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Coping with Multiple Sclerosis

BEING DIAGNOSED WITH MULTIPLE SCLEROSIS (MS) CAN CREATE turmoil in every area of a person's life. In some ways, life will never be quite the same again. Even in the absence of impairment, the worry—or effort to camouflage worry—is always there. The diagnosis often precipitates a roller coaster ride of emotions, including fear, optimism, despair, and hope. The time following diagnosis can be challenging and confusing. This chapter will help you to bring perspective to the emotional turmoil and help you think about ways to ease the distress and continue with your life.

The Crisis of Diagnosis

People have a variety of reactions to hearing the diagnosis of MS for the first time. Some experience a combination of fear and panic when first confronted with the news. These feelings may quickly be replaced by denial, a refusal to believe that this could possibly be happening. "There must be some mistake!" is an almost universal reaction to the diagnosis, often followed quickly by feelings of anger and resentment. Lisa's story provides an example of some of these feelings. When asked about her initial experience with MS and the diagnosis, she replied:

> *I was having a multitude of symptoms that I didn't understand, such as tingling and numbness in my hands and arms and legs. I was having trouble feeling the ground when I was walking. I couldn't see very well out of my left eye—it was almost like looking through an oily film. A whole bunch of odd things were happening that I didn't understand. When I finally got the diagnosis, I was really scared. I didn't know what MS was or what would happen to me. I was afraid of the whole thing.*
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> *Later I was angry—very angry. Then I decided there was no way I could really have this disease. In fact, I was second-guessing the doctors—going from one to another asking what was wrong with me. All I could think of was that can in the grocery store that you throw your loose change into—you know, the one with the picture of someone in a wheelchair. It was probably a good year before I even started to accept the fact that I have MS. There was no way I could have it—I'm too active and I do so many things. And I can't stop doing them.*

The diagnosis actually brings a sense of relief for some people, especially those who were beginning to wonder if they were "going crazy" or if the symptoms were "all in their head." These fears are sometimes reinforced by physicians who, in the absence of clear physical abnormalities, believe that emotional problems may be causing imaginary or exaggerated symptoms. A small study by Loveland (National MS Society, Health Services Research Report, 1993) found that women presenting with early symptoms of MS were significantly more likely than men to get this type of response from their doctors and that men's descriptions of physical symptoms generally were given more credence by their physicians.

Relief is also experienced by those who imagined a more distressing, or perhaps fatal, explanation for their symptoms, such as cancer. Freed from the fears of a malignant tumor, they feel confident that the symptoms they are experiencing can be successfully managed.

Jim, who was diagnosed with MS in 1988 after a long and frustrating search for some answers, spoke about fear and relief at finally learning his diagnosis:

> *It took me four years to get a diagnosis. I was scared to death when I heard "MS." I didn't even know what MS was. But I was also relieved. When you're used to not having a label for all the strange things that are*

> *going on and suddenly the problem is identified for you, that alone is a relief—all this finally has a name.*

Regardless of the initial emotional response, the diagnosis of MS creates a crisis for the individual and the entire family. The person who has been diagnosed may experience a sense of isolation, despite efforts of family members to offer support. Lisa mentioned this experience:

> *Even though people wanted to help, I was the one who had to learn to live with it and had to learn what I needed to do to live with it. You have to make your choice of how you're going to live your life. You have to do it because it's your disease and nobody can do it for you or make it go away.*

Family members are also immersed in their own concerns about the future and the impact that MS will have on their lives. The positive aspect of this type of crisis is that it provides an opportunity to assess future plans and a powerful motivation to take actions that support those plans. There is an opportunity to affirm the values and strengths of the individual and the family and all the good things that remain intact in spite of MS. In order to go forward, it is important to know that you can successfully move through the difficult emotions and continue to pursue your goals and dreams. A professional counselor—psychologist or social worker—can be a helpful ally to the person with MS and family members in working toward a positive outlook for the future.

