

Talking with your MS patients about difficult topics



Talking about the Diagnosis of Multiple Sclerosis

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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.

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Talking about the Diagnosis of Multiple Sclerosis

By Barbara Giesser, MD

An Endorsement from Jock Murray, OC, MD, FRCPC, FAAN, MACP, FRCP, LLD, DSc, DLitt

“I am happy to endorse this material about the diagnosis of MS. The education publications of the MS Society have always been of the highest order, and of great assistance to patients, families and their health professionals. This publication will be of great value and I congratulate the Society for this venture.”

About the Endorser

Dr. Jock Murray is Professor Emeritus at Dalhousie Medical School and a Former Dean of Medicine. He founded the Dalhousie MS Research Unit and has been involved in MS care and research for the last four decades. Former President of the Canadian Neurological Society, former Vice President of the American Academy of Neurology and a founder and President of the Consortium of MS Centres, Dr. Murray has won many awards and honours, including but not limited to: the Neilson Award of the Hannah Institute for the History of Medicine for contributions to medical history, the Dr. Labe Scheinberg Award for Lifetime Contributions to MS research, the Dr. A. B. Baker Award for lifetime contributions to neurological education from the American Academy of Neurology, and the Order of Canada. Dr. Murray has over 200 medical publications, 7 books, 38 textbook chapters, and has held 91 funded research grants. Most recently he has published *Multiple Sclerosis: The History of a Disease* (Demos, New York 2005).

About the Author

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Barbara Giesser is an associate clinical professor of neurology at the UCLA School of Medicine. She received her bachelor's degree from the University of Miami, a master's degree from the University of Texas at Houston, and her medical degree from the University of Texas Medical School at San Antonio. She has specialized in the care of persons with MS since 1982, and trained at the MS Research & Training Center of the Albert Einstein College of Medicine, under the direction of Dr. Labe Scheinberg.

Dr. Giesser has served as Medical Director of the Gimbel MS Center at Holy Name Hospital in Teaneck, New Jersey, and Medical Director of the Rehab Institute of Tucson. She is currently an associate professor of clinical neurology at the University of California at Los Angeles and Medical Director of the Marilyn Hilton MS Achievement Center at UCLA. She has published in the areas of cognition in MS, bladder management and women's issues.

In addition to her clinical activities, Dr. Giesser has been active in developing educational materials about MS for medical students and residents, as well as in client and professional education endeavours for the National MS Society (U.S.A).

Talking about the Diagnosis of Multiple Sclerosis

Introduction

This booklet is designed to facilitate conversations with your patients about the diagnosis of multiple sclerosis. Talking to patients about a chronic, unpredictable illness is a challenge, in part because the news is so difficult for people to hear, and also because there are so few definitive answers to offer them. The following are recommended strategies for providing the diagnosis in ways that foster realistic expectations, active participation in the treatment process, and hope.

1. When and how should I tell a patient that he or she has MS?

- Patients should be informed of the diagnosis as soon as it has been confirmed. Since some individuals may be living with MS symptoms for some time before the diagnosis can be confirmed, it is recommended that you share information about the possible diagnosis with them as well, particularly if you are planning to initiate any kind of treatment.
- Patients who have been living with mysterious symptoms for some time are often relieved to have a name for the problem.
- The diagnosis of MS may be welcome news for those who have been frightened about a brain tumour or some other potentially fatal condition.
- Those who had been told by other physicians or their family members that their symptoms are psychiatric feel vindicated by the diagnosis.
- Hearing the truth from you will enhance a person's trust and confidence, and set in motion the doctor-patient collaboration.
- While it may seem less frightening to use terminology other than "multiple sclerosis" (e.g., demyelinating disease, virus), the sooner patients have accurate information, the sooner they can begin the process of adaptation and coping. Accurate terminology also conveys your comfort and confidence in treating a person with MS.

- In an effort to soften the diagnostic message, some doctors will tell patients that they have “benign MS” or “the good kind of MS”. While patients are obviously relieved to hear this kind of reassuring news, they are subsequently devastated, angry, and confused when, as is most often the case, the disease becomes more progressive. Your best strategy is to describe the disease accurately, prescribe treatment/management strategies for whatever symptoms the person is currently having, and recommend early treatment with one of the disease-modifying agents in order to slow disease progression. Parents are sometimes reluctant for doctors to tell children with MS about their diagnosis. Parents should be encouraged to be open and frank with their children before starting them on any kind of disease-modifying treatment, and to take advantage of support programs for children with MS and their parents (Find out more about the **Young Persons with MS: Network for Families with a Child or Teen With MS** – by calling the MS Society of Canada toll-free at 1-866-922-6065).

