

Managing MS Through Rehabilitation



MS[®]

National
Multiple Sclerosis
Society

RONA
DIAGNOSED IN 1986

Managing MS Through Rehabilitation

BY LISA J. BAIN WITH RANDALL T. SCHAPIRO, MD
& SUSAN E. BENNETT, PT, DPT, EDD, NCS, MSCS

By Lisa J. Bain, professional science and medical writer; Randall T. Schapiro, MD, President, The Shapiro Multiple Sclerosis Advisory Group and Clinical Professor of Neurology (retired), University of Minnesota; and Susan E. Bennett, PT, DPT, EdD, NCS, MSCS, Clinical Professor, Rehabilitation Sciences, University at Buffalo.

Reviewed by: James Bowen, MD; Barbara Giesser, MD;
Pat Kennedy, RN, CNP, MSCN; Sue Kushner, MS, PT;
Christine Smith, OTR/L, MSCS.

© 2016 NATIONAL MS SOCIETY. ALL RIGHTS RESERVED.

Introduction

Multiple sclerosis (MS) is a chronic inflammatory, demyelinating disease of the central nervous system (CNS). The clinical course, which varies for each individual, is typically characterized by relapses (also referred to as attacks or exacerbations) and remissions. During a relapse, inflammation causes old symptoms to suddenly worsen or new ones to appear. During a remission, the symptoms partially or completely disappear as the inflammation subsides. Some people with MS experience a more steadily progressive form of MS, with or without any inflammatory relapses along the way. Regardless of the kind of MS you have, it is important for you to know how to promote your own health and wellness, manage whatever symptoms you may be experiencing, and optimize your ability to function comfortably and safely in your everyday activities. This booklet provides information about the important role rehabilitation can play in helping you live well with MS and introduces the healthcare professionals who will work with you along the way.

What is Rehabilitation?

Rehabilitation (or rehab) is focused on improving all levels of function that may have been changed or lost (following a relapse, for example) and maintaining optimal function. The goal of rehabilitation is always to maximize your independence and participation in everyday life.

Following a relapse or exacerbation, an aggressive and personalized rehab program will help you recover your strength and mobility as much as possible. The program is likely to involve stretching, strengthening and retraining muscles to improve function, and an aerobic conditioning component. When needed, the program will also teach you how to use new techniques or aids to achieve safe and independent mobility.

Periodic rehabilitation sessions are useful for regular “tune-ups” of functional mobility, strength, spasticity and cardiovascular fitness, particularly if a relapse has occurred or you have experienced other health issues. For individuals whose MS is more steadily progressive, maintenance rehabilitation can help preserve as much physical function as possible, while also promoting general health and wellness.

Once your scheduled rehabilitation sessions have ended, you will be able to maintain your achieved strength and mobility through a home-based exercise program designed specifically for your needs.

Rehabilitation professionals also address problems with self-care and task performance at work and at home, including the use of various types of adaptive equipment and assistive technology. Speech and cognitive changes, including word finding and memory, can also be addressed by rehabilitation professionals (occupational therapists or speech/language pathologists) for optimizing daily performance.

THE WORLD HEALTH ORGANIZATION USES SOME TERMS YOU SHOULD KNOW:

- **Impairment** — a problem in a body system or a body part that significantly deviates from the norm (symptoms you experience).
- **Activity limitation** — a problem in performing a task or action.
- **Participation restriction** — a problem in the manner or extent of a person's ability to be involved in a life situation.

These terms are used by rehabilitation professionals world-wide to make distinctions important to problem solving.

Suppose your MS causes your left foot to drop down each time you take a step. This is an **impairment** called "foot drop." It makes walking difficult and increases your chances of tripping. Trouble walking is an **activity limitation**. But foot drop can be corrected with a lightweight orthotic. For many people, using this type of adaptive equipment means living life as usual. But a runway fashion model would need to change or adapt her career because this impairment causes a **participation restriction** in the kind of work she does.

