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How Multiple Sclerosis Affects the Family

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Multiple sclerosis (MS) has often been compared to the unexpected visitor who arrives at your house, complete with bag and baggage, and never leaves. This visitor has the tendency to spread his belongings through every room of the house, affecting the lifestyle and activities of every member of the household. MS, with its varied symptoms and unpredictable course, is an intrusion that the whole family must learn to accommodate. While a relatively small number of people with MS experience severe disability, the uncertainty and variability of the disease create their own day-to-day stresses even for those with minimal *impairment*.

By necessity, the adjustment process is an ongoing one; as the *symptoms* of MS come and go, or come and stay, coping and adjustment ebb and flow as well. Since each family member will approach this challenge with his or her own particular coping style, effective communication will enhance the family's ability to work together to handle the day-to-day challenges of life with a *chronic* illness.

The questions in this chapter deal with the impact of MS on family life and on relationships among family members. The answers also serve to highlight the role of ongoing education, effective communication and coping strategies, and supportive counseling in a family's efforts to live comfortably and productively with this challenge in their lives.

IMPACT ON FAMILY LIFE

My boyfriend and I are talking about getting married next year. He knows that I have MS, and he says it doesn't matter to him—he loves me anyway. He has never been to the doctor with me and seems reluctant to go. I think it's important for him to hear what the doctor has to say so that he knows what he's getting himself into. How can I explain this to him?

You might want to have a conversation with your boyfriend about how challenging marriage can be even without going into it blindfolded. Since your MS is a challenge you will both be living with, it is a good idea to begin life together by facing it head on. Although love is an important part of a successful marriage, the ability to talk, problem-solve, and make decisions as a couple is also essential—particularly when life involves an unpredictable chronic illness. Explain to him that you would be more comfortable sharing your life with him if you were confident that he had some understanding of what that might entail. If you are concerned that your boyfriend might be frightened by what your physician has to say, tell him so and assure him that you would rather start dealing with his fears and doubts now than be overwhelmed by them later.

We have worked hard to save money for our daughter's education. Soon my husband, who is in a wheelchair, may need a van to drive himself to work. How can we possibly choose between a college education and a van my husband needs to get to his job?

The heavy expenses related to chronic illness can drain family resources and necessitate compromise on the part of every family member. Before you start trying to choose between a van and a college education, however, be sure to look into possible funding sources for each. Education loans and scholarships based on financial need are often available, and chronic illness in the family is a valid and recognized financial hardship. You can start by calling the National Multiple Sclerosis Society (800-FIGHT-MS; 800-344-4867) to ask about their scholarship program, or read about it online at www.nationalmssociety.org/Scholarship. Some automobile companies also have programs to help people meet the cost of adaptive equipment. Once you have gathered all the financial information, sit down as a family to review your options and decide which choices make most sense for your family. You might also want to consult a financial planner (see Chapter 23) who has expertise in the area of chronic illness, or call the National Multiple Sclerosis Society to learn about the free financial consultations offered through Financial Education Partners, a collaborative program with the Society of Financial Services Professionals.

Our son recently told me that he didn't like to bring friends over anymore because the whole house is starting to look like a surgical supply store. There's no space to "hang out" without tripping over one piece of equipment or another. How should we deal with this?

All members of the family need to feel "at home" in the house. When the needs of one person begin to crowd out everyone else, the balance is out of kilter and needs to be restored. Ideally, there should be space for all of you to relax, converse, and entertain without tripping over medical equipment or mobility devices. Have a family meeting to talk over the problem and see if together you can come up with any space-saving, organizational ideas for managing the assistive equipment and creating equipment-free areas. The essential point to share with the whole family is that it is important for each of you to feel comfortable in the home.

You may also want to discuss with your son his feelings about MS. Depending on his age, he may be feeling embarrassed or self-conscious about your disability and the need for *assistive devices*. He may be concerned about what his friends will think, and he may be uncomfortable with their questions. If he seems to have difficulty talking this over with you, you can offer him age-appropriate reading materials from the National Multiple Sclerosis Society (available on the Society's web site at www.nationalmssociety.org/KidsandTeens) and alert him to the possibility of talking or writing to youngsters his own age who also have a parent with MS. Your local National Multiple Sclerosis Society chapter can help him to make these kinds of connections.

Our family used to do a lot of hiking and camping. Since my wife got MS, she can't really hike for any distance, and she's uncomfortable "roughing it." I don't know whether I should take the children camping without her or give up camping and try to find another kind of inexpensive family vacation.

