

Stair Lifts, Ramps, and Wheelchairs

ast August, InsideMS looked at how to buy adapted vehicles. Buying "durable medical equipment" (DME) is different. Wheelchairs and scooters are medical equipment. But not the ramps or lifts that make using them more feasible. Go figure.

No matter. The process starts when your doctor writes a prescription. It is not a moment anyone looks forward to. While you are still struggling with the psychological aspects, you need to be a smart consumer. That means paying the lowest possible price for the best possible DME.

Your prescription will fit your physical needs, but doctors don't necessarily know the best and latest equipment. So ask for a referral to an occupational or physical therapist (OT or PT) and for the names of reputable local vendors.

Shop at a medical equipment provider, sometimes called a rehabilitation technology supplier. If you are a Medicare or Medicaid beneficiary, ask if the vendor participates in the programs. Be sure your vendor is accredited by RESNA, the Rehabilitation Engineering & Assistive Technology Society of North America, and try to work with someone with at least two years of experience.

How do I make sure it's right for me?

Wheelchairs

Measurements are the key. An OT or PT should measure and fit you for your chair, measure your house to be sure the equipment will fit, and project future measurements in case, for example, you gain

weight. Your insurance policy probably covers only one chair every five years. You have to build time into all your choices. Equipment vendors may also want to measure you.

Why double measurements? Christy Springfield, lead clinician for inpatient physical therapy at Raleigh, North Carolina's WakeMed Rehabilitation Hospital, explained that PTs trust some experienced vendors to take good measurements, but they scrutinize the recommendations in order to justify them medically. Without professional oversight, a vendor may order inappropriate equipment for you. A qualified therapist should compare measurements, override anything inappropriate, and make the final call.

Susan Kushner, MS, PT, associate professor of physical therapy at Slippery Rock University of Pennsylvania, recommends a visit to a seating or wheelchair clinic, by you and your therapist. Seating clinics are sometimes affiliated with hospitals. It would be worth a search, she noted, because "these specialists know the latest and greatest for the patients." Seating experts may have pressure-mapping equipment to document the kind of cushion you need, including tilt and recline mechanisms. And they have the moxie to get it across to your insurance case manager that it's cheaper and healthier to reimburse you for a high-tech cushion than to pay for surgery and rehabilitation after skin breakdown.

Medicare's criteria for durable medical equipment are unfairly restrictive. Despite a concerted effort by Society advocates last spring, Medicare retained a restriction on wheelchairs and scooters "for home use only." This means that doctors or therapists must justify medical necessity on the basis of need for home—not community, mobility. Yet clearly some people with MS can manage just fine around the house but need wheeled help for socializing, shopping, going to school, worship services, or work. The Society's Advocacy Program has put a priority on changing these rules next year, but for now, the restrictions hold.

Springfield has found it's possible to justify a lightweight wheelchair for inhome use because fatigue and weakness can make it difficult for some people with MS to propel a standard-weight chair independently. She has also successfully made the case for a power wheelchair in the home by carefully documenting a person's need for safety.

"If you can't independently get from Point A to Point B, or get out of harm's

way if there's an emergency, you need a power wheelchair," she pointed out. Once you are reimbursed for a chair for home use, nothing can stop you from using it wherever you need it.

Always look ahead, said equipment vendor Jerry Stalls, of Stalls Medical Inc. in Raleigh. A good vendor can help you to consider functionality for the future as well as today. He also advises new buyers that

a scooter or a powered wheelchair needs powerful accessories: a van accessible to its use, ways to lock it in the vehicle, and ramps or lifts for the heavy weight of these devices. Which brings us to the next section.

Lifts ... and ramps

Say you don't live in a one-story house or an apartment building with an elevator, and you don't want to move. Ramps can get you in, while stair lifts provide precious upward mobility. Built for straight or curved stairs and powered by rechargeable batteries or household current, lifts are fitted to stair treads, which must be in good shape for installation.

Lifts vary: Some look like a seat on rails. Users transfer in and out, leaving their wheels behind. Others lift a person in a wheelchair. These heavy-duty machines require more power. If you consider one of these, be sure to check what



This modular ramp was built over a weekend by Boy Scout volunteers. The Minnesota Ramp Project has the facts.

you and your equipment weigh together against the lift's weight limit. A reliable medical equipment vendor can ensure that any lift, interior or exterior, meets the safety codes established by the American Society of Mechanical Engineers (www.asme.org).

You'll probably obtain a ramp from a local builder, not a medical equipment vendor. Whether designed for your specific space or prefabricated, your ramp should meet regulations for the proper slope. The formula calls for one unit of height to 12 units of distance. This is a more gradual slope—making for a longer ramp—than most people expect. Anything steeper can be dangerous and almost impossible to use. You or your builder should also check any neighborhood covenants before building an exterior ramp. To help defray costs, ask if a local service organization, school carpentry class, or carpenter's union would build your ramp as a service project. Staff at the Society chapter nearest you may know of similar projects. Call your chapter first!