Rehab professionals focus on reducing participation restrictions and activity limitations.

Who Can Benefit from Rehab?

Everyone with MS, whether the person's symptoms are mild or severe, can benefit from rehabilitation. Scientific studies have demonstrated sustained functional benefit for individuals with MS who participated in supervised rehabilitation programs.

For people with mild or “invisible” symptoms, a rehabilitation approach emphasizes education, energy management and physical fitness. Participating in rehabilitation early on can establish positive behavior patterns that will come in handy should other problems surface later. When activity limitations exist, rehabilitation focuses on making the most of existing strength and abilities. When challenges occur with memory and/or multi-tasking of daily activities, a rehabilitation specialist should be consulted for evaluation and treatment.

Rehabilitation can also have important benefits for a person's relationships with family and friends. Part of a rehab program may involve learning how to deal with changes in mobility; utilizing tools and mobility aids that allow full participation in activities with others; modifying environments to reduce restriction; and teaching other people how to provide assistance in ways that are physically and emotionally beneficial.

Finding or Building a Program

Your neurologist, family doctor, nurse or other healthcare professional may refer you to a rehabilitation clinic or to independent therapists. If appropriate and indicated, some therapies may be provided in your home through a home healthcare agency.

Most comprehensive MS centers offer a team approach in which the medical, psychosocial, and rehabilitation aspects of care are integrated. Integrated programs not solely devoted to MS can be found in physical medicine and rehabilitation (physiatry) departments of many major hospitals. They may be offered on an inpatient or outpatient basis and are usually run by a neurologist or physiatrist (an MD who specializes in physical medicine and rehabilitation).

Each person with MS has a unique set of symptoms and circumstances that requires a personalized combination of rehabilitation techniques. Evaluation is the first step. In addition to assessing your physical abilities, cognition and personal goals, your evaluation may also include an assessment of your environment to see if modifications to your home or workplace would be useful.

Whether or not you go to an MS center, it is important to be an educated consumer. You should consider the expertise and experience that prospective therapists have with MS. The National MS Society (1-800-344-4867) can provide referrals.

THINGS YOUR DOCTOR SHOULD KNOW

The National MS Society's paper, **Rehabilitation: Recommendations for Persons with Multiple Sclerosis**, recommends that:

- People with MS should be referred for assessment by rehabilitation professionals when there is an abrupt or gradual worsening in functional limitations or increase in impairment that has a significant impact on mobility, safety, independence and/or quality of life.
- Assessment for rehabilitation services should be considered early in the disease when behavioral and lifestyle changes may be easier to implement.
- The frequency, intensity and setting of the rehabilitative intervention must be based on individual needs.
- Third-party payers should cover appropriate and individualized services for people with MS.

Visit [nationalMSsociety.org/rehabrecs](https://www.nationalmssociety.org/rehabrecs) to read more or call 1-800-344-4867 to request a hard copy.

Rehabilitation therapists who specialize in MS may be credentialed as MS Certified Specialists (MSCS). These professionals have demonstrated their years of clinical experience and knowledge in MS through formal application and review by the Consortium of MS Centers and by passing a national examination.

A good source of information on assistive devices for people with disabilities is ABLEDATA. For information, contact: ABLEDATA, 103 W Broad Street, Suite 400, Falls Church, VA 22046, 1-800-227-0216, abledata.com.

About MS Rehabilitation Professionals

Physical Therapists (PTs)

Physical Therapists (PTs) who work with individuals with MS focus on all aspects of mobility at home and in the community, and address many of the impairments that challenge or restrict mobility (e.g., weakness, spasticity, balance dysfunction).

Mobility

To keep mobile, a person with MS may need gait (walking) training, assistive devices when appropriate, and specific exercise programs to address the impairments, and medication(s), if needed (for example, Ampyra®)

to increase walking speed and medications to address spasticity — see page 13).

