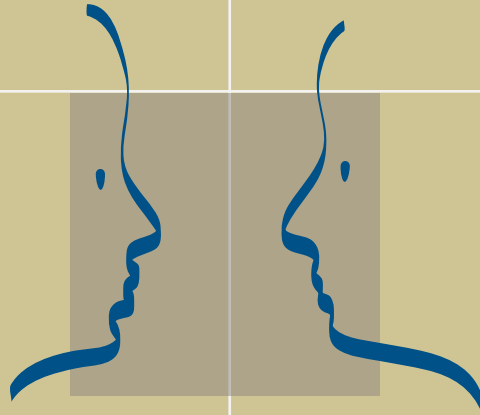




National
Multiple Sclerosis
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*Talking with Your
MS Patients about
Difficult Topics*



Talking about Cognitive Dysfunction

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The National MS Society's Professional Resource Center (PRC) has long been a resource for health professionals providing care to people with multiple sclerosis. The PRC, which houses a comprehensive library of MS information, provides continuing education opportunities and offers multidisciplinary expertise on MS disease process and management questions, health insurance issues, long-term care options, and the development of MS specialty clinics. The goal of these services is to enhance quality of care and increase access to care for people with multiple sclerosis.

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Introduction

This booklet deals with cognitive changes—one of the most sensitive and difficult topics for physicians to discuss with their MS patients. It was not too many years ago that this was a taboo subject. As a result, there is limited clinical literature to guide providers in dealing with these problems. Cognitive dysfunction, which affects approximately 50% of people with MS, not only threatens a person's confidence and self-esteem, but potentially disrupts employment, social interactions, and daily routines as well. These changes in cognitive functioning present a special set of challenges for the

healthcare provider since they can be subtler, more complex, and more upsetting to both patients and families than some of the physical symptoms of MS. This booklet provides a variety of suggestions for responding to these special challenges. The material in this booklet is based on a combination of research, clinical experience, and common sense. Much of what is presented was learned directly from patients and their families, and the myriad ways in which they have responded to the disturbing news that “MS has affected your thinking and memory.”

1. When should I address the topic of MS-related cognitive changes?

- It is important to discuss cognitive symptoms sooner rather than later in the disease course.
 - Since many consumer-oriented books and other publications on MS now discuss this topic openly, it is no longer a secret or taboo subject. If you do not bring up this topic, your patients may conclude that you are uncomfortable talking about it and might hesitate to mention their questions or concerns.
 - Beginning at the time of diagnosis, cognitive dysfunction should be mentioned as one of the possible changes that can occur in MS. Many people with MS are relieved to know that the cognitive changes they are experiencing are related to their MS rather than to Alzheimer's disease or an emotional problem of some kind.
 - It is important to ask the patient about cognitive changes at every office visit.
- Approaching the topic in a matter-of-fact way along with other MS symptoms makes it easier for the person to air concerns about these changes.
- Global questions such as “Are you experiencing any memory problems?” or “Are you having any problems with your thinking?” may yield false negatives; specific questions about difficulties at work or with activities of daily living tend to make it easier for people to describe changes and provide more specific answers.
 - Questions about cognitive changes or problems sometimes elicit conflicting responses from patients and family members. For example, patients may report problems that family members have not acknowledged or recognized; family members may have recognized changes that the patient is not ready or willing to acknowledge.

2. How can cognitive changes be assessed?

- The mental status exam that is often administered as part of the neurological examination has been shown to miss 50% of patients with MS-related cognitive dysfunction.
- Screening techniques such as the Mini Mental State are likewise only able to detect the most severe impairments.
- More sensitive screening batteries, requiring 20–30 minutes to administer, have been specifically designed for people with MS. Brief test batteries, requiring 60–90 minutes, have also been used.
- A full neuropsychological battery (typically requiring 6–8 hours) is the most sensitive way to assess cognitive dysfunction in MS. However, the sensitivity of this approach must be weighed against its high cost in time and dollars.
- The decision concerning how and when to assess cognitive dysfunction should be considered in light of why the assessment is being performed and how the information will be used. A patient who is reporting problems at work, for example, can derive significant benefit from a neuropsychological test battery that identifies deficits and strengths, and points to possible work accommodations that might enable the person to remain employed.