The Adjustment Process

The initial variable reactions to the diagnosis of MS inevitably give way to a feeling of deep sadness. This is related to the addition of a serious chronic illness to one's identity and self-image. Chronic illness forces each person to confront the frailty and vulnerability of the human condition in a personal and immediate way. One also faces the painful reality of society's negative attitudes about disease and disability. This process involves grieving for one's former self-image and integrating the realities of MS into one's identity. Sadness, anger at the disease, and self-absorption are experienced during this time.

Grieving is necessary for a person to move forward, just as it is following the loss of a loved one. Unlike the grieving we associate with death, the grieving process in chronic illness tends to ebb and flow with the symptoms and physical changes that occur over time. Grief may be postponed, but it can never be totally avoided. Sometimes these feelings may be channeled inappropriately, such as anger at one's spouse or children or at health professionals who cannot cure the illness. It is important for everyone involved to understand this grieving process and to communicate their care and support.

The period of intense grieving may last from a few weeks to several months, with gradually diminishing intensity. As it subsides, at least for the time being, one can again begin to focus on and enjoy special relationships and daily activities. Ideally, there is a gradual acknowledgment of the permanence of MS in one's life, while maintaining a sense of continuity between the past and the future as well as a commitment to maximizing quality of life.

Depressive feelings are to be expected as part of the initial grieving process or in response to subsequent changes or losses imposed by the illness. Over the course of the disease, however, individuals with MS are at greater than average risk for depression. They need to be able to recognize when some kind of treatment intervention would be beneficial. Symptoms of significant depression include ongoing and pervasive sadness, loss of interest in or enjoyment of important activities and relationships, feelings of hopelessness and despair, sometimes including suicidal feelings or thoughts, and changes in sleeping and eating patterns. Intervention is recommended if any of these symptoms continue for an extended period of time or seem to be worsening. It is important to realize that relief from depression is readily available. Counseling and/or antidepressant medication are successful in relieving its symptoms. Seeking help for this problem demonstrates an understanding of its significance, not personal weakness or deficiency.

Jim comments on his experience with depression:

> *I was pretty depressed, so I went to see a psychologist. She was connected with a rehabilitation facility, so her primary interest was working with people who are chronically ill or disabled to help them find comfortable ways of living and thinking about themselves. It was a perfect match because that's just what I needed at that point.*

One hallmark of MS that must be addressed as part of the adjustment process in its "unpredictability." When several focus groups were held by the National MS Society to identify what aspects of the disease people found most troubling and challenging, the resounding answer was the unpredictability of the disease course and the uncertainties related to future ability/disability. What symptoms and impairments might occur, when would new symptoms appear, when would they go away, or would they go away? Amy, who was diagnosed eight years ago, addressed this issue:

> *I think not knowing what will happen is the hardest thing for people when they're diagnosed with MS. They totally freak out and wonder 'what's this disease going to do to me?' They have to realize that what happens to someone else is not necessarily going to happen to them. And if it does, well, you will have to deal with it.*

Flexibility is a key element in living with the unpredictability of MS. Goals need to be assessed and revised, with a "plan for the worst, hope for the best" outlook. A college student named Leslie was pursuing a career in horticulture, which necessitated spending a fair amount of time in greenhouses. Her early symptoms included heat sensitivity, with temporary blurred vision and extreme fatigue when she was exposed to warm temperatures. Although this problem remitted, any future recurrence would have prevented Leslie from performing her job. After careful thought, she switched to teaching, an occupation that heat sensitivity or most other possible MS symptoms would not prevent her from continuing. Similarly, the purchase of a new home should involve consideration of issues of mobility and accessibility. Many people with MS are not significantly bothered by problems with walking. However, since mobility impairment is a problem at some point for a fair number of people with MS, it is simply good planning to consider this possibility when choosing a home, even while being reasonably optimistic that serious walking difficulties will not occur.

Coping Strategies

Coping strategies reflect an individual's personality and usual style of interfacing with people and events. By adulthood, strategies have been selected and refined through an unconscious process; most of us do not consciously choose and evaluate our coping mechanisms. However, it becomes important to look at those coping styles critically so that they can be boosted when necessary and modified or discarded when they are counterproductive. The following are examples of two types of strategies.

