Patient Education

Western Multiple Sclerosis Center at UWMC



Rehabilitation Techniques

For persons with multiple sclerosis

Multiple sclerosis (MS) affects the brain, spinal cord and optic nerves. It causes varying degrees of degeneration of central nervous system pathways. Medications can slow this process, but at this time no medications are available to reverse it. Even if a cure were found today that would stop the progression of MS, a patient would still be left with residual loss of function caused by damage to the central nervous system. Rehabilitative techniques can be used to improve function, reduce handicap and enhance quality of life.

Overview

In our Center, assessment of MS patients includes an evaluation of physical, social, psychological and vocational functioning.

The physical assessment is often the most familiar. Physical measures such as the stretching of tight and spastic muscles are used. To some extent, strength may be increased with resistive exercises. Cardiovascular fitness and your sense of well being may be improved with aerobic conditioning. With more severe impairment, orthotic management may be required to substitute for lost strength and stability. For example, a plastic ankle-foot orthosis (AFO) may be used for a patient with ankle weakness. With even more severe physical impairment, stability and function may be further improved with use of a cane, walker, or wheelchair. If issues such as fatigue, tremor, or more severe disability are present, an electric scooter may be needed.

But, rehabilitation does not just involve physical issues. The problems produced by MS are not isolated. They can affect cognitive function, emotional health, work, and financial status, and they can have a profound effect on your family.



Our Center believes that there is value in an integrated rehabilitation program for persons with MS. In many ways, the most severe impairment caused by MS is cognitive loss. While cognitive loss has only been recognized in the last several decades, we have researched and learned of strategies to manage cognitive and emotional deficits.

It is now known that for every clinical exacerbation there are several new MS lesions that do not manifest themselves in motor, sensory, visual, or other easily identifiable pathways. These new lesions may affect cognition, memory, and emotions in the large part of the brain that controls "higher functioning."

Cognitive and emotional deficits can be managed with pharmacological (medicines), psychological, and substitutive techniques (such as writing things down rather than committing them to memory). Vocational rehabilitation interventions must be directed at these deficits, as well as to the physical losses. Thus, not only must the MS patient's job accommodate the physical losses, it must also be structured to allow for memory impairment.

Rehabilitation is clearly the only practical means to significantly improve function for persons with MS, and is a major emphasis at the Center.

To better explain the range of services offered at the Western Multiple Sclerosis Center at UWMC, the issues that relate to rehabilitation are divided as follows. Certainly, they do not impact persons with MS in isolation, nor do we think about them in isolation. Our team works together to help with issues related to your:

- Weak muscles
- Daily tasks (examples: bathing, cooking, etc.)
- Memory, thinking and emotions
- Job

Weak Muscles

Exercise and Physical Therapy

Muscles weakened by MS can often be strengthened through certain types of exercise. Commonly, the most affected muscles are those that control the ankles. If exercises are not enough to restore ankle control, then, as mentioned, braces, canes, walkers, or scooters may help.

Research with MS patients has shown that exercise can increase:

- Strength
- Range of motion
- Endurance
- Balance
- Functional mobility

Since MS affects different people in different ways, an exercise program must be highly personalized to achieve the desired goals and it must be safe. Our role with MS patients is to assess their current status and their personal goals. No matter the level of function, every person with MS can benefit from some degree of exercise therapy.

The exercise program can include resistance training, cardiovascular exercise, balance training, and almost always, stretching. The program should be developed under the guidance of a professional who understands the nature of MS; this helps keep the program safe (and helps avoid the risks of over-training).

Effects of exercise are best achieved when:

- The patient's energy level is optimum, usually in the morning.
- Done in a cooler environment.

If exercise is done properly and consistently, the patient should notice increases in strength and mobility with decreases in pain and stiffness. Be sure to ask your doctor for a referral to a physical therapist if you wish to include exercise as part of your rehabilitation plan.

Physical therapists are available to help train persons with MS in the use of canes, walkers, and wheelchairs to improve function, if needed. They can also teach persons with MS about ways to lift and move that may reduce fatigue and improve function.

Orthotics

Some patients will need orthotic devices (such as braces and splints). Your doctor prescribes these devices. Often, they are prescribed to improve mobility, safety and help you deal with issues related to quality of life.