Since walking requires balance, coordination, upper-body control, strength and endurance, rehabilitation requires evaluation of all of these areas. Symptoms or impairments of MS that affect walking include weakness, tremor, visual disturbances, sensory changes, spasticity, and problems with balance and coordination. Physical therapy, medications, walking devices and/or appropriate footwear may be needed. Adaptations may also be needed in the home and workplace to optimize mobility, comfort and safety.

People may see assistive devices as symbols of disability or as a sign of “giving in” to the disease. Or, they may fear that using an assistive device will lead to greater weakness, so they refrain from using devices that actually enhance independence and prevent fatigue. Mobility aids help people conserve energy while carrying out their daily activities, therefore allowing them to do more throughout the day. In other words, mobility devices are helpful tools for everyday living. Look at mobility devices as tools. A carpenter can’t work without proper tools, and some people with MS can’t move about easily on their own without the proper tools.

A full range of tools are available to help people stay functionally mobile, comfortable and safe. Visit **nationalMSSociety.org/mobility** to determine if and when a mobility device might be appropriate, and learn about the comprehensive evaluation for a wheeled mobility device.

The tools for mobility are now lighter, easier to handle, more attractive, and more comfortable than ever. A physical therapist can determine which mobility tools are appropriate to your needs and teach you the skills you need to use them well. The mobility “tool chest” includes:

- **Orthotics** are braces that are used to position a weak or spastic limb. In MS, an orthotic may be used to manage foot drop (a symptom that causes the toe of the shoe to drag and scrape the ground during walking and may cause the person to trip or fall), decrease the fatigue caused by the inability to pick the foot up when walking, and can increase stability in the ankle. An ankle-foot orthosis (or AFO) is the most commonly prescribed orthotic for weakness and/or spasticity in the ankle and lower leg. The AFO fits inside the shoe and comes up along the back of the calf (plastic versions) or around from the ankle to the back of the calf using a small strut (in carbon fiber versions). In instances of knee instability, an AFO with a joint or a brace that comes above the knee to provide stability (knee ankle foot orthotic) may be prescribed.

Functional electrical stimulators (FES) can supplement the benefits of a rigid AFO by wirelessly activating the peroneal nerve on the outer part of the calf just below the knee. This device bypasses the brain’s stimulus to the nerve, activating the calf muscle to contract and pick the foot up for clearance in walking. Individuals should be evaluated by a physical therapist to determine if the FES is effective in improving their gait.

In some instances where the muscle that picks the foot up is weakened or fatigued, a dorsi-flexion assist orthosis may be recommended. These particular devices assist in picking the toes up for walking, but do not provide stability to the ankle joint, nor do they control spasticity.

- A straight **cane** or quad cane can provide support for balance and/or weakness of the legs. If one leg is weak, the cane is used in the opposite hand. Two canes (or transitioning to the use of crutches) may be needed if both legs are weak. Although decorative canes can be purchased, asking friends and family to decorate and personalize a cane is a great way to get loved ones involved and be creative. A physical therapist can help with sizing and providing instruction on the best way to utilize a cane.
- **Crutches** provide greater stability when weakness is more limiting and canes are not sufficient to provide the needed support. Forearm crutches, called Canadian or Lofstrand crutches, are stable and enable use of one hand to open a door when the forearm cuff is secured on the arm. Axillary crutches, which come up to the underarm region, provide greater stability than the forearm crutch. As with the canes, crutches should be sized for each individual with instructions in how to use them. Be sure to learn about proper use of axillary crutches, as excessive pressure in the underarm region can cause nerve injuries.
- **Walkers** may be prescribed when there is weakness in the legs or when balance is impaired. There are a variety of walkers from the standard walker with four legs, to two- and four-wheeled walkers. Most walkers fold up so they are easy to transport in the car. Standard walkers are used more with weakness in the legs, whereas wheeled walkers are more suitable for individuals with balance issues. Four-wheeled walkers have hand brakes and seats that are convenient when fatigue becomes a factor during walking.

