

Managing Cognitive Problems in MS



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National
Multiple Sclerosis
Society

Managing Cognitive Problems

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Introduction

About MS

Multiple sclerosis involves random attacks on a fatty material called **myelin** that insulates nerves within the brain and spinal cord — the structures that make up the central nervous system. Many symptoms can result from the attacks — including changes in thinking — or cognitive function.

Cognition

Cognition refers to all of the high level functions carried out by the human brain, including processing of information, attention, memory, planning and problem-solving, visual perception and verbal fluency.

MS has the potential to affect mood, personality and cognition — the attributes that make us unique — either directly or indirectly. The idea is upsetting, but the facts emerging from research are encouraging — **while mild to moderate problems are relatively common, severe damage to these aspects of the self are not.**

Physical symptoms such as numbness or visual problems, which are common in MS, are usually the result of damage to specific, easily identified areas in the brain and spinal cord. In contrast, it is not always clear what specific damage is the cause of the cognitive changes that occur.

Cognition is sensitive to many potentially disruptive factors. These include normal aging as well as disease or injury. Cognitive functions can also be affected temporarily by tension, emotional stress, depression, sleep disturbances, menopause or fatigue. In addition, they can be affected by nutrition, for example, by low blood sugar (hypoglycemia).

Some prescription medications and drug or alcohol abuse can also disrupt cognitive performance. Many of these factors can and do occur in combination.

MS fatigue is among the most frequently mentioned factors that may affect cognitive functions. People with MS may find that at certain times they are just too tired to tackle cognitive tasks. Studies have documented the existence of **cognitive fatigue** which refers to people's perception that cognitive functioning temporarily declines during an extended period of cognitive effort, such as one might experience on the job. As a result, cognitive functions may be in better working order at some times of the day than at others.

Which cognitive functions might be affected by MS?

Like all MS symptoms, cognitive problems vary from person-to-person. They can be mild and easy to manage or they may be more significant and impact daily functioning. It is possible to experience problems in one area of cognitive functioning or in all of them.

- **Speed of information processing.** Slowed information processing speed is the primary and earliest cognitive problem experienced in MS. Information processing is the foundation of cognitive function, which means that slowed processing impacts attention, learning and memory and decision-making. Therefore, processing speed has a major impact on daily activities and participation in everyday life.
- **Memory or recall.** Problems with memory — the most frequently reported cognitive challenges by people with MS — seem to be limited primarily to recall of recent events. For example, a person may have trouble remembering an important phone number learned in the past month or a phone conversation from earlier in the day. In contrast, the same person will have little difficulty remembering information from the distant past, such as the meanings of words that were learned in school.

Although memory problems are the ones most commonly reported by people with MS, the research shows that what some people experience as changes in their ability to remember things are actually problems with attention and the processing of information.

- **Attention and concentration.** Divided attention (the ability to focus and concentrate when there is more than one stimulus competing for attention) is particularly difficult for some people with MS. For example, driving while using the phone is considered hazardous because the driver's attention is "divided" between driving and talking. In everyday life many situations involve divided attention, such as trying to carry on a conversation while fixing dinner. Often referred to as "multi-tasking," divided attention can pose a real challenge for people with MS, particularly as they try to remember something that they were not able to learn adequately in the first place.

- **Abstract reasoning, problem-solving, and executive functions.** All of these functions are involved in a person's ability to analyze a situation, identify the main points, plan a course of action and carry it out. Some people with MS report that their judgment has also been affected. More often, family members or employers notice changes in problem solving or reasoning before the person with MS does.
- **Visual-spatial abilities.** These functions include the ability to recognize objects accurately and to draw or assemble things. Visual-spatial abilities are involved in many everyday tasks such as driving, finding one's way around or packing a suitcase.
- **Verbal fluency.** Fluency problems are different from the MS speech problems that slow speech down or change voice quality. A fluency problem often manifests itself as the "tip-of-the-tongue" phenomenon: a person wants to say a word, it's on the tip of the tongue, but she or he just can't think of it.

What is known about cognitive dysfunction in MS?

When cognitive problems stem from physical damage done by MS, the source is probably damage to brain tissue. Lesions (or areas of scarring) in the cerebral hemispheres (the higher areas of the brain) are the ones of greatest significance.

