Maintaining HEALTHY RELATIONSHIPS

WILLIAM (LEFT), DIAGNOSED IN 2002

National Multiple Sclerosis Society

In the early days of dealing with a new diagnosis, the focus tends to be on the disease — what it is, how to manage it, what it will mean for the future. Each person needs to come to terms with it in his or her own way, dealing with the rush of feelings and concerns that this kind of unexpected change can bring.

Fairly soon, however, it becomes clear that the diagnosis of MS affects not only the person who has it, but also other people in the person's everyday world. This chapter talks about the ways in which MS can impact family members, and then provides some ideas for how to maintain healthy relationships with people in your personal and professional life.

The impact of MS on the family

The uninvited guest

Multiple sclerosis has often been described as the "uninvited guest" who shows up at your house one day, takes up space in every room of the house and never goes home. Every member of the family will have his or her own reaction to the arrival of this guest, and each will have to find a satisfactory way to make peace with it. This challenge to the entire family is the subject of the first section in this chapter.

MS disrupts the family's rhythm

As each family grows and takes shape, it develops a rhythm of its own. Individual family members take on certain roles in the household, and patterns of interaction and communication become established. When one person in the household is diagnosed with a chronic illness, these accepted patterns can become disrupted.

What are some of the specific changes that can begin to occur? First, the individual with MS, and the family as a whole, will probably start thinking about their lives in a slightly different way.

Suddenly, there is a whole new set of questions and concerns that will affect the way the family deals with the present and thinks about the future. Second, if the person with MS is unable to carry out certain aspects of his or her role within the family, the rest of the family will need to adapt to these changes, perhaps taking on additional responsibilities and interacting in a somewhat different way. Third, the presence of a chronic illness in the household may begin to disrupt the sharing of important family resources, including money, time and emotional energy. The "uninvited guest" can sometimes get quite greedy, demanding more than its share of these resources, with the result that the needs and priorities of other family members may go unsatisfied.

> “Everyone in the family seems to have a lot of feelings about my MS, but we’re finding it hard to talk about them. Why are we all walking on eggshells?”

How the family feels about MS

How do family members generally respond to the intrusion of MS into the family? The most common reactions of family members include grief, anxiety, resentment and guilt. These feelings tend to come and go over the course of the illness, usually in response to changes in family life brought about by the MS.

Grief is a response to loss. People experience grief whenever they lose something that is important to them, whether it be a particular way of doing things, a valued activity, or even the feelings of security and general well-being. People tend to become anxious when they feel out of control or unable to predict what is going to happen next. Since one of the hallmarks of MS is its unpredictability, family members may find themselves feeling anxious a good deal of the time. Resentment is also a normal reaction to feeling out of control. Family members may, at times, feel resentful that MS has affected someone they love, that it has interfered with various aspects of family life, and that they have increased responsibilities. When family members feel resentful — particularly if that resentment is directed at the person with MS — they may also find themselves feeling guilty.

While it may not seem “fair” or “nice” to feel resentful toward a person for having an illness, family members often don’t know what to do with their angry feelings. There simply doesn’t seem to be any satisfactory place to put them.

Further complicating the feelings surrounding life with MS is the fact that family members won’t necessarily be experiencing them in unison. The person with MS may be in a period of grief over changes caused by a recent MS exacerbation, while one or another family member is feeling resentful over the impact this change has had on their lives. A father may be feeling anxious about the impact of MS on his job, while his daughter is grieving over her father’s inability to take her hiking. It can be difficult to recognize and accept another’s feelings when your own are looming so large.

> “Each person in the family seems to be dealing with my MS in a different way. How can we help each other manage this change in our lives?”

