

TALKING WITH YOUR PATIENTS ABOUT
**THE ROLE OF
REHABILITATION IN MS**

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**National
Multiple Sclerosis
Society**

The National MS Society's Professional Resource Center provides:

- Easy access to comprehensive information about MS management in a variety of formats;
- Dynamic, engaging tools and resources for clinicians and their patients;
- Clinical information to support high quality care; and
- Literature search services to support high quality clinical care.

FOR FURTHER INFORMATION:

VISIT OUR WEBSITE:

nationalMSSociety.org/PRC

To receive periodic research and clinical updates and/or e-news for healthcare professionals,

EMAIL:

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Introduction

Use this resource to help facilitate conversations with your patients about rehabilitation and MS. Because most people are unfamiliar with the role of rehabilitation in MS care, they may not know what questions to ask about these services or the clinicians who provide them. Patients may not understand the benefits of rehabilitation, or may have unrealistic expectations about the outcomes. Physicians and nurses have an important role to play in these discussions—providing timely information as well as referrals to the appropriate professionals.

Why should I discuss rehabilitation with my patients?

- A growing body of evidence indicates that a carefully-planned and individualized program of exercise and functional training can enhance mobility, performance of activities of daily living (ADL), and quality of life over the course of the disease, while helping to prevent complications and reduce healthcare utilization.
- Known complications of MS, such as contractures, disuse atrophy, pressure ulcers, risk of falls, and increased dependence may be reduced or prevented by specific rehabilitative interventions.
- In a fluctuating and often progressive disease, maintenance of function, participation, and quality of life are important outcomes.

When should I refer my patients to rehabilitation services?

- The physician should consider a referral for assessment by rehabilitation professionals when there is an abrupt or gradual worsening in functional limitations, or increase in impairment, which has a significant impact on the individual's activities, mobility, safety, independence, and/or quality of life.
- Patients who present with any functional limitation should receive an initial rehabilitation evaluation and appropriate management.
- The complex interaction of motor, sensory, cognitive, functional, and affective impairments in an unpredictable, progressive, and fluctuating disease such as MS, requires periodic reassessment, monitoring, and rehabilitative interventions.
- Research and professional experience support the use of rehabilitative interventions, in concert with other medical interventions, to address diminished quality of life (often related to changes in ability to work, engage in leisure activities and/or pursue usual life roles), and for the following impairments and activity limitations:
 - Mobility problems (e.g., impaired strength, gait, balance, range of motion, coordination, tone, and endurance)
 - Functional mobility problems (transfers, driving, recreation)
 - Fatigue
 - Pain
 - Dysphagia

- Bladder/bowel dysfunction
- Decreased independence in activities of daily living
- Communication deficits
- Depression and other affective disorders
- Cognitive dysfunction
- Employment problems

Why would I recommend rehabilitation to someone who is not experiencing a decrease in function?

- Rehabilitation also offers education in lifestyle changes, exercise, and other activities that allow the individual to maintain his or her overall health and level of function. Intervening early in the disease may make behavioral and lifestyle changes easier to implement.
- In addition to enhancing independence, minimizing complications, and maximizing overall fitness, rehabilitation can also be beneficial for purposes of establishing baseline measurements.

What type(s) of exercise can I recommend for people with MS?

- Exercise can be used as a strategy for managing certain symptoms of MS. For example, those with weakness may benefit from a strengthening program to compensate for weak muscle groups; those with spasticity and resulting loss of flexibility may benefit from a stretching program.
- A personalized exercise plan is important for optimizing benefit while limiting fatigue. Rehabilitation professionals can provide an exercise program that targets specific impairments in order to reach mutually agreed upon goals
- Exercise may also be of benefit in maintaining and/or improving overall health. Aerobic exercise, geared to a person's abilities and deficits, has been shown to reduce fatigue, increase strength, and improve mood in people with MS.
- The cooling effect of water activities can help individuals with heat sensitivity by allowing them to exercise without triggering a temporary worsening of their symptoms. Likewise, exercise in an air-conditioned room helps prevent overheating.
- Yoga and other gentle stretching routines may help maintain range of motion.
- Regardless of the type of exercise they choose, it is important to discourage your patients from "over-exercising" since the "no pain, no gain" philosophy can increase fatigue, cause overheating, vigorous exercising may also lead to injuries.

