

Solving Cognitive Problems

MANAGING SPECIFIC ISSUES



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Cherish (front cover), diagnosed in 2002.

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BY NICHOLAS G. LAROCCA, PHD
WITH MARTHA KING

Clinical Psychologist Dr. Nicholas G. LaRocca is Vice President of Health Care Delivery and Policy Research at the National MS Society.

Martha King was director of Publications at the National MS Society (retired).

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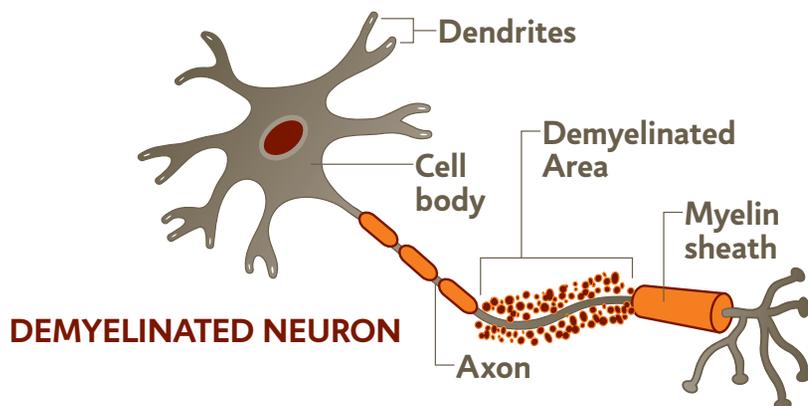
Introduction

About MS

Multiple sclerosis involves random attacks on a fatty material called **myelin** in the brain and spinal cord — the structures that make up the central nervous system. When myelin is attacked, the body is able to make some repairs, but eventually patchy areas of scarring develop on nerve fibers where healthy myelin once was. The nerve fiber (or axon) and the body of the nerve cell may also be damaged. In addition, MS can result in loss of brain tissue.

These three types of changes — loss of myelin, damage to axons and nerve cells, and loss of brain tissue — may occur in any part of the central nervous system and account, in part, for the wide variety of possible MS symptoms.

The most common symptoms include problems with balance, strength, vision, fatigue, muscle control, bladder or bowel function, sensation, and cognition.



The brain and the mind

The brain holds what we call the mind. It is the home of personality, emotions, and cognition — the attributes that make us unique. Cognition refers to all of the high level functions carried out by the human brain, including attention, memory, planning and problem-solving, visual perception, and comprehension and use of speech.

MS has the potential to affect mood, personality, and cognition, 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.**

The first step to take in dealing successfully with cognitive problems caused by MS is to learn the basic facts. This booklet is intended as an introduction.

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 drugs 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 can affect cognitive functions. People with MS may find that at certain times they are just too tired to tackle cognitive tasks. Recent studies have documented the existence of *cognitive fatigue*. This refers to a temporary decline in cognitive functioning following 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?

Although investigators are still in the process of answering this, some consistent information has emerged.

- **Memory or recall problems.** Problems with memory — the most frequently reported by people with MS — seem to be confined largely to recent events. For example, a person may have trouble remembering an important phone number learned in the past year. 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.

Several studies suggest that most people with MS are able to learn or store information adequately but may then have difficulty recalling it quickly and effectively when they need it. However, Dr. John DeLuca of the Kessler Foundation in New Jersey has offered another explanation. In his research, Dr. DeLuca found that some people with MS may take longer to learn new information. When given additional time to learn information, their ability to recall that information was equal to that of people without MS. This finding suggests that poor recall in MS may be partly the result of not having adequately learned something in the first place.

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 a cell phone is considered potentially 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 these days 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 attend to adequately in the first place.

- **Speed of information processing.** Memory, attention, and all of the other skills described here require the ability to process information quickly. Dr. Stephen Rao of the Cleveland Clinic has completed a study in which he found that people with MS performed as well as control volunteers on a specialized memory task, but they did so at a significantly slower speed. Many people with MS feel that their thinking is slowed and say they are not able to think through an issue and respond as quickly as they once did. Memory problems may therefore be related to difficulty keeping up with the flow of information — which means that some information is never getting processed 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 research shows

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.

Studies have found that areas of scarring occur with roughly equal frequency in the right and left halves of the brain. While the white matter of the brain (where myelin occurs in abundance) is the most affected, damage can also occur in the gray matter. MS lesions are particularly common near the ventricles, or inner cavities of the brain, 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 and cell bodies themselves.