As with many of the other questions in this chapter, there is no one correct answer. The solution lies in talking the options over with your wife (and children if they are old enough to understand and participate) and deciding what works best for all of you. Your goal should always be to try to balance the needs and wishes of all family members. One solution may be to compromise; go on occasional father-and-children camping excursions and, at the same time, begin investigating other, less physically strenuous possibilities for the whole family. If you give up camping altogether, the less than desirable outcome may

be that you and the children feel a bit resentful, and your wife feels guilty. Consult a travel agent who is knowledgeable about vacation opportunities for the disabled (see Appendix E). There are even camping programs for mixed groups of disabled and able-bodied people.

I've had to move back in with my mother since I can no longer manage alone in my apartment. We got along fine when I was on my own, but now we're back to the old tensions from my teenage days. How do families handle this kind of problem?

Parents and children spend many years preparing to separate. By the time the children have grown up enough to leave home, they feel ready to take personal responsibility and make decisions for their own lives. Parents let them go, usually with some trepidation and a big sigh of relief. As time passes, parents and their adult children learn to relate to each other in a slightly different way, with gradually growing separateness and mutual respect. When an adult child returns home, the parent-child relationship may need to be negotiated all over again.

Your mother once again has one of her children living with her, but her parenting role is different from what it was when you were younger. You have returned to your mother's house after having spent time on your own, running your own home, making your own decisions. Presumably, you want your mother to treat you like an independent adult, free to make your own decisions and come and go on your own schedule. She, on the other hand, wants to continue to feel that her home is her own, subject to her tastes and preferences. Additionally, she has always related to you as your mother, and may not know how to interact with you in any other way. Particularly when illness and/or disability are part of the picture, parents often feel an increased need to help and protect. Your mother may need time to learn how to balance your needs for help and support with your needs for freedom and independence. You may need the same time to reconcile yourself to being back in your mother's home and sphere of influence.

This is not an easy situation for any parent and adult child. You and your mother need to talk about the conflicts you are having and try to renegotiate your relationship. If you and your mother find that this renegotiation process is too difficult or stressful, a family therapist can help you communicate your individual needs and mutual expectations more effectively.

My husband has had MS for several years. I know that things are very difficult for him, but the MS has made things tough for me and the children as well. How can

I explain to my husband that we're all having trouble dealing with the changes and losses in our lives?

Some people have so much difficulty coming to terms with the impact of MS on their own lives that they have a hard time realizing how it affects other members of the family. Others feel so anxious and guilty about the impact of their disability on family members that they try not to think about it. Thus, there may be a variety of reasons why your husband seems insensitive to the feelings of other family members.

Presumably, you have tried to talk with him about the ways in which MS affects you and the children. If he feels that you are being selfish and unfeeling when you talk about your own needs, try communicating about them in a different way. For example, you might consult your local chapter of the National Multiple Sclerosis Society about family programs that you could attend together. Share with your husband some of the literature published by the National Multiple Sclerosis Society on families living with the disease. Perhaps he can hear your message more clearly if it comes from someone else. Knowing that all families living with MS find it stressful, and that family members cope best by helping one another, may enable him to feel less alone and more able to respond to you and the children. You may also consider working with a mental health professional to facilitate your conversation.

Although I need to use a wheelchair most of the time, I have learned to be quite self-sufficient in my own apartment. My parents want me to live with them, but I really want to stay where I am, in a familiar neighborhood, close to my friends. How can I convince my parents that I'm fine right where I am?

Your parents are probably worrying about your physical safety and your ability to get help if and when you need it. One way to reassure them is to create a home "safety net" for yourself. This is a good idea for any disabled person living alone, whether or not Mom and Dad are worried!

A portable telephone can be carried in a pouch attached to your wheelchair. This will enable you to make and receive calls even if you cannot get to the regular phone. You might also wish to install a medical alert system that gives you immediate access to emergency help (see Appendix E). This kind of system comes in several varieties, but the general principle is that the push of a single button (worn around your neck or attached to the wheelchair) alerts a central office that you are in some kind of trouble. After determining the type of problem you are having, the central office calls one of the individuals on your emergency list: neighbor, family member, physician, police, fire department, and so on. If you were to take a bad fall, for example, and find

yourself unable to get back up or reach a telephone, you could get immediate help simply by pressing the alert button.