- **Wheelchairs** or three-wheeled scooters provide mobility when walking is limited or no longer a safe means of locomotion. Motorized scooters and manual (arm-driven) or motorized wheelchairs are often used by individuals who can walk a short distance but need to conserve their energy. People who use scooters must have trunk control in order to sit comfortably and safely. Manual wheelchairs can be customized for seating, but most individuals who can propel their own chair simply use a seat cushion. Individuals who use a motorized wheelchair or “power chair” have a variety of options for seating and positioning as well as options for modifications to the hand-control for propulsion. Consult with an Assistive Technology specialist, or an occupational or physical therapist when making decisions about the type of wheelchair to purchase. In many instances, once a wheelchair or scooter is purchased through the patient’s health insurance, there is a period of time before a different device (providing more support or control) can be purchased.

Any type of assistive device, or changing from one type of assistive device to another should be done under the supervision and recommendation of a physical therapist.

Balance

A comprehensive evaluation should be performed by a physical therapist to determine the underlying cause of the balance dysfunction. Once that is identified, a PT can provide balance retraining through exercises that emphasize core stability, leg strength and flexibility, and/or specific retraining of the visual and vestibular [inner ear] systems if there is a deficit. Techniques to reduce upper-extremity and lower-extremity tremors can also be valuable when

this contributes to balance dysfunction. Sensory issues or lack of sensation in feet or other parts of the body may need to be addressed as they may contribute to balance and coordination problems.

Weakness

Weakness, whether from an MS inflammatory lesion or the result of disuse, should be addressed through specific strengthening exercises prescribed by the physical therapist. The exercise regimen should include a specific exercise program to be done at home as well as the exercise and task-specific training that would be practiced in the PT clinic or during a home care PT visit. Increasing or maintaining muscle strength is paramount to improving or maintaining mobility. It is imperative to keep strong the muscles that are intact and working, either fully or partially.

Spasticity

Normal movements require a coordinated sequence: as one muscle contracts, an opposing muscle must relax. MS can disrupt this process, resulting in involuntary contractions of muscles that can impair movement. This type of involuntary contraction is called spasticity, and may also be described as “increased tone.” The affected body part becomes stiff or difficult to move and feels heavy. The involuntary contraction may feel like a mild muscle spasm or cramp, or it may be painful. When spasticity impacts movement, (walking or transfers) or is painful, the provider managing the patient should be contacted.

Spasticity can be managed with the help of a physician and a PT. A combination of medication, exercises, and adaptive devices may be prescribed. Exercise programs will likely include stretching and range-of-motion exercises. Exercise in a cool swimming pool is helpful because the buoyancy of the water makes smooth movements easier. Passive exercise (when someone else moves the person's limbs) and regular stretching are particularly effective for managing spasticity. Specific positioning, sometimes with bracing, can also help to decrease spasticity. Medications that may be prescribed include Lioresal® (baclofen), Zanaflex® (tizanidine), and Botox® (onabotulinumtoxinA).

Physical fitness

Appropriately-designed exercise programs are of enormous benefit to people with MS. Exercise helps maintain and build endurance. After a flare-up of MS, exercise can help restore function and re-energize a person through promoting cardiovascular function that enhances oxygen and glucose to the muscles and brain. A PT, physiatrist or exercise physiologist can provide the best advice on a good program that includes aerobic and non-aerobic exercises. Seek help from someone who is experienced in working with people with MS. And choosing physical activities and exercises that are enjoyable makes it easier to continue doing them on a regular basis.

In addition to the exercise programs recommended by the rehabilitation professional, there are many other physical activities that can be beneficial and enjoyable, including going to a gym, enrolling in an aquatics program, engaging in yoga, tai chi, adaptive skiing and numerous other options that can be individualized for your interests, needs and availability.

Pain from improper posture or positioning

This type of pain results from unusual positioning of the body caused by MS symptoms; the medical term is “musculoskeletal dysfunction.” For example, hip, knee or low back pain can stem from poor posture that has developed over the years as a result of weakness, spasticity or balance dysfunction. Fatigue can make this kind of pain even worse. Overuse of certain muscles to compensate for other muscles can also lead to muscle pain.

