TALKING WITH YOUR PATIENTS
ABOUT DIFFICULT TOPICS

TALKING ABOUT

Progressive Disease

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National
Multiple Sclerosis
Society

The National MS Society's Professional Resource Center provides:

- Easy access to comprehensive information about MS management in a variety of formats;
- Dynamic, engaging tools and resources for clinicians and their patients; and
- Consultations and literature search services to support high quality clinical care.

FOR FURTHER INFORMATION:

VISIT OUR WEBSITE:

nationalMSsociety.org/PRC

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Introduction

This booklet is designed to facilitate conversations with your multiple sclerosis patients about disease progression. Like the other topics in this series, progressive disease is one that patients and their physicians often have difficulty discussing—the patients because they do not know what questions to ask and fear the answers they might receive, and the doctors because it is difficult to discuss problems for which there are no definitive answers.

1. How and when should I talk to a patient about disease progression?

- Beginning fairly early in the disease course, patients need accurate information about the natural history of MS. While the disease-modifying agents slow disease progression for many people, the disease course often becomes progressive at some point along the way.
- Accurate information about the disease encourages people with MS and their families to develop realistic expectations and plan for the worst even while hoping for the best. This kind of planning gives them time to develop the financial safety net they will need in the event that the disease becomes more disabling. Accurate information also reduces people's feelings of failure and self-blame if and when the disease progresses in spite of your and their best efforts.
- Patients generally respond well to this information when reassured that most people with MS do not become severely disabled, and that you will be working with them to manage their disease and treat their symptoms.
- Patients with progressive disease from onset need to know that while there are fewer approved treatment options available for them than for those with relapsing MS, there is still much that they can do to live comfortably with the disease. With the recent emphasis on early intervention for relapsing forms of the disease, these patients often feel neglected by the scientific community and by their doctors. They need to understand the importance of symptomatic treatments and of rehabilitation interventions designed to help them maintain and enhance function, comfort, and wellness, and reduce the risk of unnecessary complications. And they will be reassured to know that there are new drugs in the research pipeline (e.g., fingolimod, dronabinol, MN-166) that may become available in the near future.
- Patients with relapsing disease who begin or continue to progress significantly in spite of disease-modifying therapies need to understand that the disease sometimes takes this course, in spite of everyone's best efforts. It is important to discuss additional treatment options at this time (e.g., mitoxantrone or one of the other chemotherapies, and natalizumab) so that patients and families understand that treatment is available, and that you are not "giving up on them."

2. How much is the "right" amount of information to give my patient?

- Although "one size" will never fit all, it is important to provide patients with the information they need to participate actively in their care and make informed treatment and lifestyle decisions. The challenge lies in providing the information in ways that meet different people's learning styles and emotional needs. Some may want or need to have as much information as you can give them right away, while others will need to hear it more gradually.
- Patients need to know that the prognosis for a person with MS is never certain, but that progressive MS can have a significant impact on virtually every aspect of everyday life. Let them know that the goal of your MS management strategies is to minimize that impact as much as possible with:
  - Disease-modifying treatment
  - Aggressive symptom management
  - Rehabilitation to maintain function
  - Adaptive devices to conserve energy and promote safety
  - Careful attention to their overall health and wellness.
  - Referrals to community resources for education, support, services
  - Referrals to counseling, if needed
- Treatments for progressive disease generally carry with them a certain number of risks, with no guarantee of benefit. A thorough review of the anticipated benefits and risks will facilitate patients' decision-making and promote adherence once the treatment has been determined.
- Alert patients with progressive disease and their family members to the potential impact of MS on employment, and emphasize the need for sound financial planning. The National MS Society can refer people to professionals with expertise in these areas.

3. How can I convey this information in a way that will avoid feelings of failure and guilt?

- Explain that the natural history of MS in many, but not all, patients is for it to gradually become more progressive. It is important to reassure the person that progression is not a sign of failure or weakness.
- Explain that the transition to progressive disease refers to the absence of acute exacerbations and does not necessarily mean the transition to severe disability.
- Patients need to know that the symptoms of MS can often be managed effectively, even when they are becoming more severe.
- The most important message for patients is that you will be working with them to manage their symptoms and help them live comfortably with their MS, regardless of disease course or severity.

4. How do I find a balance between providing realistic, accurate information about disease progression and fostering hope and optimism?

