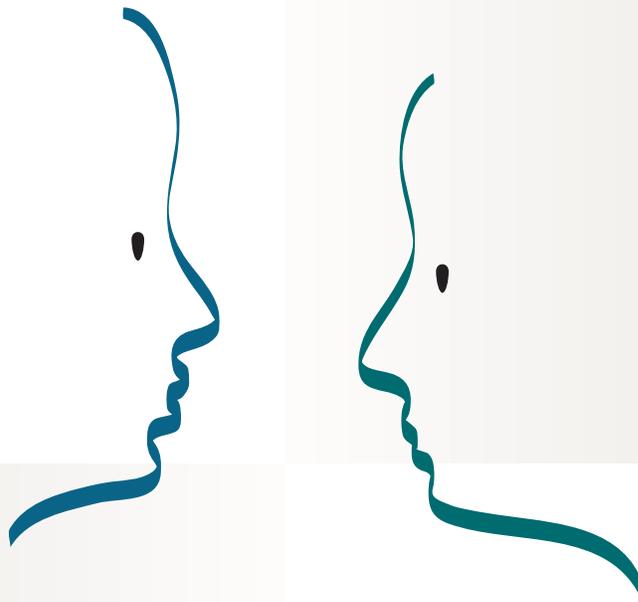


## Talking with Your MS Patients about Difficult Topics



**Rosalind Kalb, PhD, Editor**

### Introduction

This booklet is designed to facilitate conversations with your patients about the emotional aspects of multiple sclerosis. Because patients often perceive depressive feelings and other mood changes as signs of weakness or mental instability, they may be reluctant to discuss them with their physicians. They may also have no idea that the feelings and changes could be related to their MS. While these mood disturbances may not be readily apparent during a relatively brief office visit, they can have a significant impact on a patient's quality of life, general well-being, and adherence to treatment.

### 1. Why should I talk to my patients about emotional changes associated with MS?

- ◆ Depression is common among people with MS: more than half of patients will have a major depressive episode during the course of their illness.
- ◆ Patients and their family members need to be able to differentiate clinical depression from the normal grieving associated with the losses and life changes caused by MS.
- ◆ Other emotional changes also occur more frequently in people with MS: anxiety, mania and hypomania, emotional lability, pathological laughing and weeping, and euphoria.
- ◆ Family members may also become depressed and anxious as they struggle to cope with the challenges the illness presents for the entire family.
- ◆ MS-related emotional changes have different causes, treatments, and implications for the patient, family, and physician.
- ◆ For all these conditions, except euphoria, we have effective treatments. By talking about them with your patients and their families, you can facilitate early recognition and treatment of the problems, thereby minimizing suffering and enhancing the effectiveness of treatment.
- ◆ By raising these issues, you demonstrate an understanding and acceptance of patients' emotional experiences with MS, as well as a willingness to address them.

### 2. When should I talk with my patients about these emotional changes?

- ◆ Because emotional changes are common, treatable, and often part of the disease process, you are urged to talk about them with your patients as you would talk about any of the other symptoms of MS. Ideally, you will discuss the full range of possible

MS symptoms, including emotional changes, as soon as the diagnosis is made and repeat the discussion as often as necessary.

- ◆ While patients can become depressed at any time, certain times and experiences are associated with greater risk:
  - ◆ Diagnosis
  - ◆ Exacerbations (particularly the second exacerbation, which acts to confirm the reality of MS for a person who has been in denial)
  - ◆ Increasing disability
  - ◆ Points of transition to greater dependence (e.g., the use of an ambulation aid, or the need for intermittent self-catheterization or personal assistance)
  - ◆ Any major life change or loss, such as disability-related retirement
- ◆ Family members are also at risk during these times, particularly as lifestyle changes occur and caregiving demands increase.
- ◆ The discussion of emotional changes may be prompted by questions from patients and families or necessitated by clear signs on examination that the patient or family member needs treatment. Your best strategy for managing this aspect of MS is to build a strong patient-physician relationship where these kinds of problems are easily discussed. You can foster this relationship by taking the initiative from the very beginning.

### **3. How should I talk with my patients about emotional changes?**

- ◆ Many physicians worry that they will upset their patients by talking about emotional changes. In fact, most patients find it a great relief to talk about these matters. Talking about depression, anxiety, or suicidal thoughts does not precipitate these feelings or ideas; talking reassures people that they are understood and can be helped.
- ◆ While your style of communication may vary with the particular patient or situation, it is important to talk openly and matter-of-factly, conveying that emotional changes are as much a part of MS as problems with walking or bowel and bladder function.
- ◆ Patients with emotional changes often have misapprehensions about the feelings and problems they are experiencing. Simply correcting these misapprehensions can bring people significant relief. For example:
  - ◆ Learning that emotional changes are common in MS is helpful to patients who worry that they are “crazy” or unique in having these problems.