2. How and when should the information be shared with family members?

- Unless the patient is a minor, or seriously cognitively impaired, it is preferable to let the person decide who will share in the information process. In general, however, patients should be encouraged to discuss the diagnosis with their spouse or significant other.
- As permitted by the patient, the family will benefit from your willingness to discuss the disease and answer their questions. The MS Society of Canada has several publications for those who are newly diagnosed and their families. You may find it useful to provide these to your patient or suggest that he or she request them from their local chapter or division. These materials will help them clarify the questions and concerns they may want to discuss with you.

3. How much is the “right” amount of information to give my patients about the disease?

- The “right” amount is that with which the person feels comfortable. There is no “one size fits all”, even within a single family.

- Some patients will want a lot of specific information at the outset while others will process information in more gradual increments.
- Some will want you to tell them exactly what to do, while others will want you to present all the options and let them decide.
- While some people will want and need to understand the pathology of MS and view their MRI films with you, others will primarily be concerned with what they can do to feel better. Since most people have an image of MS as a hopeless, crippling disease, all patients need to hear that the majority of people with MS lead full, active lives and do not become severely disabled.
- Most people will want to know what is going to happen in the future. Beginning with diagnosis, patients need some information about the challenges inherent in MS:
 - MS is a chronic progressive disease for which we do not yet have a cure.
 - The disease is unpredictable in its course and outcome.
 - The symptoms vary considerably from one person to another and for any given person over time.
- The most important message for someone newly diagnosed with MS is that the disease is treatable, and that you will be partners in all aspects of the treatment process in an effort to slow disease progression and/or maximize the person's comfort and independence.
 - Treatment of acute exacerbations
 - Disease-modifying strategies
 - Symptom management
 - Rehabilitation

4. When do I begin to talk about disease course, disease course management, and prognosis?

- The Consensus Statement of the Canadian MS Clinics Network on the use of Disease Modifying Agents in Multiple Sclerosis, developed in 1999, recommends that treatment be considered as soon as possible following a definite diagnosis of MS with active disease (two neurological events (attacks) suggesting loss of myelin in the brain and spinal cord

separated in time and location). Treatments may also be considered for some patients with a first attack who are at high risk of developing MS (known as **clinically isolated syndrome**).

- In 2004, the Canadian Multiple Sclerosis Working Group developed criteria to help clinicians in defining optimal versus suboptimal responses to the disease modifying therapies, evidence-based guidelines regarding how to improve treatment outcomes, and practical recommendations on assessing patients and determining when it may be necessary to modify treatment in order to optimize outcomes.
- The following points should be discussed in some detail on the first or second visit after the diagnosis is confirmed:
 - The immunomodulating drugs are designed to reduce the number and severity of attacks in the hope of slowing disease progression over the long term. They have also been shown to reduce the number of new lesions visible on MRI.
 - Although MS was once thought to cause damage primarily to the myelin sheath that covers the nerve fibres in the central nervous system, we now know that the nerve fibres themselves are damaged as well. While the myelin sheath has some natural ability to regenerate, the nerve fibres do not. It is this damage to nerve fibres that may be responsible for the permanent symptoms or impairments that can occur in MS.
 - Since damage can occur in the central nervous system early in the disease course, even during periods of remission when a person isn't experiencing any symptoms, early treatment is important to reduce the likelihood of this kind of significant, permanent damage.
 - Prognosis may be inferred to some extent by the patient's history, examination, and lesion burden on MRI. Those who have few attacks in the first several years, good recovery from attacks, and a minimum of pyramidal, brainstem, or cerebellar signs, may tend to have a more benign course than patients who show these characteristics early on, or who have numerous exacerbations with poor recovery. While this information should be conveyed to patients, they need also to be reminded that one of the major challenges of dealing with MS is its unpredictability.

- None of the approved disease-modifying therapies are approved for use by women who are pregnant or nursing. Young women who are contemplating starting a family or having another child will need sufficient education about the impact of pregnancy on MS, and of MS on pregnancy, to make informed treatment and family-planning decisions.
- It is important to consider the options for those who present with a progressive disease course. While some patients with a progressive course may benefit from the disease-modifying therapies, others will not. Consider potential clinical trials of interest, or, in certain cases, off-label treatments such as chemotherapy agents (e.g., mitoxantrone). People with progressive forms of MS may feel that there are few resources for them and may even be told by physicians that there is “nothing they can do”. This can be a devastating experience for patients. Where treatment is not an option, it is critical to emphasize the symptom management and rehabilitation possibilities which can be key in improving the quality of life for your patient.
- A summary of the disease modifying therapies and an overview of provincial government coverage can be found on the MS Society of Canada website (www.mssociety.ca).