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. Damage to the structures that join the left and right halves of the brain is particularly significant.

Dr. Rao and others have found that about half (approximately 50 to 60 percent) of people with MS show some evidence of cognitive changes. The exact figure is unknown and estimates have ranged both higher and lower. Studies that recruit people with MS from the community tend to show lower figures,

while figures based on samples drawn from MS clinics are usually higher. About 40 percent have mild dysfunction, while about 5 to 10 percent have moderate to severe impairments.

In other words, research shows that nine out of ten people with MS are free of severe cognitive problems.

But what do mild or moderate problems mean in people's lives? This question is hard to answer because people's circumstances vary so much. 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 change in lifestyle at all, 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.

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, health care professionals

recognize that people with MS almost always want information — on this or any other topic. Talk over your concerns with your doctor or nurse. You may want to take a copy of this booklet to your next appointment.

- **Share with others.** Very 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 on MS research, visit the National MS Society's Web site at nationalMSsociety.org.
In MS support 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.
- **Make it a family affair.** Family members may not realize that the person with MS has experienced cognitive changes as a part of the disease. When the person with MS forgets parts of conversations, misses appointments, or misplaces things, it may be viewed as laziness, indifference, or carelessness. If this happens, family members and friends need help to develop an understanding of what is going on.
- **Get counseling if it seems appropriate.** Not everyone who experiences cognitive changes needs counseling. However, counseling or psychotherapy do help people deal with the impact cognitive problems have both on self-esteem and on practical everyday living. They also address depression or anxiety, which can adversely affect cognitive functioning.

- **Explore self-help options.** Here are some practical suggestions of ways to compensate for cognitive changes:
 - Where memory is weak, try substituting organization. Get yourself a good loose-leaf organizer and learn to use it consistently as your information center. Set up sections for appointments, to-do's, phone numbers, driving directions — anything that you need to remember but are likely to forget. Get rid of all those little scraps of paper with notes on them that are always getting lost.
 - Consider augmenting the loose-leaf organizer with some electronic technology. There are a variety of tools available for computers, tablets, personal digital assistants, and smartphones that can help with storage and retrieval of information, reminders, appointments, and alarms.
 - 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 focus on one thing at a time. If you are involved in a conversation, focus on what is being said and 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 enormous streams of muddy water flooding into every room through the open windows. Hold on to that image for a few moments and you are more likely to remember to close windows later.
- When you meet a new person, jot down his or her name as soon as you can gracefully do so. Later, make some notes in your loose-leaf organizer, smartphone, etc... on 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.
- 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.
- Talk to a doctor, nurse, or dietician about your eating habits to ensure that you are getting good nutrition.
- After consulting with your doctor, 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.

Consider professional evaluation

A professional evaluation may be helpful if you or those closest to you notice a change for the worse in cognitive functions. For example, do you have increased trouble remembering things? Is it becoming harder to stay focused on a task? Do you experience lapses of judgment, trouble coming up with words in conversation, slowed thinking, or difficulty organizing projects or daily activities?

An evaluation is particularly important if any of these changes get in the way of your work or social life, or create distress for you. Evaluation may also be of value if you are considering a career change or planning to enter school or a training program. You may also be interested in getting an evaluation because you are starting on a disease-modifying medication and want to be able to track cognitive changes over time.

Cognitive testing may also highlight other treatable symptoms. In one of Dr. Rao's studies, 40 to 50 percent of people with MS believed their cognitive functions had been affected by the disease. Professional evaluation showed this statistic to be correct. But the people who were actually affected by cognitive problems were not

always the ones who had diagnosed themselves. Some of them were instead suffering from depression. Others who were severely impaired were unaware that any changes had taken place. Testing can also identify people who are experiencing significant cognitive fatigue.

Depression can be treated with medications and/or psychotherapy. Severe fatigue can be alleviated with medication and energy management strategies. And cognitive changes can be treated through cognitive rehabilitation. But the choice of appropriate treatment depends on the right diagnosis!

A formal cognitive evaluation may require several hours, and it is costly. The decision to go ahead should be made after discussions with your physician, family, and any other professionals who might be involved in your care. Other causes for cognitive problems should be carefully ruled out, and preliminary, less expensive testing considered. Do not assume that your insurance plan covers this type of evaluation, even if your physician prescribes it. You should 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 if you are a vocational rehabilitation client and planning to try to return to school or work.

