



Walkin' & Rollin': A Guide to Mobility For People with Intellectual and Developmental Disabilities

By Catherine A. Raggio

As people age and their mobility diminishes, we need to consider how to best meet their needs while maintaining their independent functioning. First, I want you to notice the “&” in the title of this article. Walking and using a wheelchair are not mutually exclusive activities. People, myself included, often continue to be able to walk when they begin using a wheelchair.

Wheelchair usage is valuable for lessening fatigue and preventing falls when gait is unsteady. Walking is important for enhancing circulation, balance, digestion, bone density and muscle tone. Walking and standing should be encouraged when possible, not restricted, merely because the person has begun to use a wheelchair. Families and service providers may want to consult with a physical therapist for recommendations on simple exercises that will enable the person with the developmental disability to continue being at least partially mobile.

When an adult needs a wheelchair or other mobility device, their physician will prescribe it, but the purchase is often made without the benefit of consultation with a physical or occupational therapist or a certified Assistive Technology Professional. As a By Their Side advocate, I have observed this twice within the past year. Fortunately, Medicare and some private insurance companies now require referrals to a seating clinic for proper recommendations regarding wheelchair fittings. Another key Medicare requirement is that the company providing the equipment must employ certified Assistive Technology Professionals (ATP).

Many of us who use wheelchairs are still able to walk a little, and we understand the many benefits of doing so. The caveat, however, is that a person covered by Medicare will not qualify for a wheelchair if they are ambulatory within their home, even though the chair might be helpful to them when they are out in the community. Medicare only considers “in-home use” and does not take into account that the person may be able to walk around their home or apartment but not be able to manage longer distances in the community. Medicaid and other insurers tend to be more lenient.

Selecting a Wheelchair

Wheelchair technology has come far in my lifetime, yet I still see people - mostly older people - sitting in ill-fitting, uncomfortable looking chairs. Sometimes these

chairs look like they weigh more than the occupant! Let us now de-mystify the purchase of wheelchairs.

Selecting a vendor: The vendor's sales staff should be certified as an Assistive Technology Professionals (ATP) by the Rehabilitation and Assistive Technology Society of North America (RESNA). It is the only certification that Medicare accepts if the vendor is to be paid for the equipment provided. The ATP will have considerable knowledge and experience with available equipment.

Lightweight Manual Chairs: Lightweight wheelchairs are made by several companies. They are good for the user because they are easy to self-propel. They also are good for caregivers who may be pushing the person up grades or over rough terrain and because they can be folded and lifted into the trunk of a car with little effort. Obviously, the person with the disability is more likely to get out and about when their wheelchair is seen as easy to manage. There are also ultralight weight chairs (coded K0005) that have an adjustable rear wheel axle plate. The rear wheel can be adjusted anteriorly for improved efficiency of stroke and less stress on the user's shoulders.

The Chair Should Fit the Person: John Burke, ATP, formerly with NuMotion and now with Invacare, explains the value of buying a wheelchair from an ATP, "A reputable wheelchair dealer will have salespeople who are certified as ATPs and therefore trained to measure the person prior to ordering a wheelchair. The ATP will take measurements of the person from hip to knee, knee to heel, chest width, hip width, seat to axilla, seat to top of shoulder, outside shoulder width and, in some cases, seat to top of head. A wheelchair that fits the person assures comfort and good posture and promotes the likelihood of self-propulsion."

Cushions: Think about sitting in a wheelchair for more than 12 hours a day. Your comfort would be of paramount importance. Having the right wheelchair cushion assures comfort, assists in positioning, prevents skin breakdowns and distributes pressure when appropriately fitted. There are many choices, so obtaining expert advice through a seating clinic is desirable.

Power Chairs: Experienced wheelchair users prefer the term "power chair" rather than "electric chair" since it is a chair that promotes freedom rather than the end of life. Power chairs are good for people who are not able to push a chair themselves but who have the ability to control the chair with a joystick or alternative controller such as a head array or chin controller. Controlling a power chair is essential for the safety of both the power chair user and others since these chairs weigh several hundred pounds.