Denial is ignoring or minimizing the seriousness of the situation. We all engage in denial about the moment-to-moment possibility of accidental death. Intermittent denial may be useful in the early stages of adapting to MS because it enables people to deal with the immediate symptoms they are experiencing without having to contemplate all the possible problems that may occur in the future. Denial is *not* useful if these potential problems are ignored when making important life planning decisions such as purchasing disability insurance, buying a home or an automobile, or making career decisions. One of the most serious consequences of continued denial is avoidance of disease-modifying therapy. The availability of interventions that can have a favorable impact on the disease course for many people with MS is a very positive factor supporting hope for the future.

Denial can also interfere with obtaining optimal health care. Yes, a bladder infection may indicate underlying MS pathology and should be evaluated in light of that possibility. The numbness and tingling in your fingers may not be carpal tunnel syndrome, commonly associated with extensive computer use. Acknowledgment of your symptoms and paying proper attention to them will ensure that the physicians involved in your health care will provide you with the treatments you need and will not perform surgeries (e.g., for carpal tunnel syndrome or herniated disks) or prescribe treatments that are unnecessary or even harmful.

Intellectualization is focusing on available factual information to the exclusion of feelings and other psychological issues. A certain amount of intellectualization makes it possible for people to learn about the disease, assess its impact on their daily lives, and make use of their problem-solving abilities to meet the challenges imposed by MS. Intellectualization becomes excessive when it consumes enormous amounts of energy; some people expend so much effort collecting and analyzing information that they have little or no energy left to deal with their emotional reactions to the disease or with the feelings and reactions of those around them.

Looking at these two examples, the strengths and weaknesses inherent in some coping strategies can be seen. Denial is useful in allowing a person to get on with his or her life, but it is detrimental if it interferes with obtaining optimal treatment or with life planning issues. Intellectualization is useful in obtaining essential information, but it is harmful when it is used as a means to block feelings about the disease that should be expressed. The blocking of emotional awareness and expression can interfere with long-range coping efforts.

Interpersonal difficulties may arise when two people who live together and must cope with MS have conflicting coping styles. A person who copes by talking through feelings and events or by reading all the literature on MS may encounter resistance and even anger from a partner who is trying desperately to maintain denial as a way of dealing with the disease. In some situations, counseling is useful to help a couple recognize each other's coping styles and provide mutual support. An excellent resource on this topic is *Multiple Sclerosis: A Guide for Families* (see "Additional Readings").

Education About Multiple Sclerosis

While some individuals are more inclined than others to seek information about something that is stressful to them, one of the most effective things a person with MS or a family member can do to facilitate adjustment to MS is to learn about the disease—what to expect and what can be done to relieve physical symptoms and promote psychological health. People with MS have indicated in National MS Society surveys that information about the disease and its effects is their most important need. Education about MS is available through a number of sources, primarily MS health care providers and the U.S., Canadian, and other national MS Societies (see Chapter 9).

Keep in mind, however, that adults can choose to learn in a variety of ways and may choose to do so in different settings or at different times. For some, devouring every available piece of written material is the most desirable strategy. These individuals compare different sources of information, analyzing and sorting varied opinions, to create a personal perspective. The result is a sense of "ownership" over the information and its gradual integration into personal philosophy and decisions about day-to-day activities. Other people prefer a group setting that provides opportunities for the immediate testing of new ideas and feedback from peers and/or professionals.

Such group educational programs are widely available through the U.S., Canadian and other national MS Societies. The National MS Society in the United States has a mail program, called "Knowledge Is Power" for people who have been recently diagnosed with MS. The program consists of a series of modules on topics of interest sent on a predetermined schedule to people who request this service. This mail series can be obtained by calling 1-800-FIGHT-MS.

