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When MS Joins the Family

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THE VAST MAJORITY of people who have multiple sclerosis (MS) are diagnosed between the ages of 20 and 50 years. The disease thus affects people in their most active years: young adults readying themselves to leave home in pursuit of academic, vocational, or social goals; men and women in the process of launching careers and families of their own; and those in middle age who are enjoying their productive years and planning for their retirements. In each of these age groups, the diagnosis of a chronic and unpredictable disease has significant impact, not only on the individual who receives the diagnosis of MS, but also on the family members and loved ones whose lives are interwoven with that person (see Chapters 6, 8, and 9).

What is it about MS that makes its impact on the family so great?

MS is a chronic disease

ALTHOUGH WE NOW have several treatments designed to modify the course of the disease, we still have no cure for MS. Since the illness has little impact on life expectancy, the person diag-

nosed with MS will likely be living and coping with its effects for many years. MS has often been compared to the “uninvited guest” who arrives at the door one day, complete with baggage, and never goes home. The guest moves into the household, using up space in every room of the house, and taking part in every family activity.

MS is unpredictable

NO ONE CAN predict with any certainty how a person with MS will fare several years down the road. While it causes severe or incapacitating disability for relatively few, it creates a bewildering question mark for all. Individuals with MS and their family members may have difficulty anticipating what the next day or week will bring, let alone the more distant future. As a result, the established rhythms of daily life can be severely disrupted as family members attempt to respond to the demands of the illness. Planning becomes difficult, creating an ongoing need for flexibility and creativity.

MS is unpredictable not only in the course it follows, but also in the kinds of symptoms it may cause. No two people have MS in exactly the same way. Since the disease can affect almost any system in the body, people feel vulnerable both physically and psychologically. In addition to the more visible symptoms (e.g., walking difficulties or imbalance), MS can cause less obvious symptoms (overwhelming fatigue, bladder and bowel problems, changes in sexual function, visual impairment, and sensory changes), as well as intellectual and emotional changes. “What’s next?” is the question commonly asked by individuals and families living with MS. Unfortunately, it is difficult to predict the answer.

MS is expensive

ILLNESS OF ANY kind can be expensive, and a chronic disease that appears during a person’s most productive years can have major financial consequences for the entire family. In addition to

this more obvious cost in dollars and cents, there is a significant drain on other family resources, including time, energy, and emotions. Families living with MS face the daily challenge of trying to distribute these valuable resources evenly among all family members. MS should not be allowed to sap any more of these resources than it absolutely needs; otherwise, the needs of other family members may go unmet (see Chapter 11).

Emotions

LIVING WITH MS poses an ongoing challenge to the emotional equilibrium of a family (see Chapter 2). Both the person who has MS and family members experience feelings of loss and grief with each new symptom and each change in functional ability. Each progression in the illness requires the entire family to adjust to the loss and redefine themselves accordingly. “Who am I now that I can no longer do some of those things that helped to define me as me?” “Who are we as a couple now that our partnership is being redefined by MS?” “Who are we as a family now that our roles have changed and our relationships to each other and to the community are changing?”

Along with grief comes anxiety over being unable to predict what the future will bring. While all people live with uncertainty, most are not so aware of it on a day-to-day basis. As adults, we tend to take for granted our ability to plan and look forward to events. Families living with MS sometimes feel overwhelmed with “what if’s.”

Anger can also become a part of life with MS. When uncertainty, change, and loss threaten the family’s sense of order and control, individual family members may feel increasing resentment—toward the MS, toward one another as gradual shifts occur in their roles and relationships, and even toward themselves for being unable to do the things they want or need to do.

The ebb and flow of these emotions can take a toll on even the most secure and stable families. Learning to recognize, communicate, and share these feelings with one another helps family members to cope with them more comfortably.

Energy

THE ENERGY DRAIN on families living with MS comes both from the effort required to do things differently and from the emotions that surround these adjustments. Families who have experienced changes in their daily routines because of MS say that “nothing is easy or automatic any more . . . everything takes so much effort.” Part of this effort involves finding alternative ways to get things done; part of it involves dealing with the feelings that each person has about having to incorporate these changes into daily life.

Time. MS tends to slow people down. The various physical and psychological symptoms of the disease interfere with the activities not only of the person who has the illness, but also of anyone in the household who shares those activities. Time is a valuable commodity for today’s busy families, and the need to slow the pace, postpone activities, or rearrange schedules can produce a new kind of stress for all concerned.