A physician and/or PT can determine if pain is caused by nerve damage or by musculoskeletal dysfunction. If the latter has occurred, a PT can devise a program of strengthening and stretching exercises, practice of proper positioning, and use of supports, bracing, or an assistive device to prevent awkward or excessive use of joints or muscles.

Pressure sores

A person who has limited mobility runs the risk of developing pressure sores (also termed decubiti), which occur when the skin breaks down from constant pressure

caused by sitting or lying in one position. This pressure cuts off the blood supply to the underlying skin, fat and muscle. These sores usually occur over bony prominences such as the tailbone, buttock, heel, shoulder blade, elbow and sometimes the back of the head. Sores may also develop from friction to the skin (also known as shear) caused by sliding one's body across a bed or wheelchair. The skin is much more likely to break down if it is moist or infected. Thus incontinence (not being able to control urine or bowel movements, or both) can add to the problem.

Pressure sores can be prevented in the following ways: get up or change positions frequently, or have someone assist you to change your position at least every two hours. Proper positioning in a wheelchair or bed, and use of cushions and other supportive devices can also prevent skin breakdown. Keep the skin clean and dry. Check skin for reddened areas or sores during self-care routines, and make sure nutrition and fluid intake are adequate. If you suspect a pressure sore is developing, contact your provider as soon as possible. The treatment of pressure sores becomes more and more difficult as the sore advances.

Occupational Therapists (OTs)

Occupational therapists (OTs) focus on activities of daily living or “life roles” and the skills that are necessary for performing those tasks, including upper-body strength, coordination and fine-motor skills. Activities of daily living

include dressing, bathing, toileting, household chores and working at a job — all which may become hard to do in the presence of certain impairments. OTs also focus on cognitive problems and can assist with cognitive retraining and strategies to compensate for poor memory. Most importantly, OTs can help with energy management.

An OT can advise you about techniques and adaptive devices to compensate for specific disabilities you may have. The table on the next page illustrates some everyday activities and helpful devices as well as helpful techniques.

Fatigue

Fatigue is one of the most common symptoms of MS, and sometimes the most disabling one. It affects everything a person does.

If you are experiencing fatigue, your physician may prescribe medications and regular rest periods. Fatigue is also managed by conserving energy and spending it more efficiently. OTs are experts on labor-saving and energy-conserving techniques. Ask your physician for a referral to an occupational therapist if fatigue is disrupting your life.

Upper body function

An OT can provide exercises to improve the strength and coordination of the arms and hands. Doing so can improve independence and function in daily activities.

Everyday Activities

Helpful devices

Bathing

- Tub bench
- Hand-held shower
- Grab bars

Helpful techniques

- Avoid hot water
- Safe transfer techniques

Toileting

- Bedside commode
- Armrest near toilet

- Safe transfer techniques

Dressing

- Long shoe-horn
- Velcro closures
- Button hook

- Lower closet bar
- Sit while dressing
- Dress weaker side first

Eating

- Plate guard
- Specialized utensils
- Wrist support

- Elbows on table for stabilization
- Hold cup/glass with two hands

Cooking

- Microwave oven
- Wheeled utility cart
- Electric can opener
- Pot stabilizer

- Sit whenever possible
- Slide objects rather than lift them

Chores

- Reachers
- Electric appliances

- Spread tasks out over a period of time
- Do heavier chores during periods of greatest energy

An OT can provide similar recommendations for organizing your work space in the office and simplifying job-related tasks.

Driving

Driving can be affected by many MS-related symptoms. If changes are making driving difficult and potentially unsafe, an occupational therapist who is a certified driving rehabilitation specialist (CDRS) can assess a person's driving skills and determine what available adaptations might be most helpful. Evaluation by a CDRS will include clinical testing of physical, visual and cognitive abilities, as well as a behind-the-wheel driving test. The laws regarding what kinds of testing and reporting are necessary vary from state to state.