- ◆ Understanding the biological basis for emotional changes reassures patients who feel this is their fault or feel guilty or inadequate for not being “stronger.”
- ◆ Recognizing that there are effective treatments for most emotional disturbances helps patients who are feeling hopeless and despairing.

#### 4. What is the most important information about depression to convey to my patients?

- ◆ Most people with MS become discouraged and demoralized when they have an exacerbation, and most go through phases of mourning for the losses of function, lifestyle, and hopes for the future that come with increasing disability. These natural states are distinguishable from depression because they tend to be mild and time-limited, typically resolving on their own, and are best characterized by the term “grief.”
- ◆ Depression, on the other hand, is characterized by:
  - ◆ Feelings of hopelessness or pessimism
  - ◆ Feelings of guilt, worthlessness or helplessness
  - ◆ Sleep disturbances: trouble falling or staying asleep, early morning awakening, sleeping too much [easily confused with sleep disturbances caused by MS]
  - ◆ Diminished appetite with weight loss or increased appetite with weight gain
  - ◆ Decreased energy, increased fatigue, and feeling “slowed down” [easily confused with MS-related lassitude]
  - ◆ Restlessness and irritability
  - ◆ Thoughts of suicide or death
- ◆ Preoccupation with and worry about physical symptoms that do not respond to treatment or for which a physical cause cannot be found [easily confused with various MS-related symptoms and discomforts]
- ◆ More than half of all people with MS are likely to experience a depressive episode over their lifetime compared to 20% of people in the general population. Patients most at risk are those who have been depressed before or who have biological relatives with depression or alcoholism.
- ◆ There are different types of depression:
  - ◆ **Major depressive disorder**, characterized by one or more episodes of depressive symptoms that last all day, nearly every day, for a period of at least two weeks

- ◆ **Bipolar disorder**, in which episodes of depression alternate over varying time intervals with episodes of mania or hypomania (see below)
- ◆ **Dysthymia**, which is characterized by a chronic depressive state for at least two years
- ◆ While we do not fully understand how or why depressions occur, we do know that a disruption of brain chemicals (a reduction in the availability of neurotransmitters such as serotonin and norepinephrine) is the immediate cause.
  - ◆ Although people may believe that stress or something they did or did not do caused the depression, there is no scientific evidence to support this belief.
  - ◆ No one should feel that he or she brought on the depression or failed to remove the inevitable stresses of living with a chronic illness.
- ◆ Depression is most effectively treated with a combination of medication and psychotherapy. The selective serotonin reuptake inhibitors (SSRIs) are safe and effective for people with MS. Antidepressants may be prescribed by a primary care physician, neurologist, or psychiatrist (and nurses in some states).
  - ◆ Antidepressants can thoroughly eliminate the symptoms of depression, although it may be necessary to try a few different medications before finding the one that is most effective with the fewest side effects. While most patients take an antidepressant for 6–12 months, some may need ongoing treatment.
  - ◆ Psychotherapy is designed to facilitate the grieving process, promote self-esteem, and improve coping, communication, and problem-solving skills. Patients may engage in psychotherapy with a psychiatrist, psychologist, social worker or psychiatric nurse, either individually, as a couple, or in a group.

### 5. What is the most important information about other emotional changes to convey to my patients?

- ◆ Anxiety, difficulty controlling emotions (mood swings), pathological laughing and weeping (pseudobulbar affect), and euphoria also occur in MS.
  - ◆ **Anxiety**, a common response to the unpredictability of MS, is characterized by worry, agitation, apprehension, muscle tension, and a wide range of other symptoms including impaired concentration, disrupted sleep, irritability, restlessness, excessive fatigability [which could easily be confused with the fatigue of MS], and possibly panic attacks. Anxiety is treatable with medication and psychotherapy—often the same medication used to treat depression.