Challenges to Family Coping

FAMILIES EFFORTS TO cope with the intrusion of MS into their lives are challenged not only by the complexities of the disease, but also by the complexities of the families themselves. What is it about families that complicates the coping process?

Individual Needs and Coping Styles

THE FAMILY UNIT is made up of individuals, each with a unique personality and coping style, as well as age-appropriate needs and goals. Each person in the family will see the MS in a slightly different way, and respond to its demands in terms of the way it impacts his or her particular situation. Thus, the MS will mean something different to the husband with MS who can no longer handle his construction job, his wife who needs to take a job outside the home, his young daughter who relies on him to coach the soccer team, and his teenage son who suddenly finds himself with a host of new responsibilities around the house. Therefore,

the family's efforts to deal with the disease cannot be seen as a unified, coherent process, but rather as the sum total of individual, sometimes conflicting, coping efforts.

For example, a woman might respond to her diagnosis by wanting to read everything available about MS and its treatments, while her husband and children want to read and think about MS as little as possible. Or, a woman might feel the need to discuss her husband's MS with friends, relatives, and even acquaintances, while he desperately wants to keep it a secret. While each of these coping strategies might be perfectly valid, the difficulty arises from the fact that different members of the family may be trying to utilize them simultaneously.

Similarly, a child's need to know and understand what is happening to Dad may conflict with the family's wish for privacy. Not only do young children have trouble keeping secrets, but they are also unable to appreciate the potential impact of this kind of information on their father's employment or place within the community. As another example, the family's need to engage in effective financial planning may fly in the face of their need to deny the possibility of future disability. In other words, the family's response to the MS is not a simple one. At any given point in time, it is a reflection of the feelings, attitudes, needs, and priorities of each of the people involved.

Disruption Of The Family's Rhythm

OVER THE YEARS, families tend to develop a rhythm of their own—a reasonably smooth and predictable way of carrying out the routines of daily life. Each of the adults in the household has, by spoken or unspoken agreement, taken on certain important functions in the household. As they grow and develop, each of the children also takes on an increasing number of age-appropriate chores and responsibilities. If one person in the family becomes unable to carry out his or her particular role(s), the rhythm of the entire family is upset. Whether it is recognized at the time or not, this shift in roles begins to change the ways in which family members interact and communicate with one another. The disabled person may begin to feel “sidelined”—out

of the mainstream of family life. A spouse who needs to take on more and more of the responsibilities in the household may start to feel overburdened and deprived of the old partnership. Young children may gradually find themselves in a caregiver role that threatens their own feelings of security and well-being.

Disruption In Family Communication

TALKING ABOUT THESE kinds of changes within the family can be very difficult for a variety of reasons. First, these changes tend to happen slowly and therefore outside of most people's day-to-day awareness. Families do not talk about them at the time because they are not aware that the changes are occurring. Second, people often have difficulty talking about changes in family life that are caused by symptoms they cannot readily see or understand. A person who is experiencing MS-related cognitive changes or severe fatigue may find it difficult to describe to others how these symptoms are interfering with daily activities. Similarly, family members may become frustrated by their inability to see or understand why family life is not proceeding as smoothly as it once did. Third, family members tend to be quite protective of one another, with the result that painful feelings, questions, and concerns are often left unexpressed. No one wants to open a Pandora's box of stressful issues that have no apparent solutions. And fourth, people sometimes feel that "the less said, the better," as though talking about problems will confirm that they actually exist, and not talking about them will magically make them go away. The result of all this may be the "big, gray elephant" phenomenon. The entire family is tiptoeing around this big gray elephant in its midst and nobody quite knows how to mention it.

Important Resources and the Barriers to Their Use

FORTUNATELY, A VARIETY of resources exist to help families live comfortably and productively with chronic illness (see Chapter 13). Healthcare teams, voluntary health organizations, educational materials, and various types of professional and self-help groups are some of the tools available to support families' cop-

ing efforts. Unfortunately, there also seem to be significant barriers to the effective utilization of these resources.

Some of the barriers are social and economic while others are much more personal and emotional. Access to quality healthcare is not universal in this country, and access to professionals with expertise in MS is even more limited. Particularly in this new age of cost containment and managed care, individuals who have MS may feel a growing pressure to monitor and manage their own care (see Chapter 3).