There are a variety of adaptive modifications that can enable people to continue driving safely if they have lost the physical ability to manage the controls. Hand controls for braking and acceleration are available for people who cannot rely on their legs. Steering knobs can help people who have the use of only one arm. Depending on the type of equipment that's needed, training may be indicated to ensure safety behind the wheel. Some states require that a driver's license list the driving adaptation used, just as corrective glasses are listed.

Vehicle modifications can also help with transporting mobility devices such as a scooter or wheelchair. Wheelchair lifts can be installed in certain cars and vans for drivers and/or passengers.

Computers and electronic equipment

Computers, which provide entry to a world of connection, recreation and job-related activities, can be modified to meet challenges related to vision or weakness. For example, people with vision problems can use computers with high contrast and larger type on the keyboard, magnifying displays, or text-to-speech programs that read aloud the material onscreen. Visit [nationalMSSociety.org/assistivetech](https://www.nationalmssociety.org/assistivetech) for useful information on how to use accessible technology to live better with MS.

Remote controls can be used for virtually all the appliances in an environment — lights, radios, telephones, televisions, air conditioners, even doors. An OT can help determine which devices are most appropriate to compensate for a person's physical limitations, and where training can be provided if needed. OTs who have specialized training in this area are referred to as assistive technology practitioners (ATP).

Speech-Language Pathologists (SLPs)

Speech-language pathologists (SLPs) evaluate and treat problems with speech and/or swallowing that can sometimes occur in MS. Many SLPs also help with cognitive and communication problems related to functions such as attention, perception, organization, thinking, memory or word-finding that can result from MS lesions. SLPs provide intervention by training distinct cognitive processes, teaching specific functional skills, developing

compensatory strategies and support systems, providing caregiver training, and providing referrals to counseling and behavioral support services.

If it's hard to speak or swallow

When MS affects the muscles that involve the lungs, neck, shoulders, throat, voice box (larynx) jaw, lips, cheeks and tongue, speech and/or swallowing difficulties may result. These problems may be further complicated if the hip and trunk muscles (which provide body stability) are also affected.

Speech

Dysarthria, a motor speech disorder, is a common speech problem experienced by some people who have MS. In dysarthria, there may be difficulty in controlling and coordinating respiration, pitch, loudness, quality (hoarseness, breathiness) and nasality of the voice. The ability to clearly pronounce words may sound “slurred.” The natural flow of speech (prosody) may be halting, with inappropriate emphasis placed on syllables or words, and voice loudness may fluctuate. There are different types of dysarthria and the severity depends on the location and extent of damage to the nervous system. Treatment is focused on the type of dysarthria and severity of the symptoms. Treatment goals may include slowing the rate of speech, improving breath support for speech, recommending exercises for strengthening weakened

muscles and increasing range of motion of those muscles needed for speech and saliva control. If dysarthria is severe, alternative means of communication (gestures, alphabet/word boards, electronic or computer generated speaking devices) may be used.

Swallowing

The term dysphagia is used when there is difficulty moving food and/or liquid from the mouth to the stomach in a safe, effective and coordinated manner. Swallowing occurs in the following stages:

1. The oral phase of the swallowing process involves the ability to suck, chew and move food and liquid into the throat.
2. Next, the pharyngeal phase involves the beginning of the swallowing reflex. Food/liquid is squeezed down the throat while the airway is closed off to prevent food/liquid from entering the lungs (aspiration).
3. In the esophageal phase, special muscles at the top and bottom of the esophagus (food tube that leads from the throat to the stomach) relax and tighten and squeeze the food/liquid through the esophagus and into the stomach.

People with MS can experience problems in one or more of these swallowing stages. Intervention approaches are numerous and may include specific swallowing treatments (such as exercises that focus on improving muscle strength or movement), use of certain postures or positions to facilitate more effective swallowing (sitting up in a chair

with good trunk support instead of reclining in bed), and changes in the textures of food/liquids to make eating easier and safer (e.g., pastas or mashed potatoes instead of hard to chew meats or hard breads). Treatment for dysphagia is unique to each person's symptoms and type of swallowing problem. A qualified speech-language pathologist can perform a thorough evaluation of the swallow in order to determine the best treatment strategy.