- ◆ When MS affects the parts of the brain associated with emotion, people can have **difficulty controlling their emotions**, becoming angry or irritable more often or more intensely than usual; or experiencing rapid changes in their emotional state, (e.g., feeling fine one moment, but annoyed or frustrated the next). Mood stabilizers such as lithium carbonate, carbamazepine, divalproex, lamotrigine, and some of the other anticonvulsants are often effective.
- ◆ Some people begin to laugh or cry for no apparent reason or cannot control their laughing or crying; this is called **pseudobulbar affect** or **pathological laughing and weeping**. The crying can be distinguished from sadness or depression because the person does not feel particularly unhappy and cannot explain the tears. Similarly, the laughter is not associated with joy or merriment and cannot be explained or controlled. Pathological laughing and weeping can be treated with amitriptyline or levodopa.
- ◆ **Euphoria** is the term used to describe people who appear cheerful and unconcerned in the face of significant disability and disruption of their lives. Whether a problem of emotional expression or cognition, this inability to recognize and accurately appreciate their situation can be disconcerting for caregivers and family members. Typically associated with longstanding disease, severe disability, and cognitive impairment, euphoria has no known treatment.
- ◆ High dose steroids can induce manic and hypomanic reactions, particularly in people with histories of depression and family histories of depression and alcoholism. Manic episodes are characterized by grandiosity and excessive cheerfulness or irritability, decreased sleep, rapid and pressured speech, hyperactivity, distractibility, impaired insight and judgment, and inappropriate and risky activities such as spending sprees and sexual promiscuity. Less intense and prolonged episodes are considered hypomania.

### 6. At what point is it appropriate to involve family members in these discussions?

- ◆ When discussing MS symptoms, course, and prognosis with family members, it is important to include a discussion of possible emotional changes. Family members can help patients identify symptoms of depression and other emotional disturbances so that treatment can be initiated as soon as possible.
- ◆ Be alert to possible depression in family members, whether during office visits or by report from your patients. Marital discord may be a sign of depression in a spouse, as might withdrawal, irritability, or dramatic changes in lifestyle. Family caregivers of disabled persons with MS are particularly prone to depression. Children also can

become depressed, typically manifesting their difficulties by failure at school, social isolation, or disruptive, oppositional, or angry behavior at home.

- ◆ When caregivers have no relief from their burdens or when they are ill-equipped to provide care because they are too young or too old or lack adequate resources, they can become overwhelmed and fail to provide appropriate medical and personal care. Some people with MS are victims of frank abuse by their caregivers, suffering from serious neglect and physical and sexual assault.

### 7. How do I assess my patients' emotional state?

- ◆ Some patients will communicate their emotional difficulties clearly by:
  - ◆ Telling you they are depressed and asking for help
  - ◆ Appearing so sad and disconsolate that the problem is apparent to everyone
  - ◆ Functioning poorly at work or at home, with depression being the most obvious explanation
- ◆ Some patients feel too ashamed to admit that they are depressed, are unaware of what to call the distress they feel, or “medicate” themselves with alcohol or drugs. Many of these individuals are very adept at disguising their symptoms.
  - ◆ To identify these patients, inquire routinely about current mood, sleep, appetite, energy level, and substance use.
- ◆ To identify patients at risk for depression, ask about past history (*Have there been any times in the past when, for two weeks or more, you felt down, blue, discouraged, or disinterested?*) and family history (*Has anyone in your family ever had trouble with depression or alcohol?*).
- ◆ If you have any concern about depression, assess the patient's view of the future (*How do you think things are going? What sorts of things do you worry about?*) and try to determine whether the patient is suicidal (*Do you ever feel life is not worth living? Have you had thoughts about harming yourself?*).
  - ◆ If the patient has suicidal thoughts, determine whether he or she has a plan, a serious intent, and access to lethal means (*What do you think about doing? How would you do it? How likely are you to do it?*).
- ◆ Inquire periodically about neglect and abuse.
  - ◆ *Is there any kind of care you need but are not receiving?*
  - ◆ *Do you ever feel unsafe or threatened?*
  - ◆ *Does anyone ever speak to you in a hurtful or frightening way?*

### 8. How do I ensure appropriate treatment for my patients and their family members?

- ◆ While some primary care physicians and neurologists want and are able to treat the emotional disorders associated with MS, most prefer to refer their patients to a mental health professional. Psychiatrists, psychologists, social workers, and psychiatric nurses all work with patients and families in psychotherapy; only psychiatrists (and nurses in some states) can prescribe medication.
- ◆ Patients who are reluctant to seek treatment from a mental health professional may be willing to accept help from their primary care physician or neurologist. These physicians can obtain consultation and guidance from psychiatrists about appropriate medications, doses, and target symptoms, and from them or other mental health professionals about useful ways to talk with the patient about his or her concerns.
- ◆ More commonly, patients are willing to follow through on a referral if their medical caregiver explains the reasons for the referral (e.g., special expertise in the kinds of difficulties the patient is experiencing) and provides encouragement and support. Ongoing communication between medical and psychiatric caregivers is important to the patient's follow-through with treatment.

