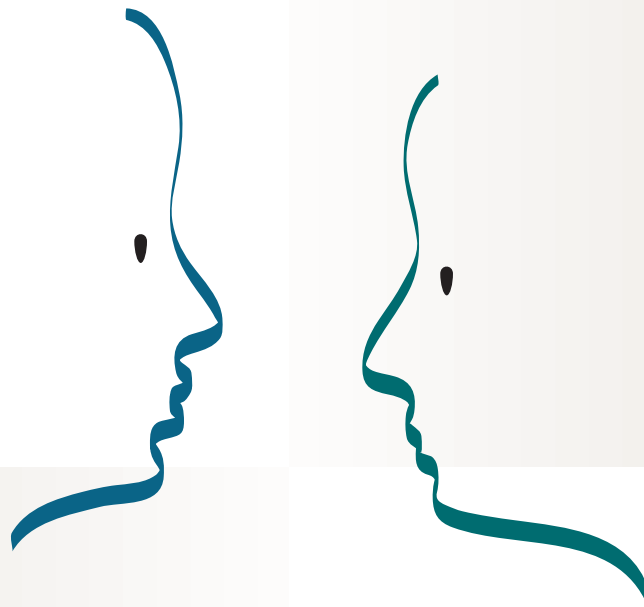


Talking with Your MS Patients about Difficult Topics



Rosalind Kalb, PhD, Editor

Introduction

This booklet is designed to 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.

1. 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.

2. 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 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 to 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)
- ▲ Fatigue
- ▲ Pain
- ▲ Dysphagia
- ▲ Bladder/bowel dysfunction
- ▲ Decreased independence in activities of daily living
- ▲ Communication deficits
- ▲ Depression and other affective disorders
- ▲ Cognitive dysfunction
- ▲ Functional mobility problems (e.g., gait, transfers, driving, recreation)
- ▲ Employment problems

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

- Rehabilitation also offers education in life style 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.

4. 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.
- Exercise can also be used to increase performance of specific activities. For example, individuals interested in improving their walking or transfers are provided therapeutic exercises and training in new techniques to enhance their abilities.

- 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, and temporarily worsen symptoms. Such vigorous exercising may also lead to injuries.

5. 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 conserving 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 assistance programs through organizations such as the National MS Society to help with funding of rehabilitation services. Furthermore, many chapters of the Society offer group exercise programs such as swimming and yoga that are inexpensive or free.

6. 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.

7. 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 handicap parking placard to conserve energy).
- 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.

8. 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 or occupational 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 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 and vocational rehabilitation/career changes, it may be too difficult for some individuals to remain employed. The National MS Society has helpful information and resources for individuals who are making job-related changes and a toolkit to assist physicians in completing Social Security Disability Insurance (SSDI) applications (<http://www.nationalmssociety.org/SocialSecurity>).

9. What other resources are available to help my patients with Rehabilitation?

- Chapters of the National MS Society (1-800-FIGHT-MS) offer:
 - ▲ Educational programs and support groups
 - ▲ Referrals to rehabilitation professionals in the community who are familiar with MS
 - ▲ Printed materials about a range of other topics, available free of charge (also available from the National MS Society website: www.nationalmssociety.org/Brochures)
 - *Exercise as Part of Everyday Life*
 - *Managing MS Through Rehabilitation*
 - *Stretching for People with MS*

- *Stretching with a Helper for People with MS*
- *Controlling Spasticity in MS*
- *Fatigue: What You Should Know*
- *Gait or Walking Problems: The Basic Facts*
- *Speech and Swallowing: The Basic Facts*
- *Tremor: The Basic Facts*
- National MS Society website (www.nationalmssociety.org) offers information on a wide variety of topics (e.g., disease-modifying therapies, symptom management, research), as well as access to local resources and events.
 - ▲ *Rehabilitation: Recommendations for Persons with Multiple Sclerosis*, an Expert Opinion Paper from the National Multiple Sclerosis Society's Medical Advisory Board. www.nationalmssociety.org/ExpertOpinionPapers
 - ▲ *Occupational Therapy in Multiple Sclerosis Rehabilitation*, a Clinical Bulletin by Marcia Finlayson, PhD, OT,(C), OTR/L. www.nationalmssociety.org/ClinicalBulletins
 - ▲ *Swallowing Disorders and Their Management in Patients with Multiple Sclerosis*, a Clinical Bulletin by Jeri A. Logemann, PhD, CCC-SLP, BRS-S. www.nationalmssociety.org/ClinicalBulletins
 - ▲ *Physical Therapy in Multiple Sclerosis Rehabilitation*, a Clinical Bulletin by Patricia G. Provance, PT. www.nationalmssociety.org/ClinicalBulletins
 - ▲ *Spasticity*, a Clinical Bulletin by Sue Kushner, MS, PT and Kathi Brandfass, MS, PT. www.nationalmssociety.org/ClinicalBulletins
- Additional recommended websites:
 - ▲ Multiple Sclerosis Society of Canada. www.mssociety.ca
 - ▲ Multiple Sclerosis International Federation. <http://www.msif.org>
 - ▲ Pharmaceutical company support programs
 - Betaseron—MSPathways. www.mspathways.com
 - Avonex—MS Active Source. www.msactivesource.com
 - Copaxone—Shared Solutions. www.sharedsolutions.com
 - Novantrone. www.novantrone.com
 - Rebif—MS Lifelines. www.mslifelines.com

- ▲ Clinical trials
 - CenterWatch Clinical Trials Listing Service™. <http://www.centerwatch.com>
 - National Institutes of Health (NIH) Clinical Trials Listing Service. <http://www.ClinicalTrials.gov>
 - Infosci Selected Links on MS. <http://www.infosci.org>
- Recommended reading:
 - ▲ Kalb R (ed.). (2006). *Multiple Sclerosis: A Guide for Families* (3rd ed.). New York: Demos Medical Publishing.
 - ▲ Kalb R (ed.). (2004). *Multiple Sclerosis: The Questions You Have, The Answers You Need* (3rd ed.). New York: Demos Medical Publishing.
 - ▲ Holland N, Halper J (eds.). (2005). *Multiple Sclerosis: A Self-Care Guide to Wellness* (2nd ed.). New York: Demos Medical Publishing.
- Other resources:
 - ▲ The Heuga Center: A non profit organization which provides health promotion programs for people living with multiple sclerosis and their family members. For more information on their programs and services visit www.heuga.org.
 - ▲ The Consortium of Multiple Sclerosis Centers: An international organization dedicated to MS Education and Research, Evidence-based Practice and an Interdisciplinary Approach to MS Management. For more information visit www.ms-care.org.

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