3. What is the most important information to give my patients concerning cognitive dysfunction?

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- Cognitive changes affect approximately 50–60% of people with MS; in most cases these changes remain relatively mild and without significant impact on daily life. Only 5–10 percent of patients experience impairment severe enough to interfere significantly with major life roles and activities.
- Cognitive changes can occur at any time during the course of the illness, *even as the initial symptom*. Individuals with little or no physical impairment can experience significant cognitive changes while those with severe physical disability may have very little or no cognitive impairment.
- Cognitive dysfunction is somewhat more common in progressive forms of MS, but can occur with any course. Several magnetic resonance imaging parameters are related to cognitive impairment, including total lesion area and extent of cerebral atrophy.
- MS cognitive changes vary considerably from person to person. Often a few specific abilities will be affected while others will be spared.
- The most common impairments include:
 - Problems with the storage, manipulation and retrieval of information (learning and memory)
 - Slowed information processing (i.e., perceiving, attending/responding to incoming information, and applying meaning to it)
 - Problems shifting attention between two stimuli (cognitive flexibility)
 - Problems attending to multiple stimuli at the same time (complex attention)

- Cognitive functions that are generally preserved in MS include general intellect, long-term memory, conversational skills, and the ability to understand what one is reading.
- Like the physical symptoms of MS, cognitive changes are likely to progress over time, though the worsening seems to be slow in most cases.
- Cognitive dysfunction may worsen during an exacerbation and then improve somewhat during the subsequent remission. However, once cognitive changes appear, they almost never disappear completely.
- Research on treatment options is limited but growing. At present there are three main treatment strategies: disease-modifying agents, symptomatic pharmacologic therapies, and cognitive rehabilitation.
- Disease-modifying agents such as the interferons, glatiramer acetate, novantrone, and natalizumab, are being studied for their potential role in stabilizing the disease and therefore slowing the progression of cognitive dysfunction.
- Symptomatic pharmacologic therapies such as psychostimulants and medications that enhance memory are being studied for possible safety and efficacy in MS.
- Cognitive rehabilitation can help people with MS-related cognitive changes to function more effectively in daily activities and compensate for impaired abilities.
- The potential benefits of exercise for cognitive impairment in MS are also being studied.
- Like fatigue, cognitive changes are a common cause of job loss in MS and should therefore be addressed promptly.

4. How do I talk about cognitive problems in a way that will be helpful and supportive without being too frightening?

- Your ability to talk comfortably about cognitive changes will make it easier for your patients to discuss the topic.
- By bringing up the subject as a routine part of each office visit, along with other MS symptoms such as fatigue, bladder problems, pain, etc., you can reduce the fear and mystery surrounding this subject.
- Some patients may wonder if these changes mean they have become “stupid” or “retarded” or if they are going to wind up like someone with Alzheimer’s disease. It may be helpful to inform patients that the cognitive changes in MS are very different from those that appear in Alzheimer’s. MS generally affects a few specific functions rather than globally impairing all cognitive functions.
- In general, patients do not find it helpful to hear dismissive statements such as “Oh, I have memory lapses myself. We’re all getting older, you know.” While meant to be reassuring, these comments are more likely to convince people that no one believes or understands the problems they are experiencing.
- If a patient complains about cognitive changes, these complaints need to be taken seriously and not automatically attributed to anxiety, depression, or age.
- It is helpful to remind people that there are intervention strategies to help them with the cognitive changes they might be experiencing.

5. When is the appropriate time to talk about cognitive changes with family members?

- If there are definite cognitive changes, it is generally helpful to bring family members into the loop as early as possible. Experience has shown that family members often misunderstand the meaning of cognitive changes. They may attribute memory lapses to laziness or lack of caring.
- Cognitive changes often lead to family strain because the person with MS is not behaving “normally”—for example, missing appointments, losing things, forgetting to do things, not recalling what was discussed, making errors in the checkbook. Educating the family helps to ease the strain and avoid misinterpretation of the behavior of the person with MS.
- Dealing constructively with cognitive changes often requires the assistance of family members, such as keeping a central family calendar, posting notes and messages, minimizing distractions during conversations, and writing directions.
- Except in circumstances of marked dementia, discussions with family members should be done with the knowledge and consent of the patient. Otherwise, patient-physician trust is likely to suffer.