Augmentative and Alternative Communication (AAC)

Sometimes MS can severely limit the ability to communicate either because the person's speech is no longer easily understood or because fatigue can make communication difficult. In these situations, augmentative and alternative communication (AAC) can replace speech or supplement existing speech if necessary. One type of AAC system is referred to as "unaided." Unaided communication systems may include body language, gestures and/or sign language. Another type of AAC system is "aided." Aided systems incorporate the use of simple equipment such as pencil, paper, or pointing to a specially developed picture/word book or alphabet board. More sophisticated systems include speech generating devices (technology that produces voice and/or written messages). Each system, or combination of systems, is designed specifically for each individual's communication needs.

Nurses

A nurse can be the cornerstone of the rehabilitation program. Nurses are trained to identify health problems, perform assessments and connect people to appropriate specialists. “Patient education” is part of their job description and nurses will make time to listen to a person’s questions and teach self-help techniques. Registered nurses can earn the credential “MS Certified Nurse” through demonstrating two years of experience working in MS and passing an examination that covers:

- Basic concepts of MS (disease course classification, pathophysiology of MS, diagnostic process)
- Pharmacologic and non-pharmacologic treatment
- Symptom management
- Psychosocial intervention
- Research and education initiatives
- Patient advocacy

Mental Health Professionals

Psychologists, social workers and counselors help people learn ways to manage the emotional challenges that can be a part of life with MS, and to deal with the impact of MS on the family. They provide emotional support, training in coping and communication skills, and stress management strategies. A mental health professional with expertise in chronic illness can be a valuable addition to your rehabilitation efforts.

Neuropsychologists

Neuropsychologists are psychologists who specialize in memory, problem solving, and other cognitive problems, and can utilize various cognitive tests to assess which functions have been affected and which remain intact. They also specialize in educational testing and intelligence testing when appropriate.

Memory loss and other cognitive difficulties

Poor recent memory is one of the most commonly reported cognitive symptom in MS. Psychologists, speech-language pathologists, and occupational therapists can recommend and teach simple compensatory strategies, such as making lists, writing notes, learning memory tricks, and keeping a “memory” notebook.

People with MS can also experience problems with slowed processing of information, concentration, reasoning, judgment, and the ability to learn. Formal evaluation of cognition may be recommended in order to design the best course of treatment. Depending on each individual’s needs and situation, this can be done by a neuropsychologist, speech-language pathologist, or occupational therapist who has had training in the diagnosis and treatment of cognitive problems. Modifying daily activities and use of compensatory strategies can be helpful. Teaching support partners how they may provide support and assistance can also be very helpful.

Even very mild cognitive problems can increase fear, anxiety, and depression — emotions that in themselves are disabling. A psychologist or other mental health professional can also provide supportive counseling.

Vocational Rehabilitation Specialists

Vocational Rehabilitation Specialists focus on retraining or use of adaptations and accommodations on the job. They may work independently or in consultation with a large rehabilitation agency. Contact your local county government office to find a vocational rehabilitation specialist in your area, or search online for “vocational rehabilitation” and your town/city name.

Referrals for other Specialists

Bladder problems

Many people with MS experience bladder problems at one time or another due to neurological changes from MS. The most common problems are increased frequency or urgency, leakage, difficulty urinating despite having the urge to do so, and the inability to hold urine in the bladder (incontinence). Sometimes the bladder does not empty completely, which can set the stage for urinary tract infections.

Diagnosis is the first step. If you are experiencing bladder symptoms, your provider may refer you to a urologist who specializes in the treatment of urinary infections, bladder problems, and sexual problems.

