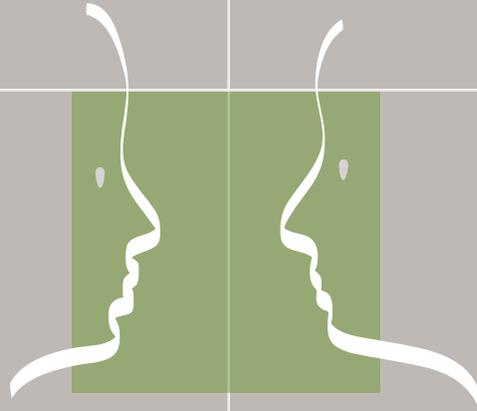




National
Multiple Sclerosis
Society

*Talking with Your
MS Patients about
Difficult Topics*



Talking about Stress

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Professional Resource Center

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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

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Introduction

This booklet is designed to facilitate conversations with your patients about stress and multiple sclerosis. Many people believe that stress can worsen their MS and worry about their ability to manage their

life stresses effectively. You can alleviate many of these concerns by initiating conversations about stress early in the disease.

1. Why should I talk about stress with my patients?

- Many patients believe that stressful events can cause exacerbations or make their MS worse.
- In the belief that it will improve their MS, patients may make important decisions regarding their lives (such as quitting their job) in an attempt to manage stress.
- Some patients may blame sources of stress, such as employers or family members for “making their MS worse”.
- Some patients may blame themselves for their exacerbations or disease progression, believing that they could have prevented them from happening with more effective stress management.

2. What is stress?

- Stress was originally an engineering term that referred to “the force exerted when one body or body part presses on, pulls on, pushes against, or tends to compress or twist another body or body part.” It entered the vernacular through Hans Selye’s use of the word to describe the effects of “noxious agents” (e.g., cold, food deprivation, or even vigorous muscular workout) on biological processes and organs.
- Today, when people talk about stress, they could be referring to any number of things, including events in their environment, their interpretations of the events, their subjective distress, or any combination of these. For example, if your patient says “My job is really stressful right now,” it could mean:
 - **Events in the environment have changed.** There has been a change in working conditions such as new boss, increased work load, change in location of work space, etc.
 - **Perceptions of the environment have changed.** The person has begun to perceive conditions at work as “stressful” or “harmful” even though none of the conditions at work have actually changed.
 - **The person is emotionally distressed.** Feelings of depression, anxiety, irritability, or being overwhelmed—all fairly common emotions in people with MS—have led your patient to begin identifying various aspects of the work environment as “stressful,” even though nothing at the office has changed.
- The three potential meanings or sources of “stress” can be present individually or in combination among patients reporting “stress.”
- Researchers and clinicians do not agree on the precise definition of stress. However, a widely accepted framework considers stress to involve *events in a person’s environment that exceed the*

person's resources and ability to adaptively manage them, and result in psychological or biological changes that may place a person at risk for medical or psychiatric disorders.

- Typically, researchers measure one of the three types of stress described above

using checklists or questionnaires to evaluate the occurrence of stressful events, perceptions of stress (e.g., a belief that one cannot control or manage aspects of one's life) or emotional distress (e.g., feeling overwhelmed).

3. What do we know about the relationship between stress and MS?

- A growing body of literature about stress and MS has generated more heat than light:
 - A recent meta-analysis found a consistent association between stressful life events and MS exacerbations. (Mohr DC, Hart SL, Julian L, et al. (2004). Association between stressful life events and exacerbation in multiple sclerosis: A meta-analysis. *British Medical Journal* Mar 27; 328(7442): 731.)
 - A review that included an evaluation of physical trauma found no relationship with MS exacerbation. (Goodin DS, Ebers GC, Johnson KP, et al. (1999). The relationship of MS to physical trauma and psychological stress: Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology. *Neurology* Jun 10; 52(9): 1737–1745.)
 - One study found that life-threatening psychological trauma (e.g., being under missile attack) may have reduced the risk of exacerbation. (Nisipeanu P, Korczyn AD. (1993). Psychological stress as a risk factor exacerbations in multiple sclerosis. *Neurology* 43: 1311–1312.)
 - A large epidemiological study found that a significant stressor—the loss of a child—significantly increased the risk of developing MS. (Li J, Johansen C, Bronnum-Hansen H, et al. (2004). The risk of multiple sclerosis in bereaved parents: A nationwide cohort study in Denmark. *Neurology* Mar 9; 62(5): 726–729.)
- Data suggest that not all stress is the same. Traumatic stress (e.g., acute and severe stress) may have no effect, or may even be associated with reduced risk of exacerbation, while stress/distress that is chronic may be associated with increased risk of exacerbation.
- While no studies have established any causal relationship between stress and MS, several possible connections between stress and MS have been suggested:
 - A feeling of distress may be an early sign of disease activity. We know that changes in brain tissue begin many months before the appearance of gadolinium enhancing lesions; such changes may somehow precipitate feelings of distress.
 - Stressful life events may be one factor among many that determine if early pathogenic disease processes progress to become gadolinium enhancing brain lesions or full exacerbations.
 - Chronic stress may cause alterations in levels of endogenous glucocorticoids, thereby altering the body's ability to regulate inflammatory pressure.

- If there is a real relationship between stressful life events and MS exacerbation, it is likely quite variable across patients; some patients may be resilient, while others may be more vulnerable.
- The evidence regarding stress and disease progression, or sustained progression, is contradictory; no conclusions can be drawn at this time.

