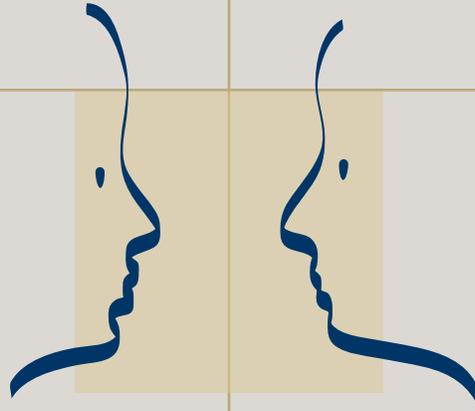




National
Multiple Sclerosis
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*Talking with Your
MS Patients about
Difficult Topics*



Talking about Wheeled Mobility

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Professional Resource Center

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The National MS Society's Professional Resource Center (PRC) has long been a resource for health professionals providing care to people with multiple sclerosis. The PRC, which houses a comprehensive library of MS information, provides continuing education opportunities and offers multidisciplinary expertise on MS disease process and management questions, health insurance issues, long-term care options, and the development of MS specialty clinics. The goal of these services is to enhance quality of care and increase access to care for people with multiple sclerosis.

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Introduction

This booklet is designed to facilitate conversations with your patients about strategies for remaining *functionally mobile* with the use of wheeled mobility devices. Many persons with MS, especially after initial diagnosis, agonize over the question, “Will I end up in a wheelchair?” In fact, over 65% percent of people diagnosed with MS are still able to walk even 20 years post

diagnosis, although they may need a mobility aid to assist them. For others, however, the severity of disease progression has a major impact on their ability to remain functionally mobile by walking. With these individuals, it is critically important to convey the value of wheeled mobility for enhancing comfort, safety, productivity, and engagement in work and social activities.

1. Why should I discuss functional mobility with my patients?

- In their efforts to “beat the disease,” stay on their feet, and avoid using a wheelchair, your patients may compromise their ability to function comfortably, safely, and effectively.
- The increased effort required to keep walking, even with the help of a cane or walker, contributes to their fatigue—gradually causing them to curtail their activities and reduce their engagement with the world.
- When walking becomes slow or unsteady, they may choose not to participate rather than appear clumsy or intoxicated, fall, or rely on others for assistance.
- Open and honest conversations about strategies to remain comfortable, safe, and functionally mobile can help your patients transition more easily to wheeled mobility if and when it will benefit them.

2. When should I bring up the subject of functional mobility with my patients?

- Mobility is functional when people are able to go where they want to go, when they want to go there, without exhausting their limited energy resources or compromising their safety. A question about a person’s ability to “to go where she or he wants to go, when she or he wants to go there” is appropriate at every appointment.
- Decreased walking speed, with or without an ambulation aid like a cane or walker, is an observable sign of a change in functional ability. You can observe/assess these changes by
 - Walking with your patients from the waiting room to your office and noticing whether you have to slow down to allow your patient to keep pace with you.
- Doing a timed walking test at every visit (e.g., the Timed 25-Foot Walk: www.nationalmssociety.org/for-professionals/researchers/clinical-study-measures/t25-fw/index.aspx).
- Asking a family member who accompanies the patient to an office visit about the pace and comfort of shared activities.
- Asking patients in urban areas whether they can make it across the street while the Walk sign is still lit.

3. How should I address a patient's concerns about "failure" and "ending up in a wheelchair"?

- Acknowledge the strong messages in our culture that reinforce the positive societal view of walking. We are all bombarded by words and images that convey the importance and value of walking:
 - "One small step for man; one giant leap for mankind"
 - "Every journey begins with one footstep"
 - "Pull yourself up by your boot strap"
 - "Standing on your own two feet"
- While acknowledging these messages, begin to point out to the person that walking may no longer be functional or effective for achieving her or his goals.
- Begin to help your patient redefine "failure." It's not about using a wheelchair or other mobility device; failure is about giving up activities they enjoy and find satisfying because they are no longer able to do them exactly the way they did them before.
- Because the majority of people with MS acknowledge fatigue as a major obstacle to activity and productivity, you may choose to introduce the idea of wheeled mobility as a treatment modality for conserving energy.
 - The catchphrase *Conserve to Preserve* may help your patients remember that conserving their energy is an effective way to preserve their mobility and productivity.
- Introduce the idea that mobility aids come in many varieties and styles, each for a different purpose. Different metaphors may work for different patients:
 - Shoes: Most people have different shoes for different activities (e.g., sneakers, dress shoes, sandals); access to several different mobility aids is much like shoes—a person can use the one that best fits the planned activity (e.g., a cane or walker around the house; a three-wheeled scooter to move around the workplace; a manual chair to put in the car to use at the soccer field or shopping mall).
 - Tools: Assistive devices are like tools in a tool chest; for any given task or activity, the goal is to use the best tool to get the job done with the least amount of effort.
- It may be helpful to remind your patients about all the "socially acceptable" wheeled mobility options used every day by ambulatory people.
 - Cars and buses, even to go short distances that could easily be walked
 - Scooters available to the public in grocery and home improvement stores to navigate the long distances
 - Golf carts to speed the time around the course

In other words, how a person thinks about a mobility aid will determine her or his comfort with using one.