Symptoms can often be managed by medications, diet changes, and in some cases self-catheterization, in which a small tube, or catheter, is inserted through the urethra into the bladder so urine can drain out. (This may sound difficult or painful, but most people can learn to do it easily and comfortably.) There are also exercises the physical therapist could teach you that involve strengthening the pelvic floor muscles for better bladder control.

Bowel problems

Constipation may occur because of MS-related nerve damage, or lack of exercise, inadequate fluids, poor diet or certain medications such as antidepressants (or even medications used to control bladder symptoms). The first line of therapy usually involves modifying the diet to include more fruits, vegetables, and whole grains, and six to eight glasses of water each day. In addition, leg exercise, massage of the lower abdomen, standing exercise and walking, if able, can help promote motility of the stool within the intestine and assist with evacuation. If these measures don't solve the problem, a referral to a gastroenterologist may be needed.

Incontinent bowel, or loss of bowel control, is a much less frequent complication and may result from leakage around impacted stool. Stool bulking agents, a regular “bowel program,” and medication may also be prescribed. A physiatrist (a physician who specializes in rehabilitation medicine) may also be very helpful with both bowel and bladder problems as well as in medical management of many of the other symptoms of MS.

Sexuality

Neurologists, urologists, sex therapists, specialized nurses, occupational therapists and psychologists may all play a role in addressing sexual problems caused by MS. Men may have difficulty getting aroused, achieving or maintaining erections, or reaching orgasm; women may experience difficulty getting aroused, impaired sensation, numbness or tingling in the genital area, insufficient lubrication, or difficulty reaching orgasm.

MS also affects sexual responses indirectly. Fatigue, pain, bowel or bladder problems, and the emotional impact of having MS can dampen sexual desire and interfere with sexual activities. Spasticity may prevent using certain positions.

Taking an active approach to sexual problems means that both partners explore adaptations in sexual expression.

If you are experiencing difficulties in this area but find these conversations difficult, a psychologist, licensed social worker or other mental healthcare specialist can help start this process. Medical treatment to manage symptoms is part of the solution, as is addressing the emotional concerns of both partners.

A final note

Living well with MS means much more than getting treatment for symptoms. It requires you to be the driving force in your health and wellness. Rehabilitation therapists will equip you with knowledge and skill to overcome many obstacles. Being vigilant about your health and wellness also means being active in an exercise program that meets your needs and interests; being conscious of the role that diet and proper nutritional intake can play in your energy level; and getting the restorative sleep that your body needs. Counseling by a psychologist, social worker or psychiatrist who has worked with people who have chronic diseases may be helpful. Ask your doctor, nurse or the National MS Society for a referral.

It may also be helpful to meet other people who live with MS. Seeking knowledge and support shows strength — not weakness. Support groups, self-help meetings, and trained peers with MS all provide a chance to share information and concerns. Visit **[nationalMSSociety.org/connectionprograms](https://www.nationalmssociety.org/connectionprograms)** or call 1-800-344-4867 to connect with trained volunteers who understand your experiences via in-person groups, online groups, or one-on-one via telephone or email.

Botox® is a registered trademark of Allergan, Inc.

Lioresal® is a registered trademark of Ciba Geigy Corp.

Zanaflex® is a registered trademark of Elan Pharmaceuticals Inc.

Ampyra® is a registered trademark of Acorda Therapeutics, Inc.

Notes

The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient’s use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at [nationalMSSociety.org](https://www.nationalmssociety.org) or 1-800-344-4867.

The Society publishes many other resources about various aspects of MS. Visit [nationalMSSociety.org/brochures](https://www.nationalmssociety.org/brochures) or call 1-800-344-4867.

Other popular resources include:

- ADA and People with MS
- Controlling Spasticity in MS
- Driving with Multiple Sclerosis
- Exercise as a Part of Everyday Life
- Fatigue: What You Should Know
- How to Choose the Mobility Device that is Right for You
- Stretching for People with MS

The National MS Society mobilizes people and resources so that everyone affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move their lives forward.



National
Multiple Sclerosis
Society

nationalMSsociety.org

1-800-344-4867