The Medic-Alert identification bracelet is another useful safety precaution (see Appendix E). If you were unable for any reason to communicate clearly about your condition (following a serious fall, for example), the bracelet would indicate that you have MS and identify the medications you are taking. Any other important information about your health status would be available in your Medic-Alert file.

Knowing that this kind of safety net is in place may help your parents feel more comfortable with your independence. Knowing that you are looking out for your own welfare and safety may make them less inclined to feel that have to do it for you.

PARENTING

Now that I've been diagnosed with MS, I don't know if I should have children. I'm afraid that I won't be able to do things for a child that a father is supposed to do. What if I can't even play catch or teach my child to ride a bicycle?

Most parents, with or without MS, will tell you that their experiences with raising children were very different from what they had expected. They will also tell you that there is no single or correct way to be a “good” parent. Your decision to have children should be based on your desire to have this experience in your life as well some assessment of your ability to provide the kind of love and security that all children need.

The diagnosis of MS should not necessarily interrupt your wishes or plans for parenthood in any way. Keep in mind that it is impossible to predict with any certainty how your MS will affect you; you might not have any of the difficulties you are anticipating. You might even have a child who has no interest in playing catch! It is certainly reasonable to expect that MS will have some impact on your future family. The best way to prepare for that is for you and your wife to educate yourselves about MS, talk to the doctor about your particular symptoms and the course they are likely to take, and talk to each other about how you plan to share the parenting and bread-winning responsibilities. Ultimately, the goal is for you and your wife to feel comfortable as an effective parenting team, with consistent ideas about raising children, mutual support, and flexible ideas about what are “father jobs” and “mother jobs.”

Please be sure to read Chapter 18, on pregnancy and MS for information related to disease-modifying therapy, pregnancy, and breast-feeding.

My children don't bring their friends around the house any more. Now that I'm in a wheelchair, they seem embarrassed about me. What is the best way to discuss this with them?

It is important that families living with MS do not automatically relate all the changes they experience to the disease. Otherwise, changes that occur because of normal maturation or because of some stress other than MS could be misinterpreted. For example, it is quite typical and normal for young teenagers to begin spending less time at home and more time with their friends. Or, children may bring fewer friends around if they sense that Mom or Dad is very tired or cranky a lot of the time.

Begin the conversation with your children by letting them know that you have noticed a change. It is important to do this in a very neutral way so that your children feel free to respond to the observation you have made rather than to the tone of your voice. Ask them if they have noticed that their friends are not over at the house as much as they used to be, and, if they have, ask them what they think has changed. If they do not offer any explanation, or if they offer one that you do not quite believe, let them know that you are concerned this might be related in some way to your MS. Assure them that you want to know about any feelings or concerns that they might have because it is important to you that they and their friends are comfortable in the house. If they do voice concerns about the MS or anything else, work with them to develop strategies to make the situation more comfortable.

Now that my wife has become a bit more disabled, the children have a lot more chores to do around the house. Will this responsibility be too much for them?

Research has indicated that children who have a parent with MS are very much like children whose parents do not have any major health problems. They continue to develop and thrive in spite of the added stresses and responsibilities. Let your children know that you are aware that they have more responsibilities than their peers and that you appreciate their efforts. Offer your children choices about which chores they take on and give them some leeway in deciding when they will complete them. Reassure them with both words and actions that, in spite of their increased responsibility, you are there to parent, protect, and take charge. Try to make sure that your children have time in their lives to be children; they need some regular opportunities, however limited, to participate in a school activity or be with friends. If, in spite of these efforts, you notice a significant change in your children's school performance, usual moods, or social relationships, it would be best to have a consultation with a child or family therapist.

I went into the hospital for a four-day course of steroids. We told our seven- and nine-year-old children about the admission ahead of time, and they seemed okay with it. But while I was away, the older one got really upset at school and my husband had to go pick him up. How should we handle this in the future if I have to be admitted again?

Children have a difficult time with the unknown, and you and your husband were right to try to prepare them in advance for your admission. In spite of parents' best efforts, however, children are often frightened by the idea of a hospital stay (since many people who go into hospitals are very sick or dying) and worried that the parent will not come home again. Having you return safely from this initial hospitalization is the first step in preparing your children for any future hospitalizations that you may need. Take the time now to describe what happened to you during this hospital stay and let them talk to you about what it was like for them while you were gone. If and when you need to be hospitalized again, ask the hospital staff if the children can accompany you during the admission process. Find out if the hospital has child-life workers on staff who can talk with them about the hospital and its procedures. Make plans with your children to talk with them by phone at a scheduled time each day—or to have a visit if that is allowed. The idea is to give your children an understanding of what happens during the admission and how it will help your MS, and assure them that you are okay and available by telephone while you are gone.

