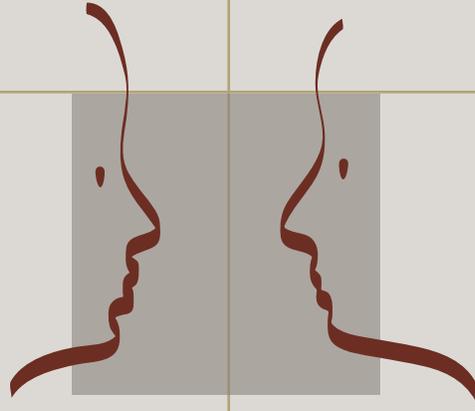




National  
Multiple Sclerosis  
Society

*Talking with Your  
MS Patients about  
Difficult Topics*



# Communicating the Diagnosis of Multiple Sclerosis

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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.

Physicians are invited to consult via email with MS specialist colleagues who serve on our National Clinical Advisory Board

**MD\_info@nmss.org**

Allied health professionals are invited to consult via email with MS specialist colleagues

**HealthProf\_info@nmss.org**

Visit our website:

**[www.nationalMSSociety.org/PRC](http://www.nationalMSSociety.org/PRC)**

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## 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 of clinically-definite MS 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 tumor or some other fatal condition.
- Those who have 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 to help 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 (*Young Persons with MS: A Network for Families with a Child or Teen With MS*—available from the National MS Society by calling 1-800-344-4867).

## **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 National MS Society has several publications for those who are newly diagnosed and their families (see p. 7). You may find it useful to provide these to your patient or suggest that he or she request them from the local chapter. These materials will help them clarify the questions and concerns they 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 maximize the person’s comfort and independence.
  - Treatment of acute exacerbations
  - Disease-modifying strategies
  - Symptom management
  - Rehabilitation
  - Psychosocial support

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

- The Disease Management Consensus Statement published by the National MS Society, and updated in 2005 and again in 2007, recommends that treatment with an interferon medication or glatiramer acetate be considered as soon as possible following a definite diagnosis of MS with active, relapsing disease, and may also be considered for some patients with a first attack who are at high risk of developing MS (known as *clinically isolated syndrome*).
- The following points of the Consensus Statement should be discussed in some detail on the first or second visit after the diagnosis is confirmed.
  - The disease-modifying therapies 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 fibers in the central nervous system, we now know that the nerve fibers themselves are damaged as well. While the myelin sheath has some natural ability to regenerate, the nerve fibers do not. It is this damage to nerve fibers 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 signs early on or 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.

## 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.
- Information about symptoms and the treatments used to manage them is available from the National MS Society. Patients can receive this information by calling 1-800-344-4867 or by going to the website at [www.nationalMSSociety.org/Treatments](http://www.nationalMSSociety.org/Treatments).
- 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 physical 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 healthcare.
  - 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. Like the general population, most people with MS die of cancer, heart disease, and stroke.
  - The recommended diet for people with MS is the same low-fat, high-fiber diet that is recommended for all adults. Special or fad diets have not been shown to impact the disease course.
  - Current research suggests that smoking is a risk factor for both the onset of MS and the transition from a relapsing-remitting to a secondary-progressive disease course.
  - While some patients feel empowered by wellness strategies such as maintaining a healthy diet, getting adequate rest and exercise, practicing stress management, or quitting smoking, others may feel anxious or guilty about their inability to persevere.

## 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 National MS Society, pharmaceutical companies, and the American Academy of Neurology.
- 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 or unbiased 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 the disease-modifying medications 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 healthcare) 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 and self-esteem
  - 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?