Lesions in the white matter of the brain (where myelin occurs in abundance) are particularly common near the inner cavities of the brain (ventricles) through which the cerebrospinal fluid flows. Research has shown that it is not only the myelin that

is damaged in MS, but also the nerve fibers (axons) and cells themselves. While the white matter has been thought to be the area most affected, we now know that significant damage can also occur in the gray matter; studies suggest that cognitive problems are more closely associated with gray matter damage.

Studies using magnetic resonance imaging (MRI) have shown that the number and volume of brain lesions and the amount of nerve tissue loss are related to the presence and severity of cognitive changes. Additional research has found that areas of damage occur with roughly equal frequency in the right and left halves of the brain. Damage to the structures and pathways that join the two sides of the brain can also cause impairment of cognitive function.

Changes in cognition are common in MS. Estimates from studies vary but show a range of 34-65percent in adults and 33percent for children with MS. Cognitive impairment occurs in both relapsing and progressive forms of MS and can even be seen when someone has their very first symptom of MS, known as clinically isolated syndrome. The prevalence and severity of cognitive impairment appears greater in persons with progressive MS but it can also occur during the very earliest stages of the disease process.

The majority of people with cognitive problems from MS experience mild dysfunction. Only about 5-10percent experience moderate to severe impairment. But what do the terms mild, moderate, or severe mean? This question is hard to answer because circumstances vary person-to-person. For

one person, mild cognitive impairment could require a major life shift — for example, the end of a career or professional practice that is particularly affected by the person’s cognitive changes. But another person with the same degree of impairment might not need to make any lifestyle shift, because he or she is able to cope using self-help measures or through reasonable accommodations on the job. Retired individuals with relatively fewer demands on their cognitive abilities are likely to be able to cope quite well with everyday activities.

How do you identify cognitive problems?

Recognition

Early recognition, assessment and treatment are important because cognitive changes can significantly affect a person’s quality of life and are the primary cause of early departure from the workforce. The first signs of cognitive dysfunction may be subtle — noticed first by the person with MS or by a family member or colleague. They include:

- Difficulty finding the right words
- Difficulty remembering what to do on the job or during daily routines at home
- Difficulty making decisions or showing poor judgment
- Difficulty keeping up with tasks or conversations

Evaluation

Scientific evidence supports early and ongoing cognitive evaluation for people with MS. Despite this, cognitive function is not openly discussed, routinely evaluated or optimally treated. It is one of the major unmet needs in MS care. To address this gap, the National MS Society gathered a multidisciplinary group of healthcare providers, researchers and individuals affected by MS to review the scientific literature and make management recommendations. This group concluded that the appropriate management of cognitive dysfunction in MS includes:

- Education for people with MS and their family members
- Early screening and ongoing monitoring throughout the disease course
- Comprehensive evaluation for any adult or child who tests positive on screening or demonstrates a significant cognitive decline
- Comprehensive evaluation for any individual who is applying for disability insurance due to cognitive impairment
- Interventions to improve cognitive functioning and participation in everyday activities

Talk to your healthcare provider if you are concerned about cognitive dysfunction. A specially trained health professional (neuropsychologist, speech/language

pathologist or occupational therapist) will administer a battery of tests and careful evaluation in order to determine the cause(s) of your cognitive changes (since cognitive function can also be affected by aging, medications, depression, anxiety, stress and fatigue.)

What can be done to alleviate cognitive problems?

- **Get it out in the open.** Years ago, professionals advocated not discussing MS-related cognitive problems in public because the issue would upset people. Today, healthcare professionals recognize that people with MS almost always want information on this topic. Talk over your concerns with your healthcare provider. You may want to take a copy of this booklet to your next appointment.
- **Share with others.** Often, fears about a problem are much worse than the reality. To keep up with the facts, ask questions, read, attend lectures if possible, and talk to others who have similar problems. For the most recent information, visit **nationalMSSociety.org**.

In MS self-help groups or educational meetings, cognitive dysfunction is a frequent topic of discussion. Sharing helps on an emotional level as well as on a practical one. Comparing notes and learning how others cope can help to expand one's own resources and remove the feeling of isolation.