How families can deal with these feelings

Learning to deal with these feelings is a major challenge for families living with MS. The best approach is to recognize these feelings as a normal response to a difficult situation, find ways to express them comfortably with one another, and begin to share them. As with any difficult challenge, teamwork makes it easier and allows each person to feel less alone. Family members tend to be very protective of one another. They may be afraid that expressing these feelings will be hurtful to others. However, feelings that are bottled up have a way of expressing themselves — in the ways people talk, act and even touch one another. It is far better — and less stressful in the long run — to have the feelings out in the open where everyone can begin to deal with them together. Family counselors who are knowledgeable about MS can provide a helpful “jump start” for families who find it difficult to initiate these kinds of conversations.

Challenges to family coping

Each family member brings to this experience a different set of personality traits and coping strategies. For example, one family member might want to learn everything there is to know about MS, go to educational meetings and support groups, and talk to family and friends about the disease. Another person might want to “put it on the back burner,” talking and thinking about it as little as possible. There is no single, “correct” way to deal with the intrusion of MS into family life, and different coping strategies may work more effectively at different points along the way.

The important thing is to be able to recognize the needs of individual family members. Too often, one person’s coping style can be misinterpreted as selfish, uncaring or misguided by someone whose style is very different.

> “How can we plan for the future when this disease is so unpredictable?”

Recommended strategies for family coping

- The single most important strategy for families living with MS is to find a place for the illness in their lives without allowing it to take more space than it really needs. In other words, the uninvited guest needs to be given a comfortable room, but doesn’t need to clutter up the whole house. Family resources, whether they be financial, physical or emotional, should be balanced so that the needs of each person can be met. Otherwise, instead of one family member with a disability, you end up with a disabled family.
- A second strategy is to plan for the worst while hoping for the best. Families often shy away from this kind of planning, not only because they find it frightening, but also because they are afraid that thinking about “the worst” might somehow cause it to happen. The purpose of learning about the potential impact of MS and preparing for the future is to give the family more of a sense of security and control. Families who avoid thinking about what the future might bring are caught off guard each and every time there is a change in the illness. As a result, they feel constantly off balance and out of control.

  Examples of effective planning might include: consulting with a financial planner about ways to save for an unpredictable future; looking carefully into different health and disability insurance plans to see what might provide the greatest protection for the family; buying a one-story house rather than a three-story Victorian; or selecting an automatic rather than a stick-shift vehicle.

  If the MS never progresses to the point of causing major disability (as is true in most cases), nothing has been lost and family members have enjoyed the security of knowing that they were as prepared as they could be for all possibilities. If the MS does prove to be more disabling, the family has created a safety net for itself and feels more prepared to deal with whatever comes to pass.
- The third strategy is to make use of available resources. Whether the MS is relatively mild and stable, or more progressive, it represents a major intrusion into family life. No family should feel that it needs to “go it alone.” There are a variety of resources available to help families learn about the disease, talk about it and cope with its effects. Too often, families wait until there is a crisis

Joseph (left), diagnosed in 2008

to ask for help. Utilizing available resources along the way can help to avert crises and keep family life on a more even keel. The National MS Society has information and support programs to help you and your family live more comfortably with MS.

No one wants the "uninvited guest" to move in, and everyone wishes it would leave. In the meantime, family members can work together to adapt to the demands of the illness while maintaining a sense of control over their own lives.

Maintaining healthy relationships with others in your world

The chapter on **Taking the First Steps** discussed disclosure and the kinds of decisions each person needs to make regarding whom to tell about the MS diagnosis and when to tell them. This section deals with communication as well, but focuses on the people in your life whom you have already told about your MS. Now that they know about the diagnosis, what's next? What do they know — or think they know — about MS? What do they expect or need from you?

What do they think you need from them? Does it feel as though your relationships have changed? The answers to these questions are likely to be very different from person to person and situation to situation.

- Some people will feel comfortable asking you a lot of questions about it; others will not.
- Many may want to give you advice or recommend treatments that they have heard about in the news or on the internet; others may act as though you haven't mentioned the diagnosis at all.

