

## Rehabilitation: Recommendations for Persons with Multiple Sclerosis

### RECOMMENDATIONS

The Medical Advisory Board (MAB) of the National Multiple Sclerosis Society has adopted the following recommendations to provide guidance to physicians, nurses, therapists, insurers, and policy makers, regarding the appropriate use of rehabilitative therapies in MS. This document addresses physical rehabilitation. Cognitive and vocational rehabilitation will be addressed in future documents.

**Definition:** Rehabilitation in MS is a process that helps a person *achieve and maintain* maximal physical, psychological, social and vocational potential, and quality of life consistent with physiologic impairment, environment, and life goals. *Achievement and maintenance* of optimal function are essential in a progressive disease such as MS.

While the disease course cannot be altered by rehabilitation, a growing body of evidence indicates that improvement in mobility, activities of daily living (ADL), quality of life, prevention of complications, reduction in health care utilization, and gains in safety and independence, may be realized by a carefully planned program of exercise, functional training, and activities that address the specific needs of the individual. Thus, rehabilitation is considered a necessary component of comprehensive, quality health care for people with MS, at all stages of the disease.

- ◆ The physician\* should consider referral of individuals with MS for assessment by rehabilitation professionals\*\* when there is an *abrupt or gradual* worsening of function or increase in impairment that has a significant impact on the individual's mobility, safety, independence, and/or quality of life.

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\* or nurse practitioner or physician's assistant

\*\* includes rehabilitation physician, occupational, physical, speech and language therapists and others

- ◆ Patients who present with any functional limitation should have an initial evaluation and appropriate management.
- ◆ Assessment for rehabilitation services should be considered early in the disease when behavioral and lifestyle changes may be easier to implement.
- ◆ 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.
- ◆ 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. The health care team should determine the most appropriate setting. Whenever possible, patients should be seen by rehabilitation therapists who are familiar with neurological degenerative disorders.
- ◆ Research and professional experience support the use of rehabilitative interventions\*\*\* in concert with other medical interventions, for the following impairments in MS:
  - ◆ Mobility impairments (i.e. impaired strength, gait, balance, range of motion, coordination, tone and endurance)
  - ◆ Fatigue
  - ◆ Pain
  - ◆ Dysphagia
  - ◆ Bladder/bowel dysfunction
  - ◆ Decreased independence in activities of daily living
  - ◆ Impaired communication
  - ◆ Diminished quality of life (often caused by inability to work, engage in leisure activities and/or to pursue usual life roles)
  - ◆ Depression and other affective disorders
  - ◆ Cognitive dysfunction
- ◆ Appropriate assessments and outcome measures must be applied periodically to establish and revise goals, identify the need for treatment modification, and measure the results of the intervention.
- ◆ Known complications of MS, such as contractures, disuse atrophy, decubiti, risk of falls, and increased dependence may be reduced or prevented by specific rehabilitative interventions.
- ◆ In a fluctuating and progressive disease, maintenance of function, optimal participation, and quality of life are essential outcomes.

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\*\*\* Includes: exercise, functional training, equipment prescription, provision of assistive technology, orthotics prescription, teaching of compensatory strategies, caregiver/family support and education, counseling, and referral to community resources.

- ◆ Maintenance therapy includes rehabilitation interventions designed to preserve current status of ADLs, safety, mobility, and quality of life, and to reduce the rate of deterioration and development of complications.
- ◆ A thorough assessment for wheelchairs, positioning devices, other durable medical equipment (DME) and environmental modification by rehabilitation professionals is recommended and will result in the use of the most appropriate equipment.
- ◆ Regular and systematic communication between the referring health care provider and rehabilitation professionals will facilitate comprehensive, quality care.
- ◆ Third party payers should cover appropriate and individualized restorative and maintenance rehabilitation services for people with MS.