### 9. What other types of resources are available to help my patients with emotional changes?

- ◆ Chapters of the National Multiple Sclerosis Society (1-800-FIGHT-MS) can provide physicians with names of mental health professionals in the community who are experienced with treating the emotional disturbances associated with MS. The chapters also offer educational programs, support groups, and other resources to support patients' coping efforts and help them deal with MS-related emotional 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 from their local chapter (1-800-FIGHT-MS) or in the Library section of the website at [www.nationalmssociety.org/Brochures](http://www.nationalmssociety.org/Brochures):
  - ◆ *A Guide for Caregivers*
  - ◆ *Multiple Sclerosis and Your Emotions*
  - ◆ *MS and the Mind*

- ◆ *Taming Stress in Multiple Sclerosis*
- ◆ *Fatigue: What You Should Know*
- ◆ *PLAINTALK: A Booklet about MS for Families*
- ◆ Recommended websites:
  - ◆ National MS Society ([www.nationalmssociety.org](http://www.nationalmssociety.org))—offers information on a variety of topics relating to life with MS
    - ◆ Web Spotlight on Emotional Aspects of MS (<http://www.nationalmssociety.org/Emotions>)
  - ◆ MS World ([www.msworld.org](http://www.msworld.org))—on-line information and support for people with MS, including chat rooms and bulletin boards
- ◆ Clinical Trials
  - ◆ CenterWatch Clinical Trials Listing Service™ <http://www.centerwatch.com/>
  - ◆ National Institutes of Health (NIH) Clinical Trials Listing Service <http://www.ClinicalTrials.gov>
- ◆ Recommended readings:
  - ◆ Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (3rd ed.). New York: Demos Medical Publishing, 2004.
    - ◆ Ch. 10: Kalb R, Miller D. *Psychosocial Issues*
    - ◆ Ch. 11: LaRocca N. *Stress and Emotional Issues*
  - ◆ 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. 2: LaRocca N. *Emotional and Cognitive Issues*
    - ◆ Ch. 6: Crawford P, Miller D. *Parenting Issues*
    - ◆ Ch. 7: Miller D, Crawford P. *The Caregiving Relationship*
  - ◆ Pitzele S. *We Are Not Alone: Learning to Live with Chronic Illness*. New York: Workman Press, 1986.
  - ◆ Minden S. *Pseudobulbar Affect (Uncontrollable Laughing and/or Crying)* (<http://www.nationalmssociety.org/pdf/forpros/Pseudobulbar.pdf>).

**Sarah Minden, MD** is Assistant Professor of Psychiatry at Harvard Medical School, a member of the Department of Psychiatry at the Brigham and Women's Hospital, Boston, and Senior Scientist at Abt Associates, Inc. For over 20 years, Dr. Minden has worked with MS patients and their families to help them adjust to and cope with the challenges of living with MS, and to identify and treat depression and other emotional disorders. Dr. Minden is Principal Investigator of the National Multiple Sclerosis Society's Sonya Slifka Longitudinal Multiple Sclerosis Study that will provide important information on the course of MS, genetic and immunologic parameters, access to and use of health services, cost and outcomes of treatment, and quality of life. Dr. Minden has also conducted research on people with MS who are Medicare beneficiaries, on the psychological and cognitive aspects of MS, psychiatric reactions to ACTH and prednisone, and abuse and neglect of people with MS. Dr. Minden is also involved in research in mental health, including the psychological impact of medical illness, and policy development for delivery of mental health services and dissemination of information.

**Rosalind Kalb, PhD (Series Editor)** is Director of the Professional Resource Center at the National Multiple Sclerosis Society in New York City, developing and providing educational materials and services for healthcare professionals. As a clinical psychologist in private practice, Dr. Kalb has provided individual and family therapy for people with MS and their families for more than 25 years. She has authored or edited a number of publications about multiple sclerosis. She wrote *Families Affected by Multiple Sclerosis: Disease Impacts and Coping Strategies*, a monograph published in 1995 by the National MS Society, and is senior author of the *Knowledge Is Power* series for individuals newly diagnosed with MS. Dr. Kalb has edited two books—*Multiple Sclerosis: The Questions You Have; The Answers You Need* (3rd ed.), published in 2004, and *Multiple Sclerosis: A Guide for Families* (3rd ed.), published in 2005.

## Talking with Your MS Patients about Difficult Topics

This series is made available to you by The Professional Resource Center (PRC) of the National Multiple Sclerosis Society. The 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](mailto:MD_info@nmss.org). Allied health professionals are invited to consult via email with MS specialist colleagues at [healthprof\\_info@nmss.org](mailto:healthprof_info@nmss.org).

### Other booklets in this series:

#### **Communicating the Diagnosis of Multiple Sclerosis**

Barbara Giesser, PhD

#### **Talking about Progressive Disease**

Aaron Miller, MD

#### **Talking about Elimination Problems**

Nancy Holland, EdD

#### **Talking about Sexual Dysfunction**

Frederick Foley, PhD

#### **Talking about Cognitive Dysfunction**

Nicholas LaRocca, PhD