Transporting someone using a power chair requires a van with a ramp and secure tie-down.

Good Posture is Essential!

When we think about sitting for 12 hours or more each day, we can begin to understand the importance of good posture. "When the wheelchair user is slumped over, breathing, digestion, eye contact and social interaction will be compromised," points out Teri Litofsky, PT, ATP, SMS, Director of the Seating Clinic at Medstar Good Samaritan Hospital in Baltimore. "If the postural problem is "fixed" (cannot be changed) then the seat and back of the wheelchair would need to accommodate the issue while providing support. If the posture is "flexible" (can be changed) then the seat and back would help to provide correction in these areas and restore alignment."

Seating Clinics: Seating clinics, such as the one Teri directs at Good Samaritan, are now required by Medicare and most insurance companies for wheelchair fittings, as stated previously. They are a good investment, particularly for first time wheelchair purchases. There are several seating clinics in MD or DC listed below. A physical or occupational therapist at the clinic assesses the person's posture, strength, range of motion and skin health and recommends a wheelchair and cushion that enables the person to function as independently as possible. The wheelchair vendor's ATP must be included in the hands-on evaluation with the therapist at a seating clinic. People with Medical Assistance (Medicaid) will need to ask their doctor for a referral to a seating clinic, then Medicaid will pay for it.

Baltimore Area

The Johns Hopkins Hospital 601 North Wolfe Street Meyer 1-130 Baltimore, Maryland 21287; Phone: 410-614-3234
http://www.hopkinsmedicine.org/physical_medicine_rehabilitation/downloads/wheelchair_and_seating.pdf

MedStar Good Samaritan Hospital Comprehensive Outpatient Rehabilitation Services, 5601 Loch Raven Boulevard, Baltimore, MD 21239; Phone: 443-444-5500
<http://www.medstargoodsam.org/our-services/rehabilitation/treatments/outpatient-rehabilitation>

University of Maryland Rehabilitation & Orthopaedic Institute, 2200 Kernan Drive, Baltimore, MD 21207; Phone: **410.448.2500** or **1.888.453.7626** TDD: **1.800.735.2258**
<http://umrehabortho.org/programs/outpatient/services/wheelchair>

DC Metro Area

Adventist Health Care, 820 West Diamond Avenue, Suite 600, Gaithersburg, MD 20878; Phone: 301-315-3030

<http://www.adventisthealthcare.com/services/rehabilitation/outpatient/seating-mobility-clinic>

Doctors Community Hospital, 8118 Good Luck Road, Lanham, MD 20706; Phone: 301-324-4968

<http://www.DCHweb.org/wheelchair>

MedStar National Rehabilitation Network

<http://www.medstarnrh.org/our-services/specialty-services/services/seating-and-mobility-clinic>

- Irving Street, Washington, DC
 - o 102 Irving Street, NW; Phone: 855-546-1064

- Prince George's County
 - o 12158 Central Avenue, Mitchellville, MD 20721; Phone: 855-546-0971

- Southern Maryland
 - o 24035 Three Notch Road, Hollywood, MD 20636; Phone: 855-546-0895
 - o 3 Post Office Road, Waldorf, MD 20602; Phone: 855-546-0793

Final Thoughts: In our society, much of the narrative surrounding wheelchair use has involved pity and helplessness. Is it any wonder that people are reluctant to use wheelchairs and settle for the cheapest model made available to them? It's time to replace that perception with an understanding that wheelchairs are a means to stay actively involved in our communities when walking becomes difficult. This truth should lead to the purchase of a product that will allow the most independence and comfort.

Catherine Raggio currently serves as an advocate with By Their Side, a family-funded, non-profit organization formed in 1965 by Maryland parents who were concerned about having an advocate for their sons and daughters after they were gone. (www.bytheirsideside.org).

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