6. What is the best format for providing this type of information?

- There are three main ways to present this information: face-to-face discussion, lectures and workshops, and printed materials.
- Face-to-face discussion with a well-informed and trusted healthcare provider can go a long way toward neutralizing some of the fear that often accompanies this topic. The opportunity to ask questions and explore the implications of cognitive changes in a relaxed and reassuring environment can be very helpful. People should be reassured that it is acceptable to take notes, bring a tape recorder to their appointments, or bring another person along to help them remember what you have discussed.
- The National Multiple Sclerosis Society sponsors lectures and workshops at the local and national level on MS-related cognitive changes. These programs provide general information on cognitive dysfunction and how to deal with it. Often these programs are archived on audio or videotape or on the Internet, and can be accessed when needed.
- Printed materials on cognitive dysfunction are available from the National Multiple Sclerosis Society by calling 1-800-344-4867 or on the website at www.nationalmssociety.org/Brochures. These materials provide more detailed information and can be referred to over and over again as needed.

7. What types of professional interventions are available to help my patients with cognitive problems?

- Neuropsychologists, especially those specializing in MS, can provide an expert assessment of an individual's cognitive functions using a variety of well-validated standardized tests. Many neuropsychologists also do cognitive rehabilitation or can help to design a program of rehabilitation to be implemented by another professional such as a speech/language pathologist or occupational therapist.
- Speech/language pathologists also evaluate and treat cognitive functions, although the tools and strategies they use differ from those used by neuropsychologists.
- Occupational therapists provide cognitive interventions as well, using assessment tools and treatment strategies that focus primarily on activities of daily living.
- Cognitive rehabilitation is available in private practice settings, hospitals, and many rehabilitation centers. Neuropsychologists, speech pathologists, and occupational therapists often work together as part of a team.
- Neuropsychiatrists specialize in disorders that overlap neurology and psychiatry. Evaluation and medication management by a neuropsychiatrist may be useful if cognitive changes are accompanied by more serious affective or personality changes and/or poor impulse control.
- Although social workers do not generally evaluate cognitive functions or perform cognitive rehabilitation, they may play an important role in helping the individual and the family to understand and cope with the cognitive changes and the complex issues that accompany such changes.

8. How will the presence of cognitive impairment impact my patient's ability to understand/remember the information I am providing about this or other MS-related topics?

- MS patients with cognitive dysfunction may process information more slowly, and have difficulty understanding complex concepts and remembering all that is presented to them.
- Patients with cognitive impairment may call the office repeatedly to ask questions, clarify appointment times, or review treatment recommendations.
- Information, especially complex information, is best presented in manageable chunks that the individual can process more easily.
- If information such as medication instructions can be presented both verbally and in written form, it will enhance learning.
- Audio or video tapes or CD's can also be used to provide the patient with the opportunity to review information after returning home.
- It is also useful to make sure that the patient "got it" by asking him or her to repeat what you have said.
- Cognitive dysfunction may make it more difficult for the patient to sort through the many treatment options available in MS today. Extra time and repeated explanations may be needed for a cognitively-impaired patient to arrive at these treatment decisions.

9. What kinds of emotional reactions might I expect from my patients and their family members about this topic?

- Denial is a common reaction since most people do not want to believe that MS has affected their mental abilities. For many people with MS, coping with physical limitations of the disease is eased by the knowledge that their mental abilities are intact. If these mental abilities also begin to show signs of impairment, it may feel like too much to bear.
- Feelings of loss, grief, and anxiety are common as patients grapple with limitations in prized abilities such as memory and reasoning. For those whose ability to function effectively at work or home is being threatened, loss of self-esteem and feelings of anxiety can be particularly acute. This level of anxiety, unfortunately, only serves to exacerbate the problems.
- When cognitive changes first appear, family members tend to misunderstand what is going on. Anger is a common reaction as family members attribute memory lapses to laziness, inattention, or lack of caring.

10. What is the appropriate way to deal with a patient's or family member's denial about this issue?

- It is helpful to present the information in a matter-of-fact and reassuring way.
- Let them know that cognitive change is one of the recognized symptoms of MS.
- Indicate that you and they are going to deal with these changes along with the other MS symptoms that have appeared or will appear.
- Make sure they know that there are resources to help them deal with these changes, including education, evaluation, and treatment. Spouses of people with significant impairments and/or personality changes may need additional support to deal with the loss of their marital partnership, often expressed as "This isn't the same person I married."
- Be patient. Sometimes, people need time to process the reality of cognitive change. Rather than trying to force the issue, let them know that you are going to bring it up from time to time until they are ready to deal with it.
- Make sure that psychological support is available if the patient and/or family are ready to deal with the topic of cognitive changes. Denial may be fostered if people fear being left alone with the problem once they begin to acknowledge and talk about it.