4. If the relationship between stress and MS is so unclear, do patients need to be concerned about it?

- If patients ask about stress, it suggests they are concerned about it and in need of information, evaluation of their life stressors, or both.
- While the nature of the relationship between stressful life events, or perceived stress and MS is uncertain, we know a lot more about the effects on other aspects of health and mental health. A large and growing literature indicates that stressful life events and perceived stress can significantly increase risk of and/or severity of cardiovascular disease, accidents and injury, psychiatric disorders, disability, and a variety of other medical, psychological and social problems.
- While the nature of the relationship between stressful life events and MS exacerbation is unclear, this does not mean that stress does not affect MS. If your patient is reporting significant effects of stress, there are good clinical reasons to address these concerns.

5. How do I evaluate stress?

- If a patient complains or asks about stress, the question or complaint should be taken seriously. It may be a question seeking information about the stress literature, or it may reflect significant psychological or social problems that require attention.
- Ask the patient about these three critical areas:
 - **Stressful life events.** Are there significant external problems in the patient's life? Most commonly these events occur in the patient's work life, family life, or problems with close friends.
 - **Patient's resources and ability to cope.** If there are new stressors, does the patient have the resources and ability to manage them? Alternatively, have there been changes in the patient's resources and abilities? For example, are growing job-related or family problems related to increasing cognitive impairment?
 - **Distress.** Is the patient depressed, anxious, irritable, or feeling overwhelmed?

6. What can be done to reduce stress?

- Most stress management strategies focus on teaching three skills:
 - **Reducing the number or severity of stressful life events.** Often patients can reduce the number and severity of stressful life events by learning to identify potential stressors before they occur and avoiding them, or by rearranging their lives to eliminate sources of stress that do not contribute to daily life in any meaningful way.
 - **Learning to reappraise those stressful situations that cannot be avoided.** Many stressful situations cannot be avoided. Often patients' interpretations or appraisals of these situations make them more distressing than they need to be. Many techniques have been developed to help patients reduce this type of "catastrophic thinking." Collectively, these kinds of techniques are sometimes referred to as "cognitive behavioral therapy."
 - **Learning to control arousal.** Learning to control autonomic arousal is a key part of most stress management programs. A variety of techniques provide these skills, including relaxation training, self-hypnosis, meditation, yoga, and others. A growing body of research shows that people who practice these techniques on a regular basis are better able to control mental and physical arousal, and may experience health benefits as well, such as lower blood pressure.

7. What are the most important strategies when conveying information about stress to my patients?

- **Empathize**
 - Let your patient know that you take his or her concerns seriously.
- **Normalize**
 - Let the patient know that many people are concerned about the health effects of stress, and that many patients with MS are worried about the effects it may have on their MS.
- **Educate**
 - Let the patient know that there is likely an association between stress and MS exacerbations, but we don't know much more than that. We do not know if stress increases the likelihood of an exacerbation, or if experiencing distress is an early sign that an exacerbation may be coming.
 - Nevertheless, stress management is good for overall physical and mental health.
- **Assess further**
 - Assess the patient for problems with depression or anxiety.
 - Ask about stressful events in the family and work environment.

- Ask about increasing impact of MS disability on ability to manage daily tasks.
- **Refer**
 - Refer for further evaluation and/or intervention by social services, psychiatry, neuropsychology, occupational therapy, as needed.
- Refer to a stress management program or clinician who can address the problem with the patient and/or the family.
- **Follow up**
 - Assess how the patient is managing stress at subsequent visits and if he or she has pursued referrals

8. What resources are available to help my patients with stress management?

- Mental health specialists with expertise in stress management techniques—be aware that not all mental health clinicians can effectively teach stress management.
- Meditation, exercise, or yoga programs.
- Chapters of the National Multiple Sclerosis Society (1-800-344-4867) can provide physicians with names of professionals in the community who are experienced with stress management and chronic illness. The chapters also offer educational programs, support groups, and other resources to support patients' coping efforts and help them deal with MS-related 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 by calling (1-800-344-4867) or in the Library section of the website at www.nationalMSSociety.org/Brochures
 - *Taming Stress in Multiple Sclerosis*
 - *Should I Work? Information for Employees*
- **Web-based resources** (www.nationalMSSociety.org/stress)
 - Information
 - Management strategies
 - Webcasts
- **Recommended reading:**
 - Davis M, Eshelman ER, McKay M. (1996). *The Relaxation and Stress Reduction Workbook* (4th ed.). Oakland CA: New Harbinger Press.
 - Elkin A. (1999). *Stress Management for Dummies*. Foster City, CA: IDG Books Worldwide.
 - Fraser RT, Kraft GH, Ehde DM, Johnson KL. (2006). *The MS Workbook: Living Fully with Multiple Sclerosis*. Oakland, CA: New Harbinger.
 - Greenberger D, Padesky CA. (1995). *Mind Over Mood: Change How You Feel by Changing the Way You Think*. Brooklyn, NY: Guilford Press.
 - Kalb R, Holland N, Giesser B. (2007). *Multiple Sclerosis for Dummies*. Hoboken, NJ: Wiley.

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Dr. Mohr received his PhD from the University of Arizona in 1991, and was on the faculty at the University of California, San Francisco from 1994 to 2006. He has been the recipient of numerous research grants from the National Institutes of Health and the National Multiple Sclerosis Society, and has published widely in the area of multiple sclerosis and behavioral medicine.

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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