The Minnesota Ramp Project offers a modular design for ramps or low steps that can be built either on or off your site. The comprehensive how-to plan comes with tips on using volunteer builders or finding financing. It can be printed free from www.wheelchairramp.org or purchased from the Metropolitan Center for Independent Living (call 651-646-8342 or write to MCIL, 1600 University Ave. West, #16, St. Paul, MN 55104-3825).

Finally, a well-built ramp doesn't have to mar your house or ruin its value. To address the aesthetic along with the practical side of ramps, take a look at books such as Gracious Spaces: Universal Interiors by Design by Irma Dobkin and Mary Jo Peterson (1999; McGraw-Hill) or the Editors of Creative Publishing International's 2003 The Accessible Home: Updating Your Home for Changing Physical Needs.

What about buying used?

Secondhand equipment can cost half the original price. Sometimes, people decide that it's better to purchase a functional second-hand chair or scooter than struggle with broken equipment while waiting out a long insurance limit. Buying used may be the best way to acquire backups or special-use wheels. While your insurance covers one primary chair, you may want an extra for upstairs, a folding lightweight chair for travel, a sports chair for wheel-chair tennis, a chair with balloon tires for mobility on the beach.

Secondhand may even be a smart choice for a primary chair—if you don't meet your insurance plan's criteria but need the help that wheels provide.

Start a search through a good medical equipment vendor. Some National MS Society chapter newsletters run classified ads for used items. So do other publications for people with disabilities. There may be offers online at sites like craigslist or eBay. Ask around.

There are potential pitfalls, chief among them safety. Give any equipment a thorough check-up. A medical equipment vendor can assess motor strength and use a voltage meter to check the battery. A good vendor will also help you select a

wheelchair with mechanical integrity and, if powered, good electronics. You may even be able to obtain a partial manufacturer's warranty if you buy a demo chair from your vendor. A PT or OT can help ensure that used equipment fits by accurate measuring. An experienced therapist can also help you pick the less problematic of two compromise choices.

If you buy used equipment from a private party, still have a medical-equipment vendor check it out—just as you'd take a used car you're considering to a reliable mechanic. The basic rule is always "Buyer beware."

How do I pay for it?

Take a deep breath. "You may have to go through three or four funding sources," said Jerry Stalls. "Maybe the last one will pay for it, but you have to go in sequence."

Most private insurance, Medicare, and Medicaid, cover prescribed durable medical equipment to some extent. However, because MS is such a variable disease, it can be tricky to gauge an exact level of disability. First-time rejections from all types of insurance are common, Susan Kushner warned. "It's almost as if they expect to reject you and hope you won't bother to come back. Be persistent, involve your prescribing physician or the therapist or team that you are working closely with, and keep pushing for what you need," she advised.

Private insurance often sets the bar even higher than Medicare, Christy Springfield noted. "You may expect at least as many requirements for reimbursement," she said. Holly Woodard of Raleigh, who has MS and runs a local nonprofit agency (IMAGINE Inc., www.ifuimagine.org) that lends mobility equipment to people who can't afford it, has found that approval "comes down to how much paperwork your doctor is willing to do for you." Springfield confirmed that it's all about making the case: "If you know how to justify the equipment that you need, you're in really good shape."

Here are the basic steps to take:

- Check insurance coverage and restrictions, including required paperwork, such as a doctor's prescription and pre-approval.
- Organize the information required for reimbursement, such as the nature



Upward mobility makes life easier for Rosanne Dawer.

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and onset of your disability, employment history, family gross income, and monthly expenses.

- Prepare a justification statement if required. Tell your health-care professional about the Society's "tool kit" for insurance claims. Professionals can ask for the Society's CD, which contains model letters that meet standard requirements.
- For Medicare, check coverage at www.medicare.gov or call 800-MEDI CARE (800-633-4227). You can maximize your benefits by using a medical supplier (vendor) who agrees to accept the Medicare-approved amount as payment in full. You pay your 20% co-pay and any remaining Medicare Part B deductible. Non-participating suppliers do not have to accept assignment. Their charges may be higher and you pay more. You will also have to wait for Medicare to reimburse you.
- For Medicaid, check coverage with your state office. Find the number in the State Government section of your phone directory, probably under Health Services or Health and Human Services (names vary by state). Or call your National MS Society chapter.
- Check your vendor's return policy and your insurance claims appeal process. Keep meticulous records. Save all letters and notes of phone conversations. If it comes to it, follow the appeals process, and complete all the steps on time.

Other resources beyond insurance

If mobility will help you find or keep paid employment, you may be eligible for a grant from your state's vocational rehabilitation agency. Call them. Next, call your National MS Society chapter and ask for referrals to foundations or agencies, such as Easter Seals. (Some Society chapters have limited funding, but most focus on their loan closet, which supplies temporary equipment for people in emergencies.) You might also consider a loan tailored for people with disabilities. The Digital Federal Credit Union, at www.dcu.org, offers members of the American Association for People with Disabilities (AAPD) special Mobility Vehicle and Access loans.