- **Get help!** Depression, which is very common in people with MS, can have a significant impact on cognitive functioning. In fact, one of the key symptoms of depression is slowed or impaired thinking. So if you think you may be experiencing changes in your memory or thinking, ask yourself whether depression may be playing a role, and ask your healthcare provider whether an evaluation for depression might be a first step toward managing those changes. For people whose cognition is affected by their mood, successfully treating the mood issue can improve their cognitive functioning.
- **Make it a family affair.** Family members may not realize that you are experiencing cognitive changes as a part of the disease. When you forget parts of conversations, miss appointments or misplace things, it may be viewed as laziness, indifference or carelessness. If this happens, family members and friends need help to understand what is going on.
- **Get counseling if it seems appropriate.** Not everyone who experiences cognitive changes needs counseling. Counseling or psychotherapy can help you deal with the impact of cognitive problems on self-esteem and on everyday life. They also address depression or anxiety, which can worsen cognitive function.
- **Explore compensatory options.** While most cognitive problems are best addressed through rehabilitation with a professional, here are some practical strategies that may help you compensate for cognitive changes:
 - > Where memory is weak, try substituting organization. Get a good organizer (paper- or technology-based) and learn to use it consistently to help with storage and retrieval of information, reminders, appointments and alarms. Record appointments, to-do lists, phone

numbers, family activities, driving directions — anything that you need to remember but are likely to forget. Use your paper or computer/tablet/smartphone organizer to replace little scraps of paper and notes that may get misplaced or lost.

- When you are trying to learn something new, give yourself extra time to practice. Studies have shown that with extra practice people with MS can improve their ability to recall information later.
- Set up a family calendar to track everyone’s activities.
- Assign a particular place for storing frequently used items such as your car keys and encourage family members to return borrowed objects to their proper spots. For example, the scissors always go in the top drawer of the desk.
- Work on your focus and concentration. Sometimes we “forget” things because we never really learned them in the first place. This can happen because we are not giving our full attention to tasks or conversations. Improving your concentration can enhance your recall. Practice focusing on one thing at a time when you are reading, watching TV, or seeing a movie. For example, if you are reading a newspaper article, focus on the main point of the article. If you are watching a movie, focus on the names of the characters. Then in everyday tasks, try to apply that focus on one thing at a time. If you are involved in a conversation, focus on what is being said — block out distractions such as noise in the immediate environment, nearby conversations and unrelated thoughts that pop into your mind.

- Plan your most challenging cognitive tasks for your best time of day. To reduce the cognitive fatigue that can occur during prolonged activities that require sustained effort or concentration, schedule periodic breaks. Whenever your thinking begins to feel foggy or slowed, take a short breather or shift your attention to something else in order to give your mind a rest, and then try again.
- Use mental pictures to aid memory. For example, to increase the likelihood that you will remember to close the windows before leaving the house, visualize streams of muddy water flooding into every room through the open windows. Hold on to that image for a few seconds and you are more likely to remember to close windows later. Another useful strategy is to take a few seconds before leaving home to visualize the route you'll drive to your destination.
- When you meet a new person, write down his or her name as soon as you can gracefully do so. Later, note in your organizer the most striking things about that person. Another strategy is to repeat the person's name to yourself in the context of your conversation with them: "Nice meeting you, **Jim**. I'm also from Nebraska."
- When you encounter word-finding problems, don't persist in trying to think of that elusive word. Try to shift your attention to something else. The word you want will come back to you later. Just express the idea you had in mind using a different word so that the flow of conversation continues and you experience less frustration about the missing word.
- Visit your library, bookstore or e-book site for books designed to help organize time or improve memory.

Some of these involve wildly complicated schemes, but many have useful suggestions.

- > Make sure you're getting enough sleep and that your sleep is not being unduly disrupted by trips to the bathroom, muscle spasms or other problems. If it is, talk to your healthcare provider about how to manage those symptoms.
- > Talk to your healthcare provider about your eating habits to ensure that you are getting good nutrition.
- > After consulting with your healthcare provider, follow a consistent exercise program to help stay in shape physically, mentally and emotionally.
- > Keep challenging your mind with puzzles, reading, stimulating conversation, video games, etc. The old saying, "If you don't use it, you'll lose it," applies here.

Should I have a professional evaluation?

Research studies show that evaluating cognitive function early in the MS disease course helps identify cognitive problems early. We also know from these studies that your cognitive function should be evaluated on a regular basis because many people who have cognitive problems from MS do not realize that they do. The earlier problems are identified the easier they can be to treat.

The expert panel that the National MS Society convened to review existing research and make recommendations suggests that your MS healthcare provider check your

cognitive functioning with a validated screening tool every time you have a neurological exam. They specifically recommend a test called the Symbol Digit Modalities Test (SDMT). This test can be done in five minutes or less and can show if you are having signs of cognitive problems. If you do show signs of cognitive problems on this test, the expert panel recommends that you have a formal cognitive evaluation. They also recommend a formal cognitive evaluation if you or those close to you have noticed a significant change in your cognitive functioning. Lastly, they recommend a formal cognitive evaluation if you are considering applying for disability insurance because of cognitive problems.