We have told our parents and a few of our closest friends about my MS. I've asked them not to talk about it because I don't want my children to know yet. My husband thinks I'm wrong to try to keep this from them. I think that eight- and ten-year-old children are too young to have to worry about this. What should we be telling them?

Eight- and ten-year-olds are very observant people who generally have a sixth sense when something is not right in the family. Your children are probably aware that you are having some sort of health problems, whether or not these problems are influencing your usual activities with them. The ideas that children conjure up for themselves are almost always more frightening than the reality, particularly if they get the idea that the "something" is so terrible that Mom and Dad cannot even talk about it. In short, not discussing your MS with the children can, in the long run, cause them more worry than talking about it would. Additionally, the longer you delay talking to them, the more you increase the risk that they will hear the news from

someone other than yourselves. By openly discussing an important issue like this one in your life, you also lay the groundwork for good parent–child communication about issues that will come up in their lives.

I know that all children need to test and “see who’s the boss” sometimes. But since I started to use a cane, it feels as though the children are testing all the time. How can I discipline my children when I can’t even keep up with them?

There are many different styles of discipline. The better your negotiation and communications skills, and the more consistent you are in using them, the less you will have to depend on being mobile to provide discipline. Different approaches to parenting and discipline are described in the parenting literature (see Recommended Readings). Additionally, many community centers and schools offer parent effectiveness programs designed to help you build confidence and consistency in using these techniques. Keep in mind that being a good parent does not mean doing it all on your own. Enlist your spouse or other adults to help you learn and use these different approaches. In the meantime, remember also that children sometimes “test” in order to reassure themselves that the adults in their lives are still in charge and can still take care of them. Your children may be expressing their fears about MS and whatever effects it is having on you. Be alert to their questions and worries, and read or talk with them about the MS whenever it seems appropriate.

I always used to enjoy doing things with my children after school or in the evening before their bedtime. Now I’m so exhausted by the time they get home that I am either asleep or so cranky that they wish I were asleep! Is there any way to deal with this problem?

Fatigue is a common MS symptom that is usually best managed by prioritizing your activities and budgeting your energy. In some cases fatigue may also be helped with medication (see Chapter 4). At your first opportunity, discuss the fatigue with your physician, who can help sort out its causes(s). The physician may also refer you to a *physical therapist* or *occupational therapist* who can design a personalized exercise program to increase your energy, as well as work simplification and energy conservation strategies to help you make effective use of the energy you have (see Chapters 9 and 10). Your best day-to-day strategy is to find a time to recoup some energy before the children come home so that you can resume some of the activities that you and they are missing. Since MS-related fatigue is most noticeable in the late afternoon, try to work in a brief rest just before

the children arrive home. You may want to rearrange your daily routine so that you do more of your physically demanding chores earlier in the day and then have a chance to rest. If you are returning from work late in the day, schedule a regular rest time for yourself and make a “date” with the children for some special time together before they go to bed. Brainstorm with the children about some new “quiet time” activities that you could enjoy doing together.

Since my wife began having difficulty getting around the house and doing things for herself, she’s always after the rest of us to do, or get, or go. The children and I want to be helpful, but we don’t like being constantly on call. How can I make her understand how we feel?

There are two very difficult aspects to the situation you are describing in your family: how frustrated and out of control your wife must be feeling; and how unappreciated and burdened you and your children are feeling. One key to making home life more satisfying and comfortable for all of you is to develop some ways of talking about what is happening so that you can start building solutions together. The best way to start talking with others about your own feelings and needs is to show some understanding of theirs. This helps to facilitate open communication and cut down on everyone’s tendency to become defensive. Then you can begin to tackle specific areas of stress and conflict one at a time. Let your wife know that the family wants to meet her various needs, but that you each have needs and commitments of your own to deal with as well. Family members should speak openly about how they would like requests to be made, and how they feel when their own needs and activities are ignored. If you find that these conversations become too difficult because of all the issues that seem to emerge, keep in mind that lots of emotions may need to be sorted out. You may want to enlist the help of a family therapist who is knowledgeable about chronic illness to get you started on this process.

My 12-year-old has had to help me up from the floor a couple of times when I have fallen. Now he’s afraid to be at home alone with me. How can I help him with these feelings?