Assessment 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 generally pick up only the more severe forms of cognitive dysfunction. Janis M. Peyser, PhD, of the University of Vermont completed a study in which she found that almost half of the patients whom neurologists considered to be without cognitive problems were found to have problems when tested by a neuropsychologist.

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 rehab involves one or more sessions per week over several weeks or months. Each session typically lasts about an hour. These sessions will include a variety of activities depending on individual needs. They might include doing 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, how to manage time, or process paperwork.

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 these seem warranted.

- **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.

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. To date there have been no published studies looking at the value of physical exercise on cognitive function in MS. However, many studies have shown the value of exercise for people with MS in terms of fitness and quality of life. Studies currently underway may add improvement in cognition to this list. In the meantime, consult with your physician before beginning any exercise program.
- **Medications.** Research concerning the use of medications clearly needs to continue. At present, the pharmacy has little to offer.

A medication called Aricept® (donepezil hydrochloride) is currently used to treat memory problems in Alzheimer's disease. There has been interest in the possible use of Aricept in MS. A clinical trial in which 69 individuals with MS participated found that Aricept improved performance on memory tasks. However a larger multi-center trial of the same medication did not find any benefit.

A few published studies have also 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 small, uncontrolled studies of cognitive function. These have included testosterone gel, monthly treatments with a combination of cyclophosphamide and steroids, and erythropoietin (a drug thought to have potential neuroprotective effects in MS). However these very preliminary results need to be confirmed in larger, controlled studies.

Other drugs have been studied for possible use in treating MS-related cognitive changes. These have included memantine (a drug approved for the treatment of symptoms of Alzheimer's), C-105 (an experimental drug to improve cognitive function in MS), methylphenidate, and 1-amphetamine. Unfortunately none of these have proven to be effective in treating cognitive dysfunction in MS.

Some doctors 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 other medications for improving cognitive functioning in MS.

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.**

Most people with MS will never be troubled by severe cognitive problems, but mild problems are fairly common. Some professionals still cling to the idea that cognition is rarely, if ever, affected. An open discussion about cognitive function with health care professionals 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. Someone can have cognitive problems and be perfectly normal emotionally and mentally. While emotional problems such as depression or anxiety can adversely affect cognition, cognitive problems should not automatically be attributed to these causes.

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

Cognitive function must be assessed using a battery of standardized tests administered and interpreted by someone with the proper training. The "bedside mental status" test can detect only the most severe cognitive problems.

- **Misconception: All people with MS should have a detailed cognitive assessment.**

Not at all. A comprehensive assessment is necessary only if problems occur and then only after thorough consultation to rule out other factors.

- **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 in people who are severely disabled.**

On the contrary, people who are severely disabled physically may have no cognitive problems at all. Studies completed by Robert Heaton, PhD (formerly at the University of Colorado) and his colleagues and by William Beatty, PhD, formerly at the University of Oklahoma Health Sciences Center, have shown that there is only a very weak relationship between extent of physical disability and cognitive dysfunction in MS. On the other hand, cognitive problems can affect people who have very few physical problems.

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

Doctors Beatty and Heaton found that there is little relationship between duration of MS and the severity of cognitive dysfunction.

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

Cognitive dysfunction is likely to be somewhat worse in people with progressive MS. Memory deficits appear to be common among persons with relapsing-remitting MS, but individuals with any kind of MS can experience cognitive problems.

■ **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 can then improve as remission proceeds.

■ **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 bears little resemblance to Alzheimer's disease. MS-related cognitive dysfunction is almost never as severe as 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 will 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.

Christopher Filley, MD, and colleagues at the University of Colorado, have published a study that compared cognitive aspects of the two diseases. A recent review article confirmed the differences between what is generally observed in MS and in Alzheimer's.

Suggested reading

Multiple Sclerosis: Understanding the Cognitive Challenges, by Nicholas LaRocca and Rosalind Kalb, with John DeLuca and Lauren Caruso. New York, Demos Medical Publishing, 2006, 152 pages.

Facing the Cognitive Challenges of Multiple Sclerosis, 2nd Ed. by Jeffrey N. Gingold. New York, Demos Medical Publishing, 2011, 240 pages.

The MS Workbook: Living Fully with Multiple Sclerosis, by Robert T. Fraser, George H. Kraft, Dawn M. Ehde, and Kurt L. Johnson. Oakland, CA, New Harbinger Publications, Inc., 2006, 243 pages.

Improving Your Memory for Dummies, by John B. Arden. New York, Wiley Publishing, 2002, 336 pages, \$19.99.

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