

Talking About Cognitive Dysfunction

Talking with your MS patients about difficult topics



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The National MS Society's Professional Resource Center (PRC) is a resource for clinicians, offering professional publications, clinical consultations, and literature search services, as well as information on health insurance issues, long-term care options, and the development of MS specialty clinics. Physicians are invited to consult via email with MS specialist colleagues at MD_info@nmss.org. Allied health professionals are invited to consult via email with MS specialist colleagues at healthprof_info@nmss.org.

Rosalind Kalb, PhD, (Series Editor) is Director of the Professional Resource Center at the National Multiple Sclerosis Society in New York City, developing and providing educational materials and services for healthcare professionals. As a clinical psychologist in private practice, Dr. Kalb has provided individual and family therapy for people with MS and their families for more than 25 years. She has authored or edited a number of publications about multiple sclerosis. She is the author of the *Knowledge is Power* series for individuals newly diagnosed with MS and co-author, with Nicholas LaRocca, PhD, of *Multiple Sclerosis: Understanding the Cognitive Challenges*, published in 2006. Dr. Kalb has edited two books – *Multiple Sclerosis: The Questions you Have; The Answers you Need* (3rd ed.), published in 2004, and *Multiple Sclerosis: A Guide for Families* (3rd ed.), published in 2006.

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Talking about Cognitive Dysfunction

By Nicholas LaRocca, PhD

An Endorsement from Anthony Feinstein, MPhil, PhD, MRCPsych, FRCP (C)

“Cognitive dysfunction affects up to 40% of patients with multiple sclerosis living in the community. It may easily be overlooked. This informative and clearly-written guide provided by the Multiple Sclerosis Society of Canada therefore provides a valuable resource for patients, clinicians, and other health care providers. As such, it will make a significant contribution to the quality of care.”

About the Endorser

Dr. Feinstein obtained his medical degree in South Africa and completed his postgraduate training in Psychiatry at the Royal Free Hospital in London. Thereafter, he undertook his PhD through the University of London and the Institute of Neurology, Queen Square. He is currently a Professor of Psychiatry at the University of Toronto and Director of the Neuropsychiatry Program at Sunnybrook and Women's College Health Sciences Centre. His research interest is focused on three main areas: the neuropsychiatry of multiple sclerosis, traumatic brain injury, and how individuals react to and cope with significant, often life threatening stressors. Dr. Feinstein is the author of *The Clinical Neuropsychiatry of Multiple Sclerosis* (Cambridge University Press).

About the Author

Nicholas G. LaRocca, PhD

Nicholas LaRocca, who received his doctorate in clinical psychology from Fordham University, has been the Director of Health Care Delivery and Policy Research at the National Multiple Sclerosis Society in New York City since 1997. Before coming to work for the National MS Society, he was Director of Research at the Research and Training Center for MS at St. Agnes Hospital, White Plains, New York and Associate Professor of Neurology and Medicine at New York Medical College.

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 25 years of work in MS, Dr. LaRocca has led support groups for persons with MS and their spouses and given innumerable 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 a number of scientific papers and book chapters and serves on the editorial boards of *The Journal of Rehabilitation Research & Development*, and *Real Living with MS*.

Talking to Patients about Cognitive Dysfunction

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 little in the 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 health care 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 mind."

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 on 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 Examination 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?

- Cognitive changes affect approximately 50% 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 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)
- 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 and glatiramer acetate are being studied for their potential role in stabilizing the disease and therefore slowing the progression of cognitive dysfunction.
- Symptomatic pharmacologic therapies such as 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.
- 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 are “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 intellectual abilities.
- 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 frequently 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. Educating the family helps to ease the strain and avoid misinterpretation of the behaviour 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 health care 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.
- Printed materials on cognitive dysfunction are available from the Multiple Sclerosis Society of Canada, from Demos Medical Publishing and other publishers, and from some pharmaceutical companies. 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 pathologists also evaluate cognitive functions, although the tests they use are often different from those used by neuropsychologists and tend to focus more on language abilities.
- 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 centres. 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 tape or digital recordings, e.g., CDs, 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 for MS today. Extra time and repeated explanations may be needed for cognitively impaired patients 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?

The Multiple Sclerosis Society of Canada

- The Multiple Sclerosis Society of Canada offers educational programs, support groups, and other resources for:
 - Individuals living with a diagnosis of MS
 - Individuals awaiting a diagnosis with respect to MS
 - Individuals close to a person with MS, such as their family and friends
 - Caregivers of a person with MS

In addition to serving its primary clients, Society volunteers and staff also provide information and support to health professionals, employers, institutions and students.

Based upon needs and available resources, the MS Society of Canada's units, chapters, divisions, and national office provide Client Services that encompass:

- Information and referral
 - Advocacy
 - Education
 - Funding
 - Support
- The MS Society of Canada has educational materials on a wide range of topics. Your patients can obtain these and other materials from their local chapter or division (1-800-268-7582) or visit the website at www.mssociety.ca:
 - Solving Cognitive Problems
 - Living Well with MS: Mind Matters
 - Multiple Sclerosis and Your Emotions
 - Living Well with MS: Managing Fatigue
 - Taming Stress in Multiple Sclerosis
 - The Multiple Sclerosis Society of Canada website (www.mssociety.ca) offers information on a variety of topics related to MS as well as information regarding local services, programs, fundraising events and much more.

MS Clinics

- The Multiple Sclerosis Society of Canada is proud to work with a network of specialized MS clinics across the country. Clinic services vary, but most offer a wide range of services, delivered by a multi-disciplinary health care team. Visit our website (www.mssociety.ca) for a list of MS clinics across Canada.

Additional Recommended Websites:

- The National Multiple Sclerosis Society (U.S.A.) website (www.nationalmssociety.org) offers information and interactive programming on a wide variety of topics (e.g., disease-modifying therapies, symptom management, research):
 - Web Spotlight on MS and Cognition
www.nationalmssociety.org/Cognition
 - “MS and the Mind” A special reprint from **InsideMS**, the magazine for members of the National MS Society.
- MS World (www.msworld.org) – on-line information and support for people with MS, including chat rooms and bulletin boards
- Multiple Sclerosis International Federation/The World of Multiple Sclerosis www.msif.org
 - In Focus: Special Focus on Emotions and Cognition
www.msif.org/en/publications/ms_in_focus/index.html

- CenterWatch Clinical Trials Listing Service™ www.centerwatch.com
- Consortium of Multiple Sclerosis Centers www.mscares.org
- National Institutes of Health (NIH) Clinical Trials Listing Service www.clinicaltrials.gov

Pharmaceutical Company Support Programs:

Betaseron (Berlex)	Copaxone (Teva Neuroscience)
MSPathways	Shared Solutions
1-800-977-2770	1-800-283-0034
www.mspathways.ca	www.mswatch.ca
Avonex (Biogen)	Rebif (Serono Canada)
MS Alliance	Multiple Support Program
1-888-456-2263	1-888-677-3243
www.msalliance.com	www.serono-canada.com

Recommended Reading:

- Feinstein A. **The clinical neuropsychiatry of multiple sclerosis.** Cambridge: Cambridge University Press, 1999.
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have: The Answers You Need** (3rd ed.). New York: Demos Medical Publishing, 2004.
 - Ch. 9 LaRocca N, Sorensen P. **Cognition.**
- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.). New York: Demos Medical Publishing, 2005.
 - Ch. 2 LaRocca N. **Emotional and Cognitive Issues.**
- O'Connor PD. **Multiple Sclerosis: The Facts you Need.** Toronto: Key Porter Books, 2002.

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