- Some will assume that your MS is devastating like their great aunt's was; others will assume it is mild and easily manageable like their friend Tom's is. And many won't know anything about MS or will confuse it with some other disease like muscular dystrophy or ALS (also called Lou Gehrig's disease).
- Some people will assume that they can tell how you feel on a given day by looking at you — that if you look good you must be feeling good as well. Others will decide that anyone who has MS must feel pretty terrible all the time and begin to treat you like an invalid.

Your challenge over the coming months is to find ways to help the important people around you know whatever it is you want and need them to understand about your MS.

"I don't always feel as good as I look."

Most people don't comprehend what is meant by the term chronic illness. They tend to think in terms of illnesses like the flu or strep throat — for which one gets treatment and then gets better. It is difficult for them to understand that MS is a disease that sometimes appears active and sometimes not, that produces symptoms that come and go, and that has many treatments but no cure.

> "I feel a lot better sometimes than others. How can I begin to explain the ups-and-downs of MS to the people around me?"

Many of the most common symptoms of MS are invisible to others. The people who say "But you look so good!" may not know how tired someone with MS can feel, or how annoying and uncomfortable those sensations of numbness or pins and needles can be, or how distracting it is to have blurred or double vision or an unpredictable bladder. So while your family, friends and colleagues are trying to reassure you and bolster your spirits, they may also be trying to reassure themselves that everything is just fine — that you feel as good as you look and there is nothing to worry about. Some may also be impatient for you to get back to your "old self" — to do all the things at home or work that you have always done in the past.

It is your job to educate people around you about MS — what it is (and what it is not), how it affects you and the ways it can impact your various activities from time to time. The National MS Society has a variety of resources that can help you convey this information to others.

“My MS is very unpredictable — please don’t take it personally.”

One of the key messages to convey to others is how variable and unpredictable MS can be. No two people with MS experience it in exactly the same way, and no individual with MS can predict how he or she is going to feel at any given point in time. Some of the important people in your life may have a tendency to take it personally when you find it necessary to change social plans, miss a deadline or turn over a task that you don’t feel up to completing. Their first thought might be that they are not as important to you as they used to be. Particularly when they cannot see the symptom or problem that is getting in the way, they may tend to think that you aren’t trying as hard as you could.

Someone who has not lived with MS will likely find it hard to understand why you feel ready to take on the world one day and ready to take a day-long nap the next. It will require some patience and persistence on your part to educate people around you about how your MS behaves — and misbehaves. When it is necessary to change a plan, a deadline or any other kind of commitment, the best strategy is usually to explain the situation and offer a back-up plan or a rain check. Particularly with children, have an alternative activity in mind when a planned outing or event has to be changed. With time, family and friends will come to understand the ups and downs that come with your MS. Since deadlines at work may not allow you much flexibility, be sure to build in extra time to get things done. If you cannot meet a particular deadline, be sure to let your supervisor know the problem and your plan for completing the work in a timely fashion.

“I may need help sometimes and not others.”

Many people with MS find others to be either too helpful or not helpful enough. Some family members or friends will rush in to do everything as though you were a fragile invalid, while other people seem oblivious of the fact that some tasks or activities are harder for you from time to time. Still others may be worried that offers of assistance will offend you. To complicate matters further, people with MS don’t always give clear signals about what they need/don’t need, want/don’t want. In other words, you may find yourself feeling angry or insulted when people rush to provide help you don’t feel you need, while also feeling resentful when people don’t offer assistance. No one can read your mind, and even the people closest to you may not be able to tell how you are feeling. Your best strategy is to try and communicate your needs clearly — by asking for help when you need it, and explaining at other times that you're grateful for the offer but don't need anything at the moment. Most people are happy to provide assistance when it's needed — particularly if they know that you will give clear messages about how they can be of most help.

"I'm having difficulty doing 'this' right now, but I don't have any trouble with 'that' — how about switching with me for a while?"