11. What other types of resources are available to help my patients with emotional changes?

- Chapters of the National Multiple Sclerosis Society (1-800-344-4867) can provide names of neuropsychologists, speech/language pathologists, and occupational therapists who are experienced in the assessment and remediation of MS-related cognitive problems. They also offer patient educational programs, support groups, and other resources that support people

in their efforts to cope with MS-related cognitive changes.

- The National MS Society has created educational materials on a wide range of topics. Your patients can obtain these and other materials free of charge from their local chapter (1-800-344-4867) or in the Multimedia section of the website at www.nationalMSSociety.org/Brochures:
 - *Solving Cognitive Problems*
 - “MS and the Mind”—a special reprint from *InsideMS*, the magazine for members of the National MS Society
 - *Multiple Sclerosis and Your Emotions*
 - *Fatigue: What You Should Know*
 - *Taming Stress in Multiple Sclerosis*
 - *CogniFitness Activity Kit*—a mental exercise program in a box
- **Recommended websites:**
 - National MS Society (www.nationalMSSociety.org)—offers information on a variety of topics relating to life with MS
 - Web page on Cognitive Function <http://www.nationalMSSociety.org/Cognition>
 - MS World (www.msWorld.org)—on-line information and support for people with MS, including chat rooms and bulletin boards
 - MyMSMyWay (www.MyMSMyWay.com)—a free resource dedicated to connecting people with multiple sclerosis to accessible technologies.

• Recommended readings:

- National MS Society Task Force on Cognition and Multiple Sclerosis. *Expert Opinion Paper: Assessment and Management of Cognitive Impairment in Multiple Sclerosis*, 2006 (www.nationalMSSociety.org/ExpertOpinionPapers).
- Books:
 - Feinstein A. *The Clinical Neuropsychiatry of Multiple Sclerosis* (2nd ed.). New York: Cambridge University Press, 2007.
 - Gingold JN. *Facing the Cognitive Challenges of Multiple Sclerosis*. New York: Demos Medical Publishing, 2006.
 - Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (4th ed.). New York: Demos Medical Publishing, 2008.
 - Kalb R (ed.). *Multiple Sclerosis: A Guide for Families* (3rd ed.). New York: Demos Medical Publishing, 2006.
 - Kalb R, Holland N, Giesser B. *Multiple Sclerosis for Dummies*. Hoboken, NJ: Wiley Publishing, 2007.
 - LaRocca N, Kalb R. *Multiple Sclerosis: Understanding the Cognitive Challenges*. New York: Demos Medical Publishing, 2006.

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Dr. LaRocca has extensive experience in both psychosocial research and psychological treatment in multiple sclerosis. He has designed, administered, and analyzed a number of clinical studies in MS, including neurogenic bladder dysfunction, comparisons of inpatient and outpatient rehabilitation, and the role of stressful life events in MS. Dr. LaRocca was principal investigator of a project funded by the National Institute on Disability and Rehabilitation Research entitled “The Comprehensive Rehabilitation of Cognitive Dysfunction in Multiple Sclerosis.” He also served as principal investigator of a National MS Society-funded “Program to Facilitate Retention of Employment Among Persons with Multiple Sclerosis,” and as co-principal investigator for the National MS Society-funded project entitled “Development of a Multiple Sclerosis Quality of Life Measurement.”

During his 30 years of work in MS, Dr. LaRocca has led support groups for persons with MS and their spouses and given numerous workshops and presentations for both lay and professional audiences. In 1992, he was the invited speaker for the National MS Society audio-teleconference entitled “Multiple Sclerosis: Understanding Your Mind and Emotions.” He is the author of *Multiple Sclerosis: Understanding the Cognitive Challenges*, as well as a number of scientific papers and book chapters. Dr. LaRocca serves on the editorial boards of *The Journal of Rehabilitation Research & Development* and *Real Living with MS*.

Rosalind Kalb, PhD, is Vice President of the Professional Resource Center at the National Multiple Sclerosis Society in New York City, providing educational materials and consultation services for healthcare professionals. Dr. Kalb has authored or edited a number of National MS Society publications—the *Knowledge is Power* series for newly-diagnosed patients and the Cavallo Professional Education book series for health professionals. She has edited two books—*Multiple Sclerosis: The Questions You Have; The Answers You Need*—now in its 4th edition—and *Multiple Sclerosis: A Guide for Families*, now in its third edition. She is the senior author of *Multiple Sclerosis for Dummies*, and co-author with Dr. Nicholas LaRocca of *Multiple Sclerosis: Understanding the Cognitive Challenges*.

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