How do I best address the issue of limited insurance coverage for rehabilitation?

- Insurance coverage can be a barrier to individuals with MS receiving proper rehabilitation care.
- Limited visits and capitation on rehabilitation costs require referring physicians to carefully document and monitor their rehabilitation recommendations.
- Insurance companies are more likely to cover rehabilitation services when there is a change in function. If baseline measures are obtained, a functional change can be documented and a stronger argument made for coverage of rehabilitation.
- Developing a home exercise and activity program is one way of optimizing rehabilitation visits, as is spacing the outpatient visits at longer intervals.
- The frequency, intensity, and setting of the rehabilitative intervention must be based on individual needs. Some complex needs are best met in an interdisciplinary, inpatient setting, while other needs are best met at home or in outpatient settings. Sometimes the decision is determined by the availability of third party coverage.
- If you have uninsured or underinsured patients requiring rehabilitation intervention, there may be free or low-cost exercise programs (e.g., yoga or swimming) available from the National MS Society or other organizations.

What is the best way to address my patient's risk of falls?

- Discuss the prevalence of falls among people with MS and the risk factors associated falls.
- Recommend the Society's *Free from Falls* program, an eight-module, online program designed to increase knowledge about the risk factors and strategies to reduce fall risk.

How do I recommend the appropriate assistive device(s) for resistant patients who see them as a loss of independence?

- Encourage patients to see that the use of assistive devices may actually increase independence, improve safety, and minimize fatigue.
- Help patients see the use of mobility devices as a means to enjoy a wider range of activities, including those they may already have given up, such as visits to museums, sightseeing trips, or shopping.
- Assistive devices for ambulation (which often produce the greatest resistance amongst patients) should be introduced early in the disease as tools for energy management, minor balance problems, and weakness—rather than waiting until the mobility aids are required on a full-time basis. Earlier introduction means that the people can use the devices periodically—when fatigued, when going a long distance or walking on uneven or unfamiliar surfaces, or going up and down stairs—and get used to them gradually.

- For those patients who have adequate trunk balance and cognitive skills, a motorized scooter may carry less of a stigma than a wheelchair. If trunk balance and cognition are adequate, this mobility device may be accepted more readily.
- Refer the patient to a physical or occupational therapist for evaluation for the most appropriate mobility device and recommend the Society's brochure, *How to Choose the Mobility Device that is Right for You*.

How do I address driving with someone who may no longer be safe on the road?

- Suggest strategies to minimize risk on the road (e.g., driving at times of the day when fatigue is minimal, use of hand controls, modification of a car/van to accommodate a wheelchair, use of a disabled parking placard to conserve energy) and recommend the Society's brochure, *Driving with Multiple Sclerosis*.
- Refer the patient to a driving evaluation/rehabilitation program. These programs have adaptive driving specialists who can assess safety and driving skills and recommend vehicle modifications.
- The reasons for limiting or eliminating driving can be multi-factorial: spasticity, weakness, cognitive problems, fatigue, and vision deficits. Optimal management of these symptoms can sometimes prolong a person's ability to drive safely. In the event you feel it necessary to recommend revocation of driving privileges, the National MS Society can provide your patient with information about public or private accessible transportation options. It is important to be particularly sensitive to the loss of independence that this represents for the patient, and the extra burden this poses for family members.

How do I approach the topic of employment with someone who is struggling at work?

- Remind your patient that fatigue and cognitive dysfunction are the primary factors leading to early departure from the workforce among people with MS. Talk about optimal strategies for assessing and treating these problems. If you or your patient are aware of cognitive changes, a referral to a neuropsychologist (or occupational therapist or speech/language pathologist, depending on who is available in your community) is recommended.
- If the patient is struggling with work-related activities, a referral to a vocational rehabilitation counselor, occupational therapist and/or physical therapist is appropriate. An occupational therapist can recommend adaptations at the work site and accommodations that the employer may be able to provide. (e.g., adapted work station, voice-activated computer programs, office close to the bathroom, wheeled carts for transporting files, etc.). A physical therapist can recommend appropriate mobility devices and an exercise regimen to reduce fatigue. A vocational counselor can assess vocational skills and abilities and suggest career modifications such as: reducing work

hours; commuting at times with less traffic; telecommuting; switching to a less demanding job within the same company that may be less physically or cognitively demanding; or exploring options for a new career.

