TALKING WITH YOUR PATIENTS ABOUT DIFFICULT TOPICS

STRESS

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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.

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.
- There are effective evidence-based methods for managing stress.

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 (1950) 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 (1) the occurrence of stressful events, (2) perceptions of stress (e.g., a belief that one cannot control or manage aspects of one’s life) or (3) emotional distress (e.g., feeling overwhelmed).

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:

- Two systematic reviews found that stress may act as a risk factor for MS onset or relapse; however, both noted heterogeneity in measuring stress thus making it difficult to draw secure conclusions.[2, 3]
- A systematic review from 2015 yielded the following findings: (1) stress was significantly associated with the onset of MS, and; (2) there exists a significant positive relationship between stress and MS progression.[4]
- A review (1999) that included an evaluation of physical trauma found no relationship with MS exacerbation.[5] However, more recently, researchers have discovered contradicting evidence regarding physical trauma and MS. Cohort studies support the original finding from 1999,[6, 7] whereas case-control studies report a statistically significant association between physical trauma and risk of developing MS.[6]
- One study found that life-threatening psychological trauma (e.g., being under missile attack) may have reduced the risk of exacerbation.[8] In contrast, researchers also found that civilian exposure to war-related stress is linked with an increased risk for MS relapse.[9]
- A large epidemiological study found that a significant stressor—the loss of a child—significantly increased the risk of developing MS.[10] In contrast, a nationwide cohort study did not find a significant relationship between major stressful life events, such as losing a child or going through a divorce, and risk of MS.[11]

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. Further, frequency of MS relapses may be influenced by (accounting for about 33-42% of the variance) the nature of the stressors, age, and coping/relaxation training.[3]

The evidence regarding stress and disease progression, or sustained progression, is contradictory; no conclusions can be drawn at this time.

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 (1) information, (2) evaluation of their life stressors, or (3) 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.

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 treatment.

Ask the patient about these three critical areas:

- **Stressful life events.** Are there significant external problems causing stress 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? Is the emotional distress interfering with her or his ability to function in vocational, interpersonal, or day-to-day activities?

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.

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. The PhQ-2 (commonwealthfund.org/usr_doc/PHQ2.pdf) and GAD-2

(integrationacademy.ahrq.gov/sites/default/files/GAD-2_0.pdf) are fast and reliable screening instruments.
- 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.

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

- Mental health specialists with expertise in stress management—all mental health clinicians can effectively teach stress management.
- Mindfulness-based interventions, which can be helpful with regard to overall quality of life and physical and mental health.[12] These may include meditation, various types of exercise, and/or yoga programs.
- 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. There are 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 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:**
    - Stahl B, Goldstein, E. (2010). *A Mindfulness-Based Stress Reduction Workbook.* Oakland CA: New Harbinger Press.
    - Fraser RT, Kraft GH, Ehde DM, Johnson KL. (2006). *The MS Workbook: Living Fully with Multiple Sclerosis*. Oakland, CA: New Harbinger.
    - 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.

- Greenberger D, Padesky CA. (1995). *Mind Over Mood: Change How You Feel by Changing the Way You Think*. Brooklyn, NY: Guilford Press.
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10. Li J, Johansen C, Brønnum–Hansen H, Stenager E, Koch–Henriksen N, Olsen J. The risk of multiple sclerosis in bereaved parents A nationwide cohort study in Denmark. Neurology. 2004;62(5):726-9.
11. Nielsen NM, Bager P, Simonsen J, Hviid A, Stenager E, Brønnum-Hansen H, et al. Major stressful life events in adulthood and risk of multiple sclerosis. J Neurol Neurosurg Psychiatry. 2014;85(10):1103-8.
12. Simpson R, Booth J, Lawrence M, Byrne S, Mair F, Mercer S. Mindfulness based interventions in multiple sclerosis-a systematic review. BMC Neurol. 2014;14(1):15-23.

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

Talking about…

Cognitive Dysfunction
Diagnosis of Multiple Sclerosis
Progressive Disease
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
Life Planning
Primary Progressive MS (PPMS)
Palliative Care, Hospice and Dying
Wheeled Mobility

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