## Background

While multiple sclerosis is highly variable, most patients experience functional losses and increasing impairment over time. Many people with MS face obstacles accessing rehabilitative services because of inadequate referrals and/or inadequate third party coverage. The National MS Society determined that a statement by its expert medical advisors was therefore necessary to support the use of rehabilitative interventions and thus promote physician referral to these services and third party coverage of them.

A number of studies have demonstrated positive outcomes of rehabilitation on people with MS, and data support the use of rehabilitative interventions for a number of specific MS impairments. Patients with MS who received multidisciplinary rehabilitation in addition to IV steroids demonstrated increased improvement in functional status, mobility, quality of life, and disability over those who received steroids alone (Craig et al., 2003). A study of the effect of inpatient rehabilitation on individuals with relapsing/remitting (RR) MS suggested that inpatient rehabilitation is useful for patients with incomplete recovery from relapses who have accumulated moderate to severe disability (Liu et al., 2003). Another study showed a significant decrease in length of stay in a rehabilitation inpatient unit for patients who were given more intensive rehabilitation therapies (Slade et al., 2002). Patients with progressive MS who received out-patient rehabilitation, experienced reductions in fatigue and MS related symptoms (DiFabio et al., 1997, 2003). Furthermore, a physiotherapy program conducted at home or in a hospital outpatient clinic resulted in significant improvements in mobility, subjective well-being, and mood in patients with chronic MS (Wiles et al., 2001). This study suggests that ongoing physiotherapy might be necessary for sustaining improvement in mobility or prevention of deterioration. Other studies demonstrated positive impact of multidisciplinary rehabilitative care on the daily life of patients with multiple sclerosis (Freeman et al., 1999; Solari et al., 1999).

In studies regarding access to rehabilitation services by people with disabilities, respondents report difficulty in accessing services, largely due to insurance coverage limitations (Beatty et al., 2003). Many insurance policies and state/federal regulations require that rehabilitation services be 'restorative' rather than oriented to maintenance of function and prevention of avoidable disability and complications. However, for individuals with chronic, progressive or disabling conditions such as MS, maintenance therapy is critical for preserving overall health and functioning, maintaining

independence, avoiding institutionalization, and preventing secondary medical conditions and the associated need for costly hospitalizations that may include surgeries.

While additional research is needed, recent findings along with expert opinion and clinical experience demonstrate the value of rehabilitation in MS. Physicians should prescribe appropriate rehabilitation therapies for their patients with MS and insurers should cover these therapies.

## **Process**

The clinical care committee of the National MS Society's Medical Advisory Board (MAB) identified the need to develop and periodically update a formal position about rehabilitation as a necessary component of quality health care for people with MS, at all stages of the disease. The MAB convened a multidisciplinary task force of MS experts to develop recommendations. The task force conducted a comprehensive review of the literature and compiled professional opinion based on the literature and clinical practice. The Medical Advisory Board's Executive Committee provided final review and approval of the document.

## **Use of the Recommendations**

The National MS Society rehabilitation and MS statement is an educational and advocacy tool. It will be a component of the Society's professional education programs and will be used to promote increased access to rehabilitative therapies through legislative and regulatory determinations. It will serve as a communication device for interactions with insurers both nationally and locally. It supports self-advocacy for persons with MS and will encourage them to talk with their health care providers and insurers about whether rehabilitation is indicated.

## **Role of the National Multiple Sclerosis Society**

The mission of the National MS Society is to end the devastating effects of multiple sclerosis. Various strategies are employed to do so, including professional education and advocacy. As a representative body and advocate for people with MS and medical/health professionals who provide their care, the Society is positioned to provide structure and support for the development of an expert opinion document to facilitate access to rehabilitative therapies for disease management. The National MS Society has a nationwide network of chapters and regular contact with persons with MS and their families as well as with health care professionals. This extensive network and process for dissemination of information will ensure that the recommendations regarding rehabilitation and MS will be communicated to providers, insurers, and people with MS.

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