Your son’s feelings may be difficult for him to describe, but are probably related to a fear that he cannot do enough to help you, or that he is having to deal with a problem that is bigger and stronger than he is. For both your sakes, do everything you can to protect yourself from falls. Arrange for the two of you to have a session with an occupational therapist or physical therapist in your home. This professional can point out ways to maximize

your stability and safety, perhaps by removing area rugs, installing bathroom safety equipment, or recommending a mobility aid. The therapist can also show you different ways of performing transfers and teach your son techniques for helping if you do fall. You might also consider having a medical alert system installed in your home that enables you to notify family, neighbors, or community safety officials that you need help. These steps will reduce your son's fears by demonstrating to him that you are doing everything you can to protect yourself and that you do not expect him to be solely responsible for your safety.

Our youngest daughter will graduate from high school next year. Recently, she started talking about getting a job rather than applying to college. My husband and I are afraid that she feels worried about leaving me now that I've become so much more disabled. Should we push her to go to school?

Your daughter's second thoughts about college could be caused by any number of factors. As her parents, you should certainly discuss her plans with her and share your feelings about her going away to college. However, it would do little good to force her into a decision about leaving home; her reasons for deciding against college at this point could be very well thought out and unrelated to your illness. If her change in plans does seem to stem from anxiety or guilt about your MS, let her know what steps you and your husband have taken to manage your increasing disability. Remind her that, just because she is the youngest child, it does not mean that her role in life is to take care of you. If finances are her major concern, share with her your plans for balancing medical costs and any help you plan to give her with her educational expenses. Be prepared to help her explore options for attending college away from home or locally. The goal of the conversation should be to let her know that her needs and priorities are important to you and that you can, as a family, come up with a plan that addresses the needs of all the members of the family.

Sometimes my son or daughter has to help me with getting dressed or going to the bathroom. I don't like this any more than they do, and I'm worried about how this will affect them?

Your concern about having the children help with your personal care activities is very understandable and appropriate. Providing that kind of intimate assistance can be very confusing for youngsters who are developing their self-concepts and working to attain more independence from their parents. Additionally, your children's involvement in personal care sends a

strong message that you would be “lost” without them—a message that could have a significant impact on their plans for the future.

Some of the tasks that you need help with happen at the same time each day. Try to develop a schedule with adults in your family to help with your morning routine. Talk to your chapter of the National Multiple Sclerosis Society about the possibility of getting help from a home health agency. If, despite your best efforts, you can find no other helpers, consider involving your children in individual or family counseling. An opportunity to sort out their feelings about their caregiving role could relieve some of the stress on all of you.

My husband has been very upset and angry about the way his MS is getting worse, and he seems to take a lot of it out on the children. They try so hard to please him, but he yells a lot and criticizes everything they do. What is the best way to talk to him about this?

While your perception is that your husband’s relationship with the children is very strongly affected by his MS, he may not recognize the ways in which his reactions to the disease are spilling over onto the family. The sooner you begin to talk this over with him, the better it will be for all of you. He must begin to understand the impact of his behavior on the children. It is best to start this process by talking about a particular situation rather than about his general attitude or the way he is coping with MS. Discussing how to improve on the outcome of a specific, recent event will be less threatening. Undoubtedly, one conversation will not reverse the pattern that has developed; it will, however, lay the groundwork for future conversations.

It is not unusual for people to take out their uncomfortable feelings on those closest to them. As MS interferes with a person’s sense of independence and personal control, the natural tendency is often to try to take control in other ways—perhaps by bossing people around or “trying to organize the raindrops.” Children often feel that they get the brunt of this type of behavior. The most effective way to deal with this problem is often to help the person talk about the loss of control and brainstorm about more effective ways to restore a sense of order and independence in daily life.

Keep in mind, as well, that mood swings, irritability, and depressive feelings are also fairly common in MS (see Chapter 16). While the exact relationship between these emotional changes and the illness is not well known, and can certainly vary from one individual to another, the resulting behaviors can have a significant impact on family life. If you feel that your husband is behaving very differently from his “usual self,” you could ask him to mention it to his *neurologist* and think about going with you to a psychotherapist who is familiar with MS to talk over these changes.

Most of my MS problems don't show on the outside; fatigue and vertigo are my worst problems. How can I help my children understand how I am feeling? They are angry about things I can't do any more, and don't seem to appreciate the things I still manage to do for them.