5. When do I begin to talk about symptoms, symptom management, rehabilitation, and wellness?

- At the time of diagnosis, most people want to know the kinds of symptoms they might expect with MS. Describing the many kinds of symptoms that can occur is helpful for people because it:
 - Allows them to anticipate and therefore recognize problems that may occur in the future.
 - Explains some sensations or problems they may already have experienced without knowing the cause.
 - Prepares them for what they might encounter when they read about MS or talk to others who have the disease.
- As always, it is helpful to remind the patient that MS is a variable illness, and that they are unlikely to experience all of the symptoms associated with MS.

- Information about symptoms and the treatments used to manage them is available from the Multiple Sclerosis Society of Canada. Patients can receive information by calling their local chapter or division or by visiting the website at www.mssociety.ca.
- Symptom management may be addressed as needed. If the patient is not having any ongoing symptoms that need to be treated, he or she should be reassured that most symptoms of MS can be treated if and when they arise, and reminded to call you with any problems.
- It is appropriate to begin talking about the role of rehabilitation in MS treatment early in the disease course, particularly if fatigue is a symptom. The personalized exercise programs and energy management strategies designed by physiotherapists and occupational therapists not only address the fatigue but also give patients the satisfaction of doing something to manage their MS and feel better. Other rehabilitation modalities should be offered as needed. In general, patients should be encouraged to participate in some kind of regular exercise as tolerated, and reassured that moderate exercise is beneficial for people with MS.
- Like all other patients, people with MS need to be reminded of the importance of a healthy lifestyle and regular preventive health care.
 - Patients preoccupied with a chronic illness sometimes tend to neglect other aspects of their health or to believe that having MS somehow absolves them of having to worry about any other health issues.
 - While some patients feel empowered by wellness strategies such as maintaining a healthy diet, getting adequate rest and exercise, or practicing stress management, others may feel anxious or guilty about their inability to persevere. All patients need to be reminded that while these strategies are recommended to promote general health, they do not affect the course of their MS.

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

- Patients benefit from face-to-face time with their physician early in the disease course, and subsequently during episodes of increased disease activity when they are likely to be very anxious. They need these opportunities to ask questions, interact, and feel less alone with their MS. The ability to make contact by telephone between visits is equally valuable.

- You might want to encourage patients to bring a prepared list of questions to help them remember everything they want to talk to you about, and perhaps a relative or friend to take some notes or be a second pair of ears.
- Information can also be given via patient education materials from the MS Society of Canada, as well as pharmaceutical companies.
- Numerous websites now offer accurate, up-to-date information about multiple sclerosis (see recommendations below), as well as opportunities to communicate with others who have MS. It is important to remind patients that not all websites are equally reliable and that being a cautious and educated consumer is their best strategy for utilizing web-based information.

7. How do I find a balance between providing realistic, accurate information about the disease, and fostering optimism, hope, and a sense of personal control?

- Most people are more comfortable with the truth than with evasion. Your willingness to communicate openly and honestly about a patient's condition and prognosis facilitates coping, problem-solving, and feelings of personal control. You may find it useful to compare MS to other chronic but treatable conditions like diabetes or hypertension.
- Patients should be reminded that immunomodulators impact the course of the disease for most people, and that the current agents will be replaced by even more effective ones within the next several years.
- By actively involving patients in all treatment decisions, you convey a sense of trust in their ability to make sound decisions and problem-solve in relation to their own goals and priorities. This partnership between doctor and patient heightens the person's feelings of hope and confidence, and reassures them that they are not alone.
- Emphasizing the ongoing importance of health-promoting strategies (exercising, maintaining a healthy diet, practicing stress management techniques, and adhering to recommended guidelines for preventive health care) gives patients the means to enhance their sense of personal control and reminds them that there is more to them than their MS.

8. What is the recommended way to address patients' resistance to early intervention?

- Patients who understand the basic immunopathology of MS, and the implications of serial MRI data in tracking disease activity, will be more amenable to beginning early treatment. They also need to understand the distinction between symptomatic and prophylactic treatment strategies.
- Patients should be made aware of the following MRI study findings:
 - Even when a person is asymptomatic or in between exacerbations, active demyelination and axonal injury may be occurring.
 - Overall lesion burden on MRI will tend to correlate with long-term disability.
- It is important to reinforce the message that early intervention with one of the immunomodulators is the single best strategy they have to reduce new lesion formation and decrease the number and severity of exacerbations.