For some persons with MS, they may allow walking in a safer, more energy-efficient manner. For others, a spinal support may be prescribed for the relief of low back pain caused by weak muscles in the lower back. If patients cannot walk, sometimes braces are designed to limit painful joint movement of the foot, ankle, and knee. They can also help prevent skin ulcers, which may occur as a result of prolonged bed rest and inactivity.

Since each person presents a unique and often complex set of circumstances, please keep in mind that no one type of orthotic will be uniformly effective in treating persons with MS. In addition to the types of orthosis mentioned, at times they are prescribed for the hands, wrists and elbows. Let your doctor know if you have swelling (edema), reduced sensation or other changes that may be related to MS. This helps our team pay close attention to your needs as they relate to the use of orthotic devices.

Daily Tasks

Occupational Therapy

Occupational therapists can help teach you new ways to do daily tasks such as bathing and dressing. They work with patients who are already having problems or who may be at risk for having problems. Occupational therapists assess and treat persons with MS who have problems with:

- Tasks of daily living (often referred to as activities of daily living or ADLs) such as feeding, dressing, bathing, grooming and toileting.
- Higher level daily living skills such as homemaking and money management.
- Bathroom safety and need for related safety equipment.
- Upper extremity strength and coordination.
- Sensory processing, especially in the upper extremities.
- Hand function.
- Perceptual skills, especially visual.
- Cognitive skills including: attention, concentration, memory, ability to follow instructions, problem-solving and decision-making.
- Architectural barriers.
- Driving.

Assistive Technology Services

There is also a department at UWMC called Assistive Technology Services. The department is staffed with professionals such as physical therapists, occupational therapists, speech pathologists, vocational counselors and physiatrists. As a team, we help persons with MS who require specialized equipment to assist them with activities of daily living.

They will assess your need for and help teach you how to operate:

- Computer access environmental control units
- Augmentative communication devices
- Alternative wheelchair driving systems

They are also trained to assess wheelchair seating and positioning, if needed.

Speech and Swallowing

Multiple sclerosis can affect the ability to communicate. Speaking, understanding what others are saying, reading, and/or writing, can be affected. Changes in memory and thinking can also alter communication skills. Changes in the ability to swallow may occur. It may also be difficult to swallow food easily, causing the feeling of food "sticking" in your throat. Speech language pathologists are trained to assess and treat communication and swallowing problems. You may be referred for:

- Change in speech production abilities, such as if your speech sounds different or becomes hard to understand.
- Problems with finding words (often called word finding).
- Trouble expressing and/or organizing thoughts.
- Problems with following conversations.
- Problems with understanding and/or remembering written material.
- Problems with writing down thoughts and ideas.
- Other problems related to communication.
- Changes in your ability to swallow.

The speech and language assessment will show the areas that may require treatment. Help may be offered in a group

or on an individual basis. Some patients receive treatment both ways.

Memory, Thinking and Emotion

Because MS affects the central nervous system, not only are muscles weakened but also commonly, memory, thinking, and emotion can be affected. The Center offers many services to help in this area as well. Social workers, psychologists, neuropsychologists, and speech pathologists are some of the staff who can help persons with MS deal with issues related to memory, thinking, and emotion. Ask your doctor for a referral for any of these services, if needed.

Social Work

The social worker is on our clinic staff to promote positive changes in you, your family and in the world around you to accommodate the diagnosis of MS. Psychosocial issues include physical, financial, emotional, social, intellectual, and spiritual matters. It is the mission of the social workers to help increase well being for you, your family, and/or significant others.

Social workers can help you acquire resources for basic needs such as funding for medication, attendant care, equipment, transportation, housing, and education. They can provide information on disability rights, vocational rehabilitation, and access-related issues. They can help you or direct you to someone who can help you figure out medical coverage and payment issues. They are able to connect you to MS agencies, government-sponsored programs such as DSHS (Department of Social and Health Services), Medicare, and Medicaid. They offer guidance on how to work with complex institutions and programs (including UWMC) to obtain services. And, they can help connect you with the information, education, and support that are accessible on the Internet.