Of even greater concern, however, is the fact that many people do not make use of important resources even when they are readily available. Many families refrain from seeking help because of reluctance to acknowledge the potential impact of MS on their lives, or to think about MS more than is absolutely necessary. They may be afraid that thinking about current or potential problems will somehow make the problems seem more real. Other families seem to feel that seeking outside help or support is an indication of their own weakness or inadequacy; they would rather “go it alone.” They do not recognize that these resources are the kinds of tools that might enable them to “go it alone” more effectively.

Recommended Strategies For Family Coping

THE FIRST IMPORTANT strategy of the family should be to give MS, or the “uninvited guest,” no more space in the household than it needs. As Dr. Peter Steinglass and his colleagues have so aptly phrased it, “The goal is to find a place for the illness while keeping the illness in its place.” A family can develop and thrive only when the emotional and developmental needs of each of its members are being met. The family’s balance is threatened when MS is allowed to drain more than its share of the family’s financial, emotional, and physical resources. Instead of a family with one disabled member, the result is a disabled family.

Similarly, it is important that the interests and activities of family members not be overly restricted by the disabilities of the person who has MS. In other words, families need to learn how to strike a reasonable balance between the interests and abilities of

their disabled and nondisabled members. When guilt feelings cause family members to give up favorite activities in which the person with MS can no longer participate, the entire family may start to feel uncomfortable; the person with MS begins to feel guilty over the limitations on other family members while they, in turn, begin to resent feeling “disabled” by a disease that is not their own. The goal is for families to find a way to accommodate the limitations imposed by MS without allowing those limitations to impact every aspect of family life.

The second recommended coping strategy is often a bit more difficult for families to accept, because it involves hoping for the best while planning for the worst that might occur (see Chapters 10 and 12). Planning for the worst involves learning about the possible ways that MS can affect your life and trying to implement plans or strategies now that would cushion the blow if the worst came to pass. For example, a young woman with MS and her husband are starting to look for their first house. While the most exciting and romantic strategy might be to buy the three-story Victorian they have always wanted, the more practical strategy might be to narrow the choice to houses that are all on one level. Then, in the event that the woman’s walking difficulties become more severe, she will be able to enjoy her whole house without feeling restricted to one or another floor. Similarly, a couple in which one of the partners has MS might want to think more conservatively about the amount of money they are putting into savings. The savings will be there as a safety net if the family income is reduced because of disability. If the MS never becomes severe enough to threaten the family’s income, the worst that happens is that more money has been put aside for retirement, a child’s college education, or a wonderful vacation.

Many families resist this kind of planning strategy because thinking about “the worst” seems too frightening. There is almost a superstition that thinking about these possibilities will make them happen and pushing them out of one’s mind will prevent them. Unfortunately, these kinds of beliefs can keep families perpetually off-balance; every exacerbation or change in the person’s physical or cognitive abilities feels like an unexpected blow for which family members are totally unprepared. Becoming edu-

cated about the potential impact of MS on the family, and taking steps to protect the family's financial, social, and emotional well-being, can help each person feel less vulnerable in the face of this unpredictable disease.

Where Do We Go From Here?

THE GOAL OF this chapter is to provide a general overview of the potential impact of MS on family life. The following chapters explore in greater detail the issues that have been raised here. Each includes descriptions of some of the challenges that can arise as well as realistic strategies for enhancing each family's quality of life—now and in the future.

ADDITIONAL READINGS

National MS Society Publications (available by calling 1-800-FIGHT-MS (1-800-344-4867) or online at <http://www.nationalmssociety.org/library.asp>)

Living with MS

Minden Sarah L and Debra Frankel. *Plaintalk: A Booklet About MS for Families Someone You Know Has MS: A Book for Families*

GENERAL READINGS

Blackstone M. *The First Year—Multiple Sclerosis: An Essential Guide for the Newly Diagnosed*. New York: Marlowe and Co. 2002.
www.marlowepub.com

Holland N, Murray TJ, Reingold SC. *Multiple Sclerosis: A Guide for the Newly Diagnosed* (2nd ed.), 2001 [Spanish translation: *Esclerosis Multiple: Guia Practica Para el Recien Diagnosticado*, 2002]

Kalb R, (ed.) *Multiple Sclerosis: The Questions You Have; The Answers You Need* (3rd ed.). New York: Demos Medical Publishing, 2004.

Kramer D. *Life on Cripple Creek: Essays on Living with Multiple Sclerosis*, 2003.

Pitzele SK. *We are not alone: Learning to live with chronic illness*. New York: Workman Publishing, 1986.