A formal cognitive evaluation may require several hours, and it can be costly. Some health insurance plans do cover cognitive evaluations, but do not assume that yours will, even if your healthcare provider prescribes it. Check with your insurance carrier so you can make a fully informed decision. Under certain circumstances your state vocational rehabilitation agency may pay for this type of evaluation.

Formal evaluation of cognitive function should be done by a qualified **neuropsychologist** (a specialist in the behavioral changes caused by brain disease or trauma) — preferably one who has had experience with people who have MS. A psychologist without this training may have difficulty selecting the proper tests and interpreting the results.

In addition to neuropsychologists, appropriate and comprehensive cognitive evaluations can be done by **speech-language pathologists and occupational therapists who have experience with MS**. Each of these three professions may use slightly different tests, but all three can provide valuable insight concerning cognitive changes. In any given locale, one or more of these MS professionals might not be available, and so being able to choose any of the three is a great advantage. A **neurologist** or **psychiatrist** can perform briefer evaluations, but these are often screening tests that identify the need for a more formal evaluation.

About cognitive rehabilitation

Today, it is routine to consider some form of cognitive rehabilitation after a head injury or stroke. In the last few years, the use of cognitive rehabilitation in MS has increased dramatically as techniques have been developed for the more common problems such as memory and attention/concentration. Cognitive rehabilitation is designed to help people compensate for loss of memory, slowed learning ability and other cognitive changes. It is provided by neuropsychologists, occupational therapists or speech/language pathologists.

Ordinarily, cognitive rehabilitation involves one or more sessions per week over several weeks or months. Each session typically lasts about an hour and includes a variety of activities depending on individual needs: exercises designed to enhance memory,

concentration or spatial skills. A good deal of time may be devoted to “compensatory strategies” such as learning how to be more organized, how to use a computer effectively, or how to manage time.

The goals of treatment are individualized, and progress toward those goals may be checked periodically. In many instances, the cognitive rehab program may include meetings with family members to help them understand the nature of specific problems and how they can help.

Stress management, counseling or psychotherapy may be incorporated in the treatment plan if needed.

- **Compensatory strategies.** A systematic program of cognitive rehabilitation will train the person with MS in the consistent use of techniques that compensate for deficits. We all use some of these methods. Common memory aids include writing things down in notebooks, posting notes on the refrigerator or carrying a smartphone.

Many of us also use time-management strategies, filing systems, checklists for complex tasks, reading comprehension strategies, and special-purpose diaries. We routinely employ mental tricks to make the most of our abilities. The little poem “Thirty Days Hath September” is a compensatory strategy for remembering the length of the months.

Cognitive compensatory strategies, like their physical cousins, the cane and the walker, do not address the underlying problem. They offer an alternative way to perform a task that has become difficult. In other words, we may not be able to alter an underlying **impairment** (the

weakened memory, for example), but we can still find ways to dramatically improve **function**. Does it really matter whether we get the phone number we need out of our head or from an address book or smartphone?

- **Improving function.** It's tempting to believe that the right mental exercise might strengthen memory. Some functional improvement methods are based on theories and research concerning the “plasticity” of the brain (the ability of the brain to recover from damage, perhaps by shifting functions to undamaged areas).

With some exceptions, these appealing methods have not been as successful as originally hoped. But some retraining exercises do help. A comprehensive program of cognitive rehabilitation is likely to use a mixture of retraining and compensatory strategies. For example, supervised programs of graded practice can improve attention and concentration levels, and these improvements can then facilitate the effective use of compensatory strategies in everyday situations. (Graded practice means practice in a given task in which, over time, the difficulty is increased.)

- **Physical exercise.** There has been increasing interest in the potential of physical exercise to improve cognitive function both in healthy adults and individuals with chronic conditions such as Alzheimer's and MS. There are now several studies showing the value of physical exercise on cognitive function in MS. This suggests that exercise coupled with cognitive rehabilitation may significantly improve cognition and hence everyday function. Consult with your healthcare provider before beginning any exercise program.