Another component of the educational process relates to reports of possible treatments or "the cure" for MS. Given the variability and unpredictability of the illness over time, it is not surprising that diverse therapies have been heralded as having a significant impact on MS. When symptoms remit—as they frequently do quite naturally over the course of the disease—whatever treatment or activity is being used at the time is given credit for the improvement. Since dramatic improvement and long periods of remission are common occurrences in MS, even without any therapy, it is important to be prudently skeptical when evaluating therapies that claim to benefit people with MS. Only those treatments that have been evaluated for safety and efficacy in carefully designed and controlled scientific studies provide documentation of benefit. Other therapies, generally outside the usual medical interventions and called "complementary" or "alternative" therapies, should also be carefully evaluated. Some of these claim a boost to the immune system and are not appropriate for people with MS, who already have an overly active immune system. Any non–physician-prescribed therapy that claims to reduce MS disease activity or any therapy that claims to cure MS should be avoided. *Alternative Medicine and Multiple Sclerosis* is a comprehensive guide to this topic (see "Additional Readings").

Choice of Health Care Providers

The choice of health care providers is a critical decision relative to long-term management issues. People with MS generally have a normal life expectancy, and management of the disease is a lifelong process. The physician who manages the symptoms and disease course will interact with the other physicians involved in your health care, such as your internist, gynecologist/obstetrician, cardiologist, or any other medical specialist whose services you might require during your lifetime. Members of your chosen health care team will also provide you on an ongoing basis with information that you will need to make important life decisions relating, for example, to job choices, family planning, or the selection of an MS treatment option. Choose your health care providers carefully. Investigate your physician's board certification (neurology, family practice, or internal medicine), experience with MS, hospital or medical center affiliation, and reputation in the community. In most cases, you will need to have a relationship with an internist or family physician to monitor your general health and a neurologist to manage your MS. The local chapter (United States) or division (Canada) of the MS Society, as well as other national MS societies, can suggest several physicians in any given community who have experience in the management of MS, as well as MS specialists in certain geographic locations.

Support Networks

Family and friends provide the major support for the person who has MS. Their caring and concern are vital, especially during the difficult times following diagnosis or when a flare-up of symptoms occurs. A "sorting out" of friends and relatives may be necessary because not all people with a close relationship are able to be supportive in the same way. One person may be comfortable listening to concerns and providing emotional support, while another may find it easier to assist with more concrete activities, such as a ride to the doctor's office. Another friend or relative may be a great problem solver, helpful in finding solutions or identifying resources in troublesome situations. At the same time, a person's ability to help should not be too narrowly or rigidly determined, especially without discussing it with him or her. It is important for all those who provide support to know how important their contributions are to the person with MS.

People with MS may find it especially helpful to talk with other people who have the disease. This interaction helps to demonstrate that people with MS do indeed continue productive and satisfying lives despite the intrusion of the disease. A physician or other health care provider may be able to provide the name and phone number of someone who is willing, even eager, to talk about his or her personal experiences with MS.

Many chapters of the National MS Society have "peer counseling" programs that train selected individuals with MS to be helpful to people who have questions about the disease. They are available to answer questions, discuss issues, and relate their personal MS successes and failures. In some areas, the peer counselor is available for a telephone conversation; in other areas, the counselor may also be available at local MS center (medical) sessions. Amy commented on her experience with a peer counselor:

> *Having that one-on-one interaction, having someone to talk to who understands, who has gone through similar experiences—that was really important to me. She was a source of strength and kept helping my self-image to stay in shape.*

Some people find a group setting most helpful because they can benefit from the experiences of a number of people with MS. Group members also feel good about the group interaction and support, which is much like a family support network. In an MS support group, MS temporarily feels "normal" because it is the common experience of all members. This normalization of MS is extremely supportive of the overall adjustment process. Instead of feeling isolated, the person in a support group sees MS as one component of a full and diverse life, which can be managed with an understanding of the disease, support of family, friends, health professionals, and peers with MS. Some support groups are led by a counseling professional, such as a psychologist or social worker, while others are "self-help" and are led by one of the group members.