9. What should I expect in the way of responses from my newly diagnosed patients?

- The most common short-term reactions to the diagnosis of MS are:
 - Shock – “This can't be happening to me.”
 - Denial – “This isn't happening to me.”
 - Anxiety – “What else will happen to me?”
 - Anger – “Why can't you fix what's happening to me?”
 - Relief – “At least I finally have a **name** for what's happening to me.”
- Longer-term reactions to the diagnosis include:
 - Grief – over the losses they experience in physical and cognitive abilities, lifestyle changes they are forced to make, and threats to personal identity.
 - Anxiety – primarily in relation to loss of personal control and concerns about the future.
 - Resentment – that something as unfair as MS has entered their lives.
 - Guilt – over their inability (real or anticipated) to fulfill obligations at home and at work.
- All of these responses will ebb and flow over the course of the illness.

- The most common concerns voiced by people newly diagnosed with MS include:
 - The impact of MS on longevity. (Generally patients with MS can expect to live close to the normal life span.)
 - The impact of MS on their ability to have children. (The ability of men and women with MS to conceive and bear children is generally not affected, and pregnancy has been found to have no impact on a woman's long-term disability level.)
 - Their children's risk of developing MS. (Children of a parent with MS are at increased risk of developing the disease, but the absolute risk remains relatively small.)
 - The likelihood of becoming wheelchair-dependent. (Two-thirds of people with MS remain ambulatory, although they may require a cane or other assistive device.)

10. What resources are available to help my newly-diagnosed patients?

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 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
- Education
- Support
- Advocacy
- Funding

- The MS Society of Canada has educational materials available in both English and French on a wide range of topics. Your newly-diagnosed patients can obtain these as well as other materials from their local chapter or division (1-800-268-7582), or by visiting the website at www.mssociety.ca:
 - Key Facts for Those Affected by Multiple Sclerosis
 - Multiple Sclerosis: Its effects on you and those you love
 - Multiple Sclerosis and how we can help
 - Kids Get MS Too: A Guide for Parents Whose Child or Teen has MS
 - Living with Progressive Multiple Sclerosis
 - Medical Update Memo: MS disease-modifying therapies in Canada
 - How to Talk about MS with Your Children
 - Assets and Abilities – Your Guide to Work, Income Security, and Multiple Sclerosis
 - MS and your Emotions
 - Taming Stress in MS
 - Living Well with MS: Managing Fatigue
 - MS attacks: what they are and what you can do about them
- The MS 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):
 - MS Learn Online (live and archived programs for people living with MS)
 - Information for People Newly Diagnosed with MS
www.nationalmssociety.org/NewlyDiagnosed
 - MS and Pregnancy
www.nationalmssociety.org/Pregnancy
- Multiple Sclerosis International Federation/
The World of Multiple Sclerosis
www.msif.org
- CenterWatch Clinical Trials Listing Service™
www.centerwatch.com
- Consortium of Multiple Sclerosis Centers
www.ms-care.org
- National Institutes of Health (NIH) Clinical Trials Listing Service
www.clinicaltrials.gov

Pharmaceutical Company Support Programs:

Betaseron (Berlex)

MSPathways

1-800-977-2770

www.mspathways.ca

Avonex (Biogen)

MS Alliance

1-888-456-2263

www.msalliance.com

Copaxone (Teva Neuroscience)

Shared Solutions

1-800-283-0034

www.mswatch.ca

Rebif (Serono Canada)

Multiple Support Program

1-888-677-3243

www.serono-canada.com

Recommended Reading:

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- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.). New York: Demos Medical Publishing, 2005.
 - Ch. 1 Kalb R. **When MS Joins the Family.**
 - Ch. 5 Birk K, Giesser B. **Fertility, Pregnancy, and Childbirth.**
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (3rd ed.). New York: Demos Medical Publishing, 2004.
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 - Ch. 10 Kalb R, Miller D. **Psychosocial Issues.**
 - Ch. 13 Birk K, Giesser B, Werner M. **Fertility, Pregnancy, and Childbirth.**
- O'Connor PD. **Multiple Sclerosis: The Facts you Need.** Toronto: Key Porter Books, 2002.
- Schapiro RT. **Managing the Symptoms of Multiple Sclerosis** (4th ed.). New York: Demos Medical Publishing, 2003.

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How to Reach the MS Society

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OUR MISSION

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life

Contact the Multiple Sclerosis Society of Canada

Toll-free in Canada: 1-800-268-7582

Email: info@mssociety.ca

Website: www.mssociety.ca

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