- Realistic information does not have to preclude hope. Patients' hope and optimism for the future come from several sources:
  - Feeling informed helps people feel more in control.
  - Having options from which to choose helps people feel empowered.
  - Being prepared for a range of eventualities helps people feel less vulnerable and more in control of their lives.
  - Confidence in your commitment to their ongoing care helps them feel less afraid and more optimistic.
  - Knowing that they will be seeing you on a regular basis helps them feel less alone in their struggle with MS.
  - Knowing that there is always something that can be done to make things better—even if only a little bit—keeps people feeling hopeful.
- Most patients feel better—more optimistic, hopeful, and empowered—when they feel confident that they are hearing the truth from their doctors. They are quick to detect empty reassurances and "false hope."
- The most effective way to promote optimism and hope is to balance honest, realistic assessments with suggested interventions to address the problems.

5. How can I discuss the importance of rehabilitation (for maintenance rather than recovery purposes) without scaring or discouraging my patients?

- Although patients are initially frightened to hear that MS cannot be cured, or that symptoms like spasticity, weakness, imbalance can be chronic, they respond positively to rehabilitation when the goals are clearly explained:
  - To help them attain the highest possible level of function and comfort given their limitations
  - To help them maintain that level of function as long as possible
  - To prevent unnecessary, potentially dangerous complications
  - To provide them with the assistive devices they need to conserve energy and carry out their daily activities effectively, safely, and comfortably
- People who are frustrated and discouraged by the lack of a cure for MS respond well to the opportunity to "do something" for themselves. Rehabilitation programs give people the feeling of doing something constructive to help themselves, and provide them with home exercise programs and self-care strategies to use independently or with a care partner.

6. What is the best format for providing information to my patients?

- Discussions about significant disease worsening or changes in treatment strategies should always happen during an office visit.
  - Patients prefer to receive painful news from the doctor directly, rather than to hear it over the phone or have it left for them on an answering machine.
  - Face-to-face conversations give people the opportunity to react and ask questions.
  - Patients feel less frightened and more confident when their doctors discuss things with them openly.
  - Hearing the news from the doctor personally allows patients to decide when and how to share it with other family members, particularly their children. Messages on answering machines can be accessed by anyone.
- The patient may want to bring a family member or friend to the office to act as an "extra pair of ears." Some of these conversations are stressful enough for patients that they forget much of the information by the time they get home.
- Some patients, particularly those with cognitive symptoms, may need to take notes during their visits, or take home printed materials to read at their leisure.
- Whenever there is a major change in a person's condition, or a change in the available treatment options, it is helpful to encourage them to go home and think about it and then call you with any questions. You may want to provide written materials or suggest that your patients contact the National MS Society (1-800-344-4867 or online at www .nationalmssociety.org/Brochures) for booklets or pamphlets relevant to the subjects you have been discussing.

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

- Except in the case of severe cognitive impairment, this is generally left to the patient to decide.
- Treatment strategies that involve the participation of a significant other (e.g., injections, exercise programs, catheterization) should be discussed fairly early on with the patient and partner together.
- Interventions that significantly impact the partner (e.g., chemotherapy that might cause sterility, treatment for erectile dysfunction) also need to be discussed with both parties fairly early on.

8. What kinds of emotional reactions can I expect from patients whose disease is progressing in spite of whatever treatments they are receiving?

- Without the appropriate information about the natural history of MS, people may have very strong reactions to the progression:
  - Feelings of guilt that they did not take good enough care of themselves, did not follow your advice to the letter, did not listen to recommendations of their various well-meaning relatives and friends, did not try hard enough
  - Feelings of weakness or inadequacy that they could not "beat this disease"
  - Feelings of resentment that you did not provide them with the "right" advice, treatment, or care
  - Normal and natural feelings of grief over the accumulated losses and changes that the disease brings to their lives
- Depression, which is very common in MS under the best of circumstances, can occur in response to this additional loss of control.
- During periods of disease progression, people with MS may be particularly vulnerable to the claims of a wide variety of complementary or alternative treatments. They may try these interventions indiscriminately in hopes of finding the elusive cure. They may also believe that treatments sold without prescription are safer or healthier than those that are prescribed—particularly chemotherapies. As many as 60% of people with MS are using complementary or alternative treatments at any given time, and many are not sharing this information with their physicians.