It is difficult to describe to children symptoms that they cannot see and have probably never experienced. Try to describe your symptoms in terms that they can readily understand. For example, you might have your children experiment with ankle and wrist weights to learn how your body feels when you are fatigued. Or, you might tell them to spin themselves around a bit and then try to walk from one room to another. Reading together about MS will let them see that other parents experience very similar symptoms. The National Multiple Sclerosis Society has several excellent booklets written for children in different age groups. Many chapters of the Society also offer special programs to help children learn about the disease and its symptoms and provide ways for them to get in touch with other children who have a parent with MS. Contact your local chapter (800-FIGHT-MS; 800-344-4867) to learn more about these services. Your physician can also be a valuable resource. For example, the children might sit in during one of your office visits to learn about the neurologic exam and the ways in which your physician tests those "invisible" symptoms. He can also refer you to a child or family therapist who can help your family develop more effective ways to talk about MS and the ways it is affecting each of you.

As you try various strategies for teaching your children about MS, keep in mind that no two children learn in exactly the same way. What seems to work with one of your children may be of no interest to the other(s). One child might be interested in reading or talking with you about MS, while another might want to attend a meeting and talk with other children who have a parent with MS. Some children want simply to be reassured that you will continue to be able to take care of them.

Should I let my children's teachers know about my MS?

Under most circumstances, it is very helpful to let your children's teachers know about your diagnosis. School can be a very important source of stability and self-confidence, and the teacher is a primary player in any child's day-to-day experiences. If they are aware of the MS, teachers can be very helpful to you in gauging how your children are responding to your illness and the changes it is causing in your family. Additionally, awareness of your situation will enable the teachers to be attentive to any changes in your children's school performance and social relationships and be prepared to provide help and support as needed.

THE CAREGIVING EXPERIENCE

Everyone is always asking how my husband is. How do I let them know that my life has changed almost as much as his and that I need them to ask about me too?

Your feelings are shared by many well spouses. There is no reason to feel embarrassed, selfish, or in any way inadequate because you have needs of your own. Over the course of the illness, you will need support just as much as your husband does, but you may have to look for it from different sources. Having one special friend or relative with whom you are comfortable sharing your feelings can be much more meaningful than expressions of concern from people with whom you have a more casual relationship. Many chapters of the National Multiple Sclerosis Society sponsor spouse groups that provide the opportunity to meet with others who are sharing your experiences. The National Well-Spouse Foundation (see Appendix E) is another organization that provides support to caregiving spouses through newsletters, local support groups, and annual national meetings. An increasing amount of reading matter is available to inform, support, and empower you in your role as the spouse of someone with a chronic illness (see Appendix D).

My wife can't play tennis anymore. She gets upset when I go and play, and I feel guilty about wanting to play. Should I give up the active things that I like to do because she can no longer do them with me?

There are likely to be a variety of changes that you and your wife will have to face together in dealing with MS, and responding to changes in her level of disability is a very significant one. Before making any decisions about continuing to play tennis, try to talk the situation over with her. Your wife's distress may stem from feelings of loss and envy; she may simply find it very painful to know that you are doing something that she loves but can no longer do. Or she may be concerned that the two of you will have less time together if you continue to play without her. She may also worry that she will miss out on the social contacts the two of you had with other players. Identifying the sources of her distress will help the two of you decide the best way to deal with the situation. Make sure that your wife understands how important it is for you to keep playing tennis, while reassuring her that you are interested in finding other activities that you can do together. Support her own efforts to find satisfying and enjoyable hobbies to replace those that she can no longer do. It is important that family members not rush to give up any and all activities that the person with MS is unable to do. The eventual cost in resentment and guilt is too great.

I've started to feel more like a caregiver than a husband. I am committed to my wife, and have no wish to leave her, but I really miss the companion who shared so much with me. How do other people cope with the loneliness and loss of companionship?

The feelings of loss you are describing are particularly common for couples who have always shared many interests and activities but now increasingly spend time simply managing the consequences of MS. In the same way you have partnered each other in other aspects of your life, try to become partners in the management of MS. An important goal of this partnership is to be able to communicate effectively about ways to integrate MS-related care activities into your lives in such a way that there is still time and energy left for other enjoyable activities. This will help both of you to feel that you are managing the MS rather than the other way around. It will also help you regain your feelings of togetherness so that each feels less alone with the burdens imposed by the disease. Discussing your concerns at a couples' support group could benefit you and your wife