Our social workers are members of your clinic team. They work with clinic, hospital and community agencies to meet your needs. There are six major areas of service that social work provides for patients and families:

- Assessment of Psychosocial Needs done in clinic or by phone. You'll be asked about what you, your family, and/or significant other(s) are experiencing as it relates to your MS diagnosis and what you need or want.
- Problem Solving and Linking Assessment to Intervention – a detailed plan to meet your specific needs made after the assessment.
- Crisis Intervention and Brief Counseling help for the patient, family, and/or significant other(s) in crisis. Feelings of powerlessness, grief, social isolation and the possibly overwhelming need to make lifestyle changes to accommodate MS can be explored. This includes information and support about children. Please note that the social worker's role as counselor is not a substitute for in-depth therapy for more serious issues related to adjustment and coping. Also, the social worker does not replace the expertise provided by a neuropsychologist or speech therapist to address problems of thinking common to MS patients.
- Information and Identification of Community Services

 help connecting to local regional, state or national service and agency resources. Social workers can provide education about or referrals for stress management, exercise, communication, fatigue, social support, substance abuse or other topics that promote health and quality of life.
- *Advocacy and Referrals* help with getting referrals from your doctor for the many services provided by our Center. Social workers can assist with communication

with UWMC clinic team members so that your point of view is taken into account with regard to your care and treatment, especially if it involves cultural or philosophical factors that are not well known. Social workers can also act on your behalf with outside agencies and resources when you, your family, and/or significant other(s) are unable to do so.

• *Follow-up and Reassessment* – done to find out if the plan is working or needs changes. You and your social worker, as a team, will decide if there is more to be done.

Rehabilitation Psychology

A clinical psychologist can help you address adjustment issues and coping with changes in function that can accompany MS. Psychologists work closely with patients, their families, significant other(s) and the treatment team to facilitate emotional and social adjustment and to maximize quality of life. Some of the services they provide include individual psychotherapy, small group therapy and two program groups, Cognitive Group and Group Psychotherapy.

- *Individual Psychotherapy* may meet weekly or less often, based on the person's needs. Some of the issues that might be addressed with a psychologist include depression, anxiety, relationships, sexuality, pain management, sleep habits, decision-making, problemsolving, coping with life transitions, stress management, personality changes and anger or frustration management.
- *Small Group Therapy* an option to be seen with 2 to 4 other persons with MS. This format allows for professional guidance and peer support.
- *Cognitive Group/Group Psychotherapy* open to any person with MS being seen on an individual basis by any

other outpatient rehabilitation therapist (such as physical therapist, occupational therapist, speech therapist, rehabilitation counselor, etc.). These groups are held in 8-week sessions and pre-registration is required. Education about common thinking and emotional problems, as well as practical strategies and an opportunity to practice them in a real-life setting with plenty of peer support, are an important part of both groups.

Neuropsychology Services

Patients are referred to this service when they report problems with thinking, such as trouble with memory, reduced concentration, new troubles with planning or organizing, difficulty with spatial or mechanical tasks, or changes in speed and efficiency of thinking.

Cognitive changes are a very common symptom of MS. It can be helpful to document your areas of ability and difficulty, so that a baseline is established. This can help with developing compensatory strategies that become part of your treatment plan.

The neuropsychological evaluation consists of a detailed interview and a set of standardized tests. The testing takes one whole day, often from 8:30 a.m. till noon and then 1:00 p.m. till 4:30 p.m. If fatigue is a major issue for you, the testing can be spread out over two days.

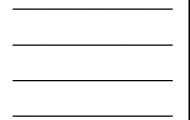
Some patients schedule a one-hour follow-up meeting with the neuropsychologist to review test results and treatment recommendations. A written report is provided in about four weeks to you, the referring doctor, and to anyone else that you request have a copy.

Questions?

Call 206-598-3344

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC Clinic staff are also available to help at any time.

Western Multiple Sclerosis Center at UWMC 206-598-3344



Job Issues

Vocational Rehabilitation Services

Many persons with MS face some uncertainty as to how to:

- Approach their employer to disclose their diagnosis.
- Plan accommodations that may be needed as a result of functional limitations.
- Ask their employer for such accommodations.

The vocational rehabilitation counselor can assist persons with MS with the listed employment issues, explaining the Americans with Disabilities Act (ADA) and further by serving as a patient advocate in employment situations. These counselors can also do a vocational evaluation, assist with a job search and make referrals to state agencies and other resources.

The vocational rehabilitation counselors can help patients understand the application process and the work incentives that are part of the Social Security program (often called Social Security Disability Insurance, SSDI, or disability). They can also help research the short and long-term disability benefits available through your employer.



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