Tax credit help

You should be able to deduct out-ofpocket costs for medical necessities from your federal taxes. To support these deductions in an IRS audit, get a letter from your prescribing doctor, and keep a copy of your prescription in your file.

On a roll: adjusting to a wheelchair

It took eons for Homo sapiens to learn to walk upright, and it's hard to go back. We dread such a day and we fear the pitying stares. However, if you approach the advent of wheels as a do-able—if uninvited—life transition, you may come to appreciate the independence your equipment brings.

So said Holly Woodard. Diagnosed in 1996, she progressed from using a cane, to forearm ("Canadian") crutches, to a rolling walker and a scooter, adding new equipment every couple of years.

Adjustment came in bits, too. At first, she felt guilty when she parked in a handicapped space and walked out of her car. "People look at you," she recalled. She learned to steel herself.

"The cane was kind of jaunty looking. You could express your personality," Woodard said. Next were the forearm crutches—"A tough one: There is no way you can pretty them up." Worse, she had to give up high-heeled shoes.

Then, in 2003, after two exacerbations in one year and many falls, she added a rolling walker to her fleet. She uses it around the house, but to cover distances, she likes her power scooter. She enjoys having the steering bar in front of her and a basket for her purse, where she can see it. The downsides are the large turning radius and being "a little lower than you'd like; it's hard to talk to people face to face."

Weathering the pressures

Ever positive, Woodard nevertheless reflected that each new device had a psychological effect. She went through periods of mourning and "why me" anger as she lost more physical ability. "You can feel sorry for yourself or you can be as active as possible," she has concluded. "Some things are more difficult than they should be, but at least I can still do them."

People can also face social pressures. Even well-meaning family members may try to talk a loved one out of using a wheelchair if it's "only" for fatigue. A little education goes a long way, Woodard noted. "Let them know that stress and exhaustion can lead to more exhaustion and maybe even exacerbations. If you conserve your energy, you'll have more for your family, more for something fun."

Woodard, who volunteers at her Society chapter as an MS Ambassador, uses



Janice Sangle knows a ramp is as important as a scooter when she's out on her own.

questions people ask as chances to educate them about life with disabilities. "People are staring at you to see how you are with it. If you're strong and firm, you're a role model, especially for the kids," she commented.

For those who are overwhelmed by thoughts of what might lie ahead, Holly Woodard had this advice, "Don't expect the worst. The great variability of MS means you don't know what course your disease may take, and new interventions keep coming down the pike." Her bottom line is simple: "My equipment is not who I am; it's what I use."

Rachel Adelson wrote about buying adapted vehicles in the August–September 2005 issue.

RESOURCES GALORE

General

- ABLEDATA: www.abledata.com or 800-227-0216. Product listings, manufacturer information, consumer guides and fact sheets, and Equipment Resale Resource Center. To download ABLEDATA's publications, go to www.abledata.com, click on "Information Center" and then on "ABLEDATA's Publications".
- Project LINK: www.phhp.ufl.edu/ ot/projectlink or 877-770-7303. Mails manufacturers' catalogs and brochures to registered users.
- Disability Resources Monthly: www.disabilityresources.org. Comprehensive site with regional resource directory and hundreds of useful links, including to funding sources.
- Infinitec: www.infinitec.org.

 "Infinite potential through assistive technology." Click "Live" tab for information on home modification, adaptive driving and more.
- National Rehabilitation Information Center: www.naric.com, clearinghouse of research and databases.
- Search the Society's Web site, nationalmssociety.org, for more resources, such as the brochure "At Home with MS." Your chapter may have an equipment loan, donation, and purchase/repair program. For more information, call your chapter at 1-800-FIGHT-MS (1-800-344-4867).

Funding

- Infinitec's "Finding the Money" online guide: www.infinitec.org/learn/money/fundinggeneral.html.
- ABLEDATA's "Informed Consumer's Guide to Funding Assistive Technology": www.abledata.com/abledata_docs/funding.htm.
- Tax code for medical equipment: Call the IRS at 800-829-1040 or go to www.irs.gov to order or download brochures about medical expenses for taxpayers with disabilities. (Check Publications 3966, 907, 502, and 524.)

Wheelchairs and Ramps

- Spinal Network: The Total Wheel-chair Resource Book, available through New Mobility, www.newmobility.com/bookstore-spinalnet.cfm. Nine Lives Press, 2002, \$29.95 direct-ordered from publisher. Or ask your Society chapter to consider it for their lending library.
- Minnesota Ramp Project's How to Build Wheelchair Ramps for Homes, at www.wheelchairramp.org.
- Wheelchair.net: Fact sheets, product descriptions, and links to wheelchair sites.
- ABLEDATA also posts a consumer guide to wheelchair selection, www.abledata.com/abledata_docs/icg_whel.htm.
- Northeast Rehabilitation Health Network: www.northeastrehab.com/ Articles/ramps.htm.