4. What kind of response can I expect when I introduce the idea of using wheeled mobility?

- The universal sign for “disability” is the little blue sign with the wheelchair rider in the middle. Just the mention of a wheelchair or the need for mobility assistance may result in a very emotional response. For many persons with MS, the need for a wheeled mobility device is the tangible acknowledgement of loss of function, control and change in self-image.
- As with many emotional discussions, the issue may have to be raised slowly and more than once. While initially resisted, the use of a wheeled mobility device—manual chair, motorized scooter, or power chair—may be the one intervention that dramatically reduces social isolation and improves the person’s social participation and overall quality of life.

5. What is the best way to address a patient’s concern that using a motorized scooter or wheelchair will result in increased loss of function?

- Exercise, especially at a moderate, consistent level, is important for everyone, including people with MS. Every person with MS should be encouraged to engage in a regular exercise program that is designed to match his or her functional abilities and limitations.
- However, moving around in one’s natural environment should not be an aerobic activity. Shortness of breath and sweating should not be regular occurrences when performing activities of daily living.
- Wheeled mobility, especially during times of “predictable” fatigue (e.g., on hot, humid days, at an outdoor event requiring long distance walking, or in the course of a long work day in a large office) can conserve energy to allow the person to “do more” in the day than just “get around.”

6. When is it appropriate to include family members in a conversation about functional mobility and wheeled mobility options?

- With the patient’s permission, engaging family members in these conversations can often be very helpful:
 - Family members may welcome their loved one’s use of a wheeled mobility device for several reasons: the opportunity to resume shared activities; the ability to walk at their natural pace rather than having to slow down enough to match that of their loved one (which they report to be frustrating and exhausting); the ability to enjoy shared outings without having to be hyper-
 - vigilant about their loved one’s safety and without having someone hanging on their arm.
- Family members who do not support the use of wheeled mobility because they believe incorrectly that it will be detrimental for their loved one can be educated about the importance and value of functional mobility.
- Couples that have experienced major shifts in their respective household and parenting roles may be relieved to discover that enhanced functional

mobility can reduce fatigue and increase a person's ability to re-engage in activities previously "lost" to MS. This re-engagement can go a long way toward reestablishing a healthy and satisfying balance in the relationship.

- Patients who worry that they might embarrass their family members or let them down by using wheeled mobility might be relieved and encouraged by having a shared conversation about it with you.

7. Where should I direct my patients to explore mobility options?

- Physical and occupational therapists can provide education about energy conservation and mobility options.
- Online resources include:
 - How to Choose the Mobility Device That is Right for You: www.nationalMSSociety.org/MobilityGuide
 - Mobility Alternatives From Canes to Wheelchairs (free publication): www.unitedspinal.org/pdf/canes_to_wheelchairs.pdf
 - User's First—Mobility Map: www.usersfirst.org/resources/mobilitymap/index.php?pg=kb.book&id=41
- Resources in your community may include:
 - Knowledgeable service providers: Your patients who are currently using a wheeled mobility device may be able to recommend their service provider. They may also be willing to be "peer advisors" to patients who are new to the wheeled mobility world.
- Facility-based "wheelchair clinics": In these facilities, therapists and wheelchair suppliers work together to conduct a full needs assessment, including an evaluation of posture, skin integrity, the person's environment (home, work, and neighborhood), and mobility. Training on safe use of any recommended device is also provided by clinic staff.
- Physical or occupational therapists and equipment suppliers who have earned the RESNA credential of "ATP—Assistive Technology Professional": A state-by-state listing of all credentialed ATPs is available from RESNA (Rehabilitation Engineering and Assistive Technology Association of North America) can be found at www.resna.org. Patients seeking a credentialed ATP professionals should inquire whether the person specializes in Seating and Mobility.

Jean L. Minkel, PT, ATP is a physical therapist and master clinician well recognized for her work in Assistive Technology (AT). She is Senior Vice President, Rehabilitation Services for Independence Care System, a long term care program in New York City. Jean is also an independent consultant for all members of the AT team—consumers, therapists, suppliers, manufacturers and payers. Prior to entering the private sector, Jean was the director of the Seating and Mobility Program at the Center for Rehabilitation Technology at Helen Hayes Hospital in West Haverstaw, NY. She produced the videotape series, "Spending or Investing—Funding Assistive Technology." She is co-author of the *Wheelchair Selection Guide: How to use the ANSI—RESNA Standards*; the *Manual Mobility Training Guide* and the *Power Mobility Training Guide*. The AT community has recognized Jean's contributions by awarding her the RESNA Fellow award in 1995 and the Sam McFarland Mentor Award in 2012.

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