9. What resources are available to educate and support my patients?

- The National MS Society has created educational materials on a wide range of topics. Your patients can obtain any of the following materials at no charge from their local chapter (1-800-344-4867) or in the multimedia section of the website at www.nationalMSsociety.org/Brochures:
  - *Managing Progressive MS*
  - *So You Have Progressive MS?* (authored by a woman with primary-progressive multiple sclerosis)
  - *Hiring Help at Home: The Basic Facts*
  - *A Guide for Caregivers*
  - *Fatigue: What You Should Know*
  - *Multiple Sclerosis and Your Emotions*
  - *Solving Cognitive Problems*
  - *Managing MS Through Rehabilitation*
  - *Stretching for People with MS*
  - *Stretching with a Helper for People with MS*
  - *Clear Thinking About Alternative Therapies*

  as well as information about
  - Disease-modifying drugs
  - Impact of MS on the family
  - Life planning
  - Long-term care
  - Employment
  - Multiple sclerosis and the mind
- National MS Society support groups—for people newly diagnosed with MS, for couples—offering education, support, problem-solving

- **Additional recommended websites:**
  - Multiple Sclerosis Society of Canada
    www.mssociety.ca
  - International Federation of Multiple Sclerosis Societies/ The World of Multiple Sclerosis
    www.msif.org
  - Pharmaceutical Company Support Programs
    - Betaseron
      BETAPLUS
      www.mspathways.com
    - Avonex
      MS Active Source
      www.msactivesource.com
    - Copaxone
      Shared Solutions
      www.sharedsolutions.com
    - Novantrone
      www.novantrone.com
    - Rebif
      MS Lifelines
      www.mslifelines.com
    - Tysabri
      TOUCH Prescribing Program
      www.tysabri.com
  - Clinical Trials
    - CenterWatch Clinical Trials Listing Service
      www.centerwatch.com
    - National Institutes of Health (NIH) Clinical Trials Listing Service
      www.clinicaltrials.gov
    - National MS Society Clinical Trials
      www.nationalMSsociety.org/ClinicalTrials
  - 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.
  - **Recommended readings:**
    - Coyle PK, Halper J. *Living With Progressive Multiple Sclerosis.* New York: Demos Medical Publishing, 2007.
    - Holland N, Halper J (eds.). *Multiple Sclerosis: A Self-Care Guide to Wellness* (2nd ed.). New York: Demos Medical Publishing, 2005.
    - 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. *Managing the Symptoms of Multiple Sclerosis* (5th ed.). New York: Demos Medical Publishing, 2007.

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Aaron Miller, MD, graduated from Brandeis University in 1964 and received his MD degree from New York University School of Medicine in 1968. Following his residency in neurology at the Albert Einstein College of Medicine, he received additional postdoctoral training in neurovirology and immunology at the Johns Hopkins University School of Hygiene and Public Health and at Einstein. In March 2004, Dr. Miller assumed the position of Medical Director of the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at the Mt. Sinai School of Medicine. For 23 years prior to that, he headed the Division of Neurology at Maimonides Medical Center in Brooklyn, NY, where he continues to serve as co-director of the MS Care Center. Dr. Miller is also a Professor of Neurology at the Mt. Sinai School of Medicine in New York.

Dr. Miller is chief medical officer and chairman of the National Clinical Advisory Board of the National Multiple Sclerosis Society. He formerly served as president of the Consortium of MS Centers and was the first chairman of the Multiple Sclerosis section of the American Academy of Neurology. Dr. Miller has participated in numerous clinical trials of new treatments for MS and has recently authored a book, *Multiple Sclerosis in Clinical Practice,* with colleagues Fred Lublin and Patricia Coyle. He has also published many articles and chapters on MS and other neurologic subjects.

Dr. Miller is very active with the American Academy of Neurology. He developed a popular seminar entitled *MS: Patient Management,* for four years directed a course entitled *Update on Multiple Sclerosis,* and for the past three years has directed a course on *Hot Topics in MS.* He currently serves as editor of *Continuum,* the Academy's bi-monthly continuing education publication. From 1997–2003, he served as co-chairman of the Education Committee and Chairman of the Annual Meeting Subcommittee. Prior to assuming that position, he served as chairman of the Program Accreditation and Development Subcommittee.

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*.

Other resources for
Talking with Your MS Patients about Difficult Topics
include:

Talking about…

Cognitive Dysfunction
Diagnosis of Multiple Sclerosis
Elimination Problems
Sexual Dysfunction
Depression and Other Emotional Changes
Initiating and Adhering to Treatment with Injectable Disease Modifying Agents
Family Issues
Reproductive Issues
The Role of Rehabilitation
Stress
Life Planning
Primary Progressive MS (PPMS)
Palliative Care, Hospice and Dying
Wheeled mobility

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