- **Medications.** At present, there are no medications that have been found in large, well designed clinical trials to improve cognitive function in MS; research clearly needs to continue. A few published studies have looked at the effects of some of the MS disease-modifying medications on cognitive function. The results of these studies have been mixed, with some but not all showing benefits on cognitive function. However, since all of the approved disease-modifying therapies have been shown to reduce the number and severity of MS attacks and reduce signs of damage to brain tissue as seen on MRI, they may all, in the long term, have beneficial effects on cognitive function. A few other medications have shown some promising results in studies of cognitive function. However these very preliminary results need to be confirmed in larger, controlled studies. Some healthcare providers prescribe other types of medications to treat cognitive changes in MS. These include medications designed to improve attention. However, there are no published studies to support the use of these medications for improving cognitive functioning in MS. These medications have also not been approved for use in MS by the U.S. Food and Drug Administration (FDA).

Clearing up misconceptions

Cognitive dysfunction is probably subject to more misconceptions than any other topic in MS, in part because we tend to avoid discussing it. Let's dispel some misconceptions.

- **Misconception: MS does not affect cognitive functions or affects them only rarely.**

Many people with MS will never be troubled by severe cognitive problems (as in Alzheimer's), but mild to moderate problems are fairly common. Unfortunately, cognition is often inadequately assessed by many healthcare professionals. An open discussion about cognitive function with your healthcare providers is a good way to start dealing with it.

- **Misconception: People who have cognitive dysfunction are emotionally unstable or have a mental illness.**

Cognitive dysfunction is not an emotional or mental disorder — it is a neurological problem. Someone can have cognitive problems and be perfectly normal emotionally and mentally. While emotional problems such as depression or anxiety can make thinking clearly more difficult, cognitive problems should not automatically be attributed to these causes.

- **Misconception: Cognitive functioning can be assessed by asking a few simple questions.**

There are screening tests for cognitive function that can be used by any healthcare provider to help identify cognitive problems in people with MS. However, to fully and accurately assess all areas of cognitive function, a formal assessment using a series of standardized tests should be done.

- **Misconception: Screening for cognitive function is not necessary for everyone with MS.**

The National MS Society recommends that all people with MS be screened at least annually for cognitive problems. If that screening suggests that problems exist, a full assessment is recommended.

- **Misconception: When cognitive problems appear, they worsen rapidly.**

Although very few long-term studies have been completed, results thus far suggest that these problems progress slowly in most people.

- **Misconception: Cognitive problems only occur late in the course of MS.**

Changes in cognition can occur anytime in the disease course, including very early. Cognitive changes are sometimes the first sign of MS.

- **Misconception: Cognitive problems only occur in people with progressive MS.**

Cognitive dysfunction is likely to be somewhat worse and more common in people with progressive MS. However, cognitive problems can occur in any form of MS. They can even occur in someone having the very first signs of MS, called clinically isolated syndrome.

- **Misconception: Relapses or attacks of MS do not involve cognitive functions.**

Not true. People with MS can have attacks in which cognitive problems become dramatically worse very quickly. The problems may then improve as remission proceeds. However, recent studies have shown that “Isolated Cognitive Relapses” (relapses that affect only cognition, without necessarily including sensory/motor signs) may result in longer term cognitive problems.

- **Misconception: People with MS-related cognitive problems have euphoria.**

Euphoria involves exaggerated and unrealistic expressions of happiness, often accompanied by a lack of concern about oneself. Euphoria is actually rare, affecting less than 10 percent of the MS population. It occurs almost exclusively in people with the most severe cognitive impairments.

- **Misconception: Cognitive problems in MS are similar to Alzheimer's disease.**

Not true. MS and Alzheimer's are completely different diseases. MS-related cognitive dysfunction is not the same and is almost never as severe as the cognitive dysfunction seen in Alzheimer's.

MS-related cognitive problems are usually limited to the functions discussed in this booklet. The problems may stabilize at any time, and no further progression may occur. The actual rate of progression will vary from person to person as is the case with the physical symptoms of MS.

In contrast, Alzheimer's affects many different functions. The deficits it causes increase rapidly and often predictably. Language declines along with memory, and a person with Alzheimer's will eventually be unaware of where he or she is and forget even his or her own name.

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.

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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:

- At Home with MS: Adapting your Environment
- Hiring Help at Home: The Basic Facts
- Managing Progressive MS
- Mood & Cognition in MS: What You Can Do (book and video)
- So You Have Progressive MS?

The National MS Society's mission is for people affected by MS to 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 services designed to help people with MS and their families move their lives forward.



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