- Even with job modifications, vocational may be too to remain employed. The National MS Society has helpful information and resources for individuals who are making job-related changes and toolkits to assist physicians and their patients in completing Social Security Disability Insurance (SSDI) applications (nationalMSSociety.org/SSDGuide).

What other resources are available on this topic?

- The National MS Society offers information, resources and support for individuals with MS and their families, as well as resources for healthcare professionals.
 - MS Navigators (1-800-344-4867) provide information, referrals to healthcare providers in the community, support
 - Educational materials on a wide range of topics are available for your patients at no charge by calling an MS Navigator or online at nationalMSSociety.org/brochures.
 - Exercise as Part of Everyday Life booklet
 - Managing MS Through Rehabilitation booklet
 - Stretching for People with MS booklet
 - Stretching with a Helper for People with MS booklet
 - Controlling Spasticity in MS booklet
 - Fatigue: What You Should Know brochure
 - Gait or Walking Problems: The Basic Facts booklet
 - Speech and Swallowing: The Basic Facts booklet
 - Tremor: The Basic Facts booklet
 - Professional publications are available online at nationalMSSociety.org/PRC
 - Rehabilitation: Recommendations for Persons with Multiple Sclerosis, an Expert Opinion Paper from the National Multiple Sclerosis Society's Medical Advisory Board.
 - Occupational Therapy in Multiple Sclerosis Rehabilitation
 - Swallowing Disorders and Their Management in Patients with Multiple Sclerosis
 - Physical Therapy in Multiple Sclerosis Rehabilitation
 - Spasticity in Multiple Sclerosis
- Recommended readings
 - Haselkorn JK, Hughes, C, Rae-Grant, A et al. Summary of comprehensive systematic review: Rehabilitation in multiple sclerosis. Report of the Guideline Development, Dissemination and Implementation Subcommittee of the American Academy of Neurology. Neurology. November 24, 2015 vol. 85 no. 21 1896-1903.
 - Veldhuizen valn Zanten JJ, Pilutti LA, Duda JL, Motl, RW. Sedentary behavior in people with multiple sclerosis: Is it time to stand up against MS? Mult Scler. 2016. 22(10):1250-6.

About the author

Brian Hutchinson is Director of the Multiple Sclerosis Achievement Center in Sacramento, CA. The Multiple Sclerosis Achievement Center provides wellness programs for people living with MS through a series of programs to address physical, cognitive and emotional wellness. As Director, Mr. Hutchinson oversees the program development, staffing and administration. Prior to his position as Director, Mr. Hutchinson served as a Medical Science Liaison for Acorda Therapeutics from 2008-2013. He has also served as CEO of The Heuga Center for Multiple Sclerosis (currently CAN DO MS), a nonprofit organization which conducts interactive, educational programs designed to incorporate physical activity and wellness into the lifestyles of persons living with MS.

Prior to The Heuga Center, Mr. Hutchinson was a physical therapist at the Rocky Mountain Multiple Sclerosis Center in Englewood, CO and remained a consulting physical therapist through participation in an interdisciplinary spasticity clinic in Denver from 1997-2008. His volunteer service has included the executive committee of the board of governors for the Consortium of MS Centers (including Board President) and on the National Multiple Sclerosis Society – Clinical Advisory Committee. Mr. Hutchinson also worked as a Clinical Consultant for the National Multiple Sclerosis Society.

Other resources for
Talking with Your MS Patients include:

Cognitive Dysfunction
Diagnosis of Multiple Sclerosis
Progressive Disease
Elimination Problems
Sexual Dysfunction
Depression and Other Emotional Changes
Initiating and Adhering to Treatment with Injectable Disease Modifying Agents
Family Issues
Reproductive Issues
The Role of Rehabilitation
Life Planning
Primary Progressive MS (PPMS)
Palliative Care, Hospice and Dying
Wheeled Mobility



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