Even when symptoms are interfering with some of your normal activities, chances are that there are many things that you can still do with ease. This is the time to think about swapping tasks with others. "I can't handle the grocery shopping right now, but I'll be happy to take over the bill-paying ... I can't mow the lawn in this heat, but I'd be happy to take care of the laundry ... Since my double vision is making it hard for me to drive right now, how about if you take my carpooling days, and I take your kids while you go to the gym..."

If other people begin to take over more and more of your usual responsibilities, without any "payback" from you, neither you nor they are likely to feel good about it. Even the most caring and understanding of family members, friends and colleagues will begin to feel overwhelmed by too many responsibilities. And nothing will do more damage to your self-esteem and self-confidence than feeling as though you're not contributing your fair share.

In any important relationship, each person needs to be on both the giving and receiving end. It may be easier for you to suggest these kinds of trades than for others to do it since you have a better sense of what you can and cannot manage. In addition, people may worry about hurting your feelings by raising the subject.

"MS has become a part of my life, but it isn't all of my life or all of me."

Once you have disclosed your diagnosis, you may find that some people — even people you thought of as very close friends — seem to shy away from you. Perhaps they don't call as often or include you in as many plans. While there are certainly some people in the world who just aren't very nice or caring, this is not true of most. Many are, however, somewhat frightened by illness and disability, uncertain of how to react or what to say, and worried about saying or doing the wrong thing. The longer people put off calling, the harder they may find it to pick up the phone or send that email.

> “Now that I have MS, some people seem to be keeping their distance. How can I re-establish those ties without MS getting in the way?”

Again, much of the burden for re-establishing contact may land on you. Decide which of the people in your life are most important to you — family members, friends, colleagues, neighbors — and reach out.

Keep in mind that people will tend to take their cue from you. If all you talk about is MS and symptoms and doctor visits, people may feel awkward talking to you about other things. If you never mention your MS or how you feel, they may think that the subject is taboo. If you can’t participate in some kinds of activities with your friends but don’t suggest alternatives, they may feel that you don’t want to be with them. This is your opportunity to remind significant people in your life that although MS is now a part of your life, it isn’t all or even the most important part.

Things to think about

- When one person in the family is diagnosed with MS, everyone in the family is affected. Try to be alert to the ways in which the changes brought about by MS impact the lives of everyone in the family.
- Each family member will react in his or her own way, and not necessarily “in sync” with anyone else. Conflicting reactions may cause a disruption in the normal family rhythm.
- Communication is the key.
- Don’t wait until there’s a crisis to seek help; all families can use help at one time or another in their efforts to communicate.
- Your ongoing challenge is to find ways to help the important people in your life understand your MS — and to realize that although MS in now part of your life, it isn’t all or even the most important part.
- While there are some people in the world who aren’t very nice or caring, this is not true of most.

Resources

Thousands of resources, pieces of information and shared experiences about MS are available in print and on the internet. Some of the information you come across may be strictly experiential, anecdotal, unsupported or even inaccurate. Always consider the source; ask your healthcare provider or the National MS Society to help you identify credible resources.

From the National MS Society

For answers to questions about MS and how it impacts your relationships, contact the National MS Society at 1-800-344-4867 or visit **nationalMSsociety.org** or the following topic-specific pages:

- **nationalMSsociety.org/living**
- **nationalMSsociety.org/family**
- **nationalMSsociety.org/KIPrelationships**

The Society produces many other resources about various aspects of MS. These resources are available online or call 1-800-344-4867 to request.

- **nationalMSsociety.org/educationalvideos** (also at youtube.com/nationalMSsociety)
- **nationalMSsociety.org/brochures** (or see the Catalog of Informational Resources mailed with this book if you received it by mail)

Contact an MS Navigator® or visit our website to see what educational or recreational programs may be available to you and your family.

Books

Books may be available at bookstores and/or online booksellers.

- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.) (2006). (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (5th ed.) (2012). (NY:DemosHealth)
- Kalb R, Giesser B, Costello K. **Multiple Sclerosis for Dummies** (2nd Ed). (NJ:Wiley) (2012).

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The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.

The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

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Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.

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