- *Knowledge Is Power*—a six-week, home-based educational series for those who are newly diagnosed—is available at no charge from the National MS Society by calling 1-800-344-4867 or online at [www.nationalMSSociety.org/Knowledge](http://www.nationalMSSociety.org/Knowledge).
  1. Taking the First Steps: What is MS? Dealing with Your Diagnosis and Disclosure
  2. Disease-Modifying Treatments for MS
  3. Maximizing Your Employment Options
  4. Treating Yourself Well [symptom management and wellness]
  5. Maintaining Healthy Relationships: Family, Friends, and Colleagues
  6. Working with Your Doctor
  7. Building and Maintaining Intimate Relationships [optional]
  8. Parenting with MS [optional]
- Additional National MS Society materials are available without cost on a wide range of topics. Your newly-diagnosed patients can obtain these and many others from their local chapter or from the website at [www.nationalMSSociety.org/Brochures](http://www.nationalMSSociety.org/Brochures):
  - *What Everyone Should Know About Multiple Sclerosis* (overview of MS, suitable for the whole family)
  - *What Is Multiple Sclerosis?*
  - *Diagnosis: The Basic Facts*
  - *The Disease Modifying Drugs* (summarizes information on the six approved medications, including how each is taken, side effects, benefits, and pharmaceutical support programs and financial assistance programs)
  - *Genetics: The Basic Facts*
  - *Fatigue: What You Should Know*
  - *Information for Employers*
  - *Disclosure: The Basic Facts*
  - *Vision Problems: The Basic Facts*
  - *Living with MS* (addresses questions frequently asked after diagnosis of MS is received)
  - *Should I Work? Information for Employees*
  - *“But You Look So Good”* (coping with invisible MS symptoms)
  - *Clear Thinking About Alternative Therapies*
  - *Qué es la Esclerosis Múltiple?*
  - *Diagnóstico: Hechos Básicos sobre Esclerosis Múltiple*
  - *Comparación de los Medicamentos Modificadores de la Enfermedad*
  - *Lo Que Todo el Mundo Debe Saber Sobre la Esclerosis Múltiple*
  - *“¡Pero si te ves tan bien!”* (algunas maneras de manejar los síntomas “invisibles” de EM)
  - *La Fatiga: Lo Que Usted Debe Saber*
- National MS Society website ([www.nationalMSSociety.org](http://www.nationalMSSociety.org)) offers information on a wide variety of topics (e.g., treatment, research, psychosocial issues) and access to local resources.
  - *MS Learn Online* Communicating the Diagnosis of Multiple Sclerosis (live and archived programs for people living with MS), and access to local resources and events.
  - Information for people newly-diagnosed with MS ([www.nationalMSSociety.org/NewlyDiagnosed](http://www.nationalMSSociety.org/NewlyDiagnosed))
  - MS and Pregnancy ([www.nationalMSSociety.org/Pregnancy](http://www.nationalMSSociety.org/Pregnancy))

• **Additional recommended websites:**

- Multiple Sclerosis Society of Canada  
[www.mssociety.ca](http://www.mssociety.ca)
- International Federation of Multiple Sclerosis Societies/  
The World of Multiple Sclerosis  
<http://www.msif.org/>
- Pharmaceutical Company Support Programs
  - Betaseron  
BETAPLUS  
[www.mspathways.com](http://www.mspathways.com)
  - Avonex  
MS Active Source  
[www.msactivesource.com](http://www.msactivesource.com)
  - Copaxone  
Shared Solutions  
[www.sharesolutions.com](http://www.sharesolutions.com)
  - Novantrone  
[www.novantrone.com](http://www.novantrone.com)
  - Rebif  
MS Lifelines  
[www.mslifelines.com](http://www.mslifelines.com)
  - Tysabri  
TOUCH Prescribing Program  
[www.tysabri.com](http://www.tysabri.com)
- Clinical Trials
  - CenterWatch Clinical Trials Listing Service  
<http://www.centerwatch.com/>
  - National Institutes of Health (NIH) Clinical Trials Listing Service  
<http://www.ClinicalTrials.gov>

- National MS Society Clinical Trials List  
[www.nationalMSSociety.org/ClinicalTrials](http://www.nationalMSSociety.org/ClinicalTrials)
- National MS Society support groups—for people newly diagnosed with MS, for couples—offering education, support, problem-solving
- Counseling by a therapist familiar with MS can help individuals and families cope more comfortably with MS-related challenges, understand their feelings, and communicate and problem-solve more effectively. National MS Society chapters can provide names of therapists with expertise in MS.
- **Additional readings:**
  - Holland N, Murray TJ, Reingold SC. *Multiple Sclerosis: A Guide for the Newly Diagnosed* (3rd ed.). New York: Demos Medical Publishing, 2007.
  - Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (4th ed.). New York: Demos Medical Publishing, 2008.
  - Kalb R, Holland N, Giesser B. *Multiple Sclerosis for Dummies*. Hoboken, NJ: Wiley Publishing, 2007.
  - Schapiro RT. *Symptom Management in Multiple Sclerosis* (5th ed.). New York: Demos Medical Publishing, 2007.

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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 Clinical Director of the MS Program 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 endeavors for the National MS Society. She is co-author of *Multiple Sclerosis for Dummies*, published in 2007.

**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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