes to the patient's home to evaluate the wheelchair.

I recommend driving the wheelchair into the bathroom and bedroom. Make sure that it fits through the doors and around the corners. Some vendors only take the wheelchair to the living room. Insist on driving it to the bathroom, bedroom and other rooms that are important.

The vendor then completes and submits an advanced determination of medical necessity to Medicare or to another insurance company. The insurance company responds to it and determines what is agreed upon as medically necessary. For example, the insurance company might not consider the seat elevator necessary. If this is important other means of funding can be discussed with the vendor. Options include the Muscular Dystrophy Association (MDA) or the wheelchair company.

After the chair is ordered it takes 3-4 weeks until the chair is delivered. From the time of the prescription until delivery takes about 3 months until the wheelchair available.

Are there any wheelchairs that should never be considered in ALS?

Scooters and standing wheelchairs are not suited for people with ALS. People with ALS will often have difficulty reaching and gripping that make the driving mechanism of a scooter is a problem. ALS patients also have a problem with positioning legs on the scooter. Trunk weakness also becomes a problem for comfort and posture on a scooter.

Use of a standing wheelchair is controversial. When legs and trunk lose their strength the standing function of the wheelchair can not be used.

Any other standard upright wheelchair that does not follow the previous specifications will not allow for enough comfort and function during the course of this progressive illness.

Other Important Issues to Consider:

Even the best wheelchair is not perfect. A close relationship with the vendor is very important. The vendor will do the repairs on the wheelchair and will supply additional wheelchair when they are needed. The vendor should be considered part of your care team and must be responsive, flexible, understand electronics and the mechanism of the wheelchair. I think service is most important of these. Some of my patients have called the vendor during off hours to see how they respond as part of the decision in choosing the best one.

Also remember to read the warranty of the wheelchair. If the wheelchair is delivered, don't sign for it at the door. First, make sure it fits and drives as expected. Signing might make the chair harder to return.

Used Wheelchairs:

There is a used wheelchair market but its hard to find one that comes with a warranty or a commitment from insurance companies and Medicare to pay for repairs. Often, vendors don't like to work on used wheelchairs, because they don't know what has been done before and don't want to assume liability of previous work. Also, used chairs will not fit perfectly and usually need a complete overhaul to match a patient's needs and body type. I think this is bad policy but it is reality in most cases. Currently other countries with national health insurance reuse expensive wheelchairs.

Wheelchairs from MDA clinics are returned and recycled through the loan closet. But this does not cover the cost of a full overhaul of the loaner equipment. MDA pays up to \$500/ year for wheelchair repairs and up to \$2000 over 5 years for pieces or durable medical equipment. A link to the MDA-Website is provided below.

Web-links related to this article:

MDA website: www.mda.org

MDA website for MDA services:

<http://www.mdausa.org/publications/mdasvcs/index.html>.

Two wheelchairs that meet the specifications in this article:

<http://www.permobilusa.com/templates/ProductPage.aspx?id=1295>

http://www.invacare.com/cgi-bin/imhqprd/inv_catalog/prod_cat.jsp?s=0&oidOfProduct=null&oidOfCategory=-1610621937

Link to consumer reports concerning wheelchairs:

<http://www.usatechguide.org/>

Name of Clinic
Name of physician, M.D.
Street
Town, State, Zip

Phone _____ **Fax** _____

Date _____

Name: _____

Address _____

Dx. **Amyotrophic Lateral Sclerosis**

Rx:

Power wheelchair specifications

Power wheelchair with mid wheel or front wheel drive secondary to tight turning radius needed; electronics which can be upgraded (secondary to progressive neurological weakness); power recline for weight shifts; power tilt for re-positioning and respiratory status; power elevating leg rests (secondary to the risk of developing edema); positioning which can be upgraded (secondary to loss of muscle tone in the trunk, arms, and legs); pressure relieving cushion (secondary to loss of independent weight shift and 8 to 10 hours in wheelchair); 2-3 inch flat swing away arm rests (for transfers); right side joystick control (if right handed or right hand is only functional hand); removable padded head rest; vent tray ready or adaptable; power elevating seat for transfers; ½ lap tray for equipment.

_____ MD

John Doe, MD

State License #

DEA#