Disclosure

Disclosure about one's illness—whether to family members and friends, new acquaintances, or employers and colleagues—is a significant issue for most people living with MS. Many people are uncertain how much information they want or need to disclose, especially because there often is no visible impairment and some of the symptoms caused by the illness can easily be attributed to a less serious cause. Considerations about disclosure at the workplace are discussed in Chapter 9.

The first and most important group or people to consider are your family members. They are the easiest to make recommendations about, but sometimes the most difficult group to tell. Close family members need to know about your MS—what to expect and what they can do to help. In general, parents, siblings, and other close adult relatives should be told calmly and directly about the diagnosis. They need to begin learning what MS is and what is known about your prognosis and limitations.

Children also should be told about the diagnosis. Even very young children are aware when something is wrong and tend to imagine the worst possible scenario. They need to be given some concrete information about the disease that they can relate to and understand (e.g., that Mommy will be extra tired sometimes, may have trouble walking, or will need to hurry to the toilet). They also need to be reassured that Mommy is not going to die and that she will be able to take care of them. Children need to know that, although the parent may not be able to be as physically active as before, the family will work together to solve any problems that arise. Parents should also explain that no one can "catch" MS the way a cold can be caught from another person, that the children did not cause the MS, and that they have no control over making it better or worse. Parents tend to underestimate the impact of MS on their children; they are at least as affected by their parents' emotional state and the emotional climate within the household as they are by any physical limitations imposed by illness. *Multiple Sclerosis: A Guide for Families* provides a comprehensive discussion of this topic (see "Additional Readings").

What to tell friends and acquaintances may need to be determined on a case-by-case basis. How much you choose to tell will depend very much on the relationship you have with another person. Informing your friends will allow them to provide the emotional support you need and will relieve you of energy-consuming efforts to conceal the problem.

Disclosure also is an issue for people who are dating. When is the best time to tell, and how much should be revealed? As with other questions about MS, no single answer suits every individual or situation. In general, you have no obligation to talk about your MS before extending or accepting an invitation for a date. Nor should you feel any need to discuss MS before you have decided whether you like a person. Once you have decided that a relationship is worth pursuing, the following guidelines may be helpful:

- Remember that secrets and half-truths do not make a firm foundation for a healthy relationship.
- Think about when you would like to know important health-related information about the other person.
- Keep in mind that revealing your MS may become increasingly difficult as your investment in the relationship increases.

Wellness Orientation

In contrast to a *disease orientation*, which focuses on minimizing the impact of the chronic disease on all aspects of your life, a *wellness approach* looks at achieving the positive state of maximal health despite the presence of a chronic illness. Jones and Kilpatrick, in the *Families in Society Journal* (May 1996), propose a definition of wellness as the state of harmony, energy, positive productivity, and well-being in an individual's mind, body, emotions, and spirit. This model encompasses interpersonal relationships as well as relationships with the environment, the community, and society in general. The wellness orientation is comprehensive in its promotion of mind-body unity within the individual, as well as integration of the individual within the community and society as a whole.

A practical example of a wellness orientation is the practice of aerobic and general conditioning exercises, which have an orientation different from that of traditional physical therapy designed primarily to address disease-imposed impairments. Nutritional programs designed for general health (e.g., the prevention of heart disease and certain forms of cancer) go beyond traditional dietary measures that target specific MS-related problems such as constipation and urinary infections. Resources in this area include *Living with Multiple Sclerosis: A Wellness Approach* and *Alternative Medicine and Multiple Sclerosis* (see "Addditional Readings").

Practices such as yoga, meditation, and Tai Chi also fall within the wellness concept and are sometimes categorized as "complementary therapies" that work along with—rather than against or in place of—traditional medical therapy. The term *complementary therapy* is new and not clearly defined, with the result that certain nonmedical therapies are considered unproven, speculative, or even dangerous by the medical community. However, there is growing support by medical professionals for a wellness orientation and for selected aspects of complementary therapies. It is hoped that this shift in attitude will lead to more controlled studies of the risks and benefits of some of these therapies. Lisa again comments on her experiences, focusing on wellness behaviors:

> *I learned to watch fats and learned more about what I should eat. Now when I finish school, I usually go straight to the swimming pool and exercise for 30 to 40 minutes.*

In following a wellness approach, it is important to remember that one cannot directly impact the disease process through health-promoting behaviors. People must recognize that their control over MS is limited and that the disease may become active in spite of the health practices they have initiated. People should feel good about the wellness activities they pursue in order to enhance their general health and well-being, but they should not feel guilty or blame themselves when a relapse occurs. Although a wellness approach cannot control the unpredictable nature of MS, it *can* enable you to improve your health and devise creative ways to continue activities that are satisfying and enjoyable.

Similarly, people often believe that they can control their MS if they simply try hard enough to "fight" it. Those who engage in this kind of thinking tend to experience a sense of failure when the disease worsens. Assuming this kind of personal responsibility for disease progression is both harmful and self-defeating. Your energy—emotional and otherwise—is better channeled into pursuing wellness, always recognizing that the goal is an overall improvement in general health rather than control of the disease process.

Individuals who struggle to control their MS sometimes feel that they are losing the battle or "giving up" if they begin to use an assistive device. These devices actually extend your abilities by conserving energy, promoting safety, and reducing effort. For example, those who fatigue easily or struggle to be ambulatory with a cane or crutches will find that their activities become severely limited. All their energy is used simply to get from one place to another, leaving little or no effort to do or enjoy whatever activity had been planned. Struggling to get to the supermarket may mean that there is no energy left to shop. People with MS should use whatever techniques, tools, or devices are available to maximize and extend their activities and opportunities. Someone who is comfortable walking for short distances may choose to use a motorized scooter on a trip to an amusement park, shopping mall, or museum. A worker in a large office who normally uses a cane might also choose to use a scooter to conserve energy and enhance productivity. The effective use of assistive devices is an important extension of the wellness philosophy. These tools should be seen as a means of maintaining a full, productive, and enjoyable life rather than as a symbol of defeat.

Parting Thoughts

Lisa relates her personal philosophy:

> *If I had never had MS, I would never have traveled the way I did. I took a year off after I was diagnosed and traveled all around Europe. I decided I was going to do things while I could because I didn't know when something might be taken away from me. And I think one thing I've learned from MS is to do things while I can. It's a lesson for everyone. We should all live each day to the fullest, because we never know when something might happen to take it away.*

Jim relates what gets him through:

> *I would say that I have a lot of support from my family and friends. That probably helped me through. I had quite a few conversations, talks,*

> *heart-to-heart discussions with different people and that helped me quite a bit. Also, I'm somewhat religious and that helped.*

Mary speaks about giving up denial:

> *I am not crazy. I have this disease, I have done nothing to deserve it and there is nothing I can do about having it. I just have to begin to take each day, one at a time, do my best and accept whatever comes. The sheer honesty of admitting that I have an illness is a great weight off my mind. I am more attentive to details in my life, and more willing to do what my body tells me to do, instead of fighting against it. I have found a new calm I had not known before.*

A religious or spiritual orientation has been linked with successful coping in a number of studies. It seems that religion helps some people find meaning in their illness or at least put it into a meaningful context. Amy also refers to spirituality, as well as her own personal characteristics, as a support:

> *Since I grew up in a single parent household, I always had to draw on my own resources. So I worked real hard on that—and on my own sense of spirituality. I just had to—I've always depended on myself. I've always demanded a lot from myself and I guess I just drew it from within.*

Amy refers to a key aspect of the coping process—a person's inner strengths. With an adult-onset disease, coping strategies have already been tested in other areas, creating a base on which to build. These strengths surface as the sense of crisis recedes. Amy has more advice for dealing with MS and with life in general.

> *Another thing is to laugh—to have a sense of humor. Don't take things so seriously. If you don't have a sense of humor, it's all for naught, you know. Life is too short. It can just really drag you down if you let it—you can't let that happen. Just try to take things one day at a time. One day at a time and "slow is fast enough," you don't really have to be in that much of a hurry. Take your time and take it easy and don't be afraid to ask for help.*