



**National
Multiple Sclerosis
Society**

733 Third Avenue
New York, NY 10017-3288

Clinical Bulletin

Information for Health Professionals

Emotional Issues of the Person with MS

by Linda Samuel, MSW and Pamela Cavallo, MSW

Adapted with permission from Samuel L, Cavallo P. Emotional issues. In van den Noort S, Holland N (eds): *Multiple Sclerosis in Clinical Practice*. New York: Demos Medical Publishing, 1999.

The diagnosis of multiple sclerosis is frightening news that provokes a variety of emotional responses. While no two responses are alike, a number of emotional issues are commonly shared among persons who are diagnosed and living with MS. An understanding of these concerns can be of tremendous benefit to health care providers who strive to offer comforting and comprehensive care to persons with MS

What is the most common initial emotional reaction?

As in other medical conditions, physicians and nurses have tremendous influence over how a person perceives the diagnosis of MS, and a positive, hopeful approach whenever possible is ideal. However, most patients will hear only the words, "You have multiple sclerosis," and remember little about treatment options, symptom management, long-term planning, and other issues. Patients and family members should be encouraged to take notes and to prepare questions for their next meeting with the physician or nurse.

Patients should be immediately referred to their local chapter of the National MS Society, which can send the newly diagnosed patient the appropriate educational materials. A mail program called "Knowledge is Power" allows patients to learn about their illness at their own pace and to share this information with family members. The National MS Society also offers regular meetings for newly diagnosed patients and family members. It is important that patients be aware of the options for learning more about MS and for finding support from others.

What are the common reactions after the shock of the initial diagnosis wears off?

A diagnosis of MS is experienced as a loss by most people, who proceed through fairly typical stages of grieving. There is a period of denial, followed by anger and frustration, then often a re-emergence of denial that is well supported by a disease whose symptoms remit for long periods of time. Denial

can be protective and adaptive, allowing people to function in the face of potentially overwhelming fear and anxiety. Gradually, most people come to terms with the diagnosis and proceed with their lives in a healthy way.

Patients need reassurance that the feeling of grief is normal, and that anger, sadness and depression will eventually subside. Again, the National MS Society can offer support for patients dealing with these emotions. By interacting with other persons who are coping well and leading satisfying lives, newly diagnosed patients are enormously reassured.

What is MS like for family members?

MS is a “family affair,” since the diagnosis can greatly affect employment, caregiving needs, self-perception, and the roles that others play within the family. Family members experience reactions very similar to the person with MS: grief, fear, sadness, anger, guilt and frustration (often with the medical establishment). Family members frequently embark on gathering medical information and may encourage the patient to seek out other physicians. The National MS Society is an important resource in helping families to adjust.

Is depression common in MS?

Because of the uncertainty over the future and the feelings of loss, as well as neurologic changes caused by the disease itself, depression is very common among persons with MS. At least 50 percent will experience a major depressive episode at some point over the disease course. Fatigue—which can be an outgrowth of depression or occur as a primary symptom—frequently compounds depression in persons with MS. The health care provider should suspect a clinical depression if at least five of the following symptoms are present for at least 2 weeks:

- ◆ Depressed mood, feelings of hopelessness and despair
- ◆ Markedly diminished interest or pleasure in most activities
- ◆ Changes in appetite and significant weight loss or gain
- ◆ Insomnia or hypersomnia
- ◆ Feelings of excessive restlessness or sluggishness
- ◆ Fatigue or loss of energy
- ◆ Feelings of worthlessness or excessive or inappropriate guilt
- ◆ Diminished ability to think or concentrate, or indecisiveness
- ◆ Recurrent thoughts of death or suicidal ideations

Intervention with psychotherapy and/or antidepressants is usually effective. The passage of time also helps many people. Physicians are quite influential in seeing that patients receive help. A few people with MS experience global changes in personality, cognition or outlook on life that seem to be disease-related. At that point, help should be directed toward helping family members adjust to the changes in their loved ones.

What distinguishes individuals who cope well with MS?

Certain characteristics seem universal among the people who learn to cope well with MS. The more of these factors that are present in one's life, the better a person will handle MS over a lifetime:

- ◆ Support: People who reach out for help report feeling strengthened and encouraged.
- ◆ Connectedness: A positive sense of well-being and protection from isolation comes from feeling connected to others.
- ◆ Sense of humor: While there is nothing funny about MS, much of life is humorous, and laughter is a healing force that promotes a positive outlook and feelings of hope.
- ◆ Spirituality: Having a spiritual sense about one's life fosters other positive traits, such as connectedness to others, positive self-perception, and optimism about one's future.
- ◆ Openness: A willingness to talk openly about MS and its challenges is conducive to positive coping. Families who talk about MS are better able to live effectively with MS.

Is suicide a concern in MS?

Although most persons with MS are remarkably resilient, some lose the desire to live. The National MS Society has supported two national studies on the risk of suicide in the MS population. These studies concluded that level of disability is not the key predictor of suicide risk, since many patients report feelings of satisfaction in spite of having chronic progressive disease. Rather, suicide risk is more related to a lack of connectedness with other people, and a negative self-perception of one's self, body, and future. The vast majority of people who cope well with MS are those who have a good emotional support network, maintain contact with the National MS Society, and have adequate financial resources (Berman AL, Samuel L. Suicide among people with multiple sclerosis. *J Neuro Rehab* 1993; 7(2):53–61).

What does the National MS Society offer for people with MS and their families?

The mission of the National MS Society is to end the devastating effects of MS. Through its national office and local chapters, the Society meets a variety of needs among the MS population. Educational programs, literature, support groups, and medical equipment-loan programs are a few of the services offered by the Society. In addition to these direct services, chapters are aware of existing community resources and the network of support available to persons with MS and their families.

Physicians who refer their patients to the National MS Society can be confident that Society staff will be sensitive to all aspects of the disease and will be deeply committed to providing all possible assistance.

This publication is supported by an unrestricted educational grant from Biogen.

Special thanks to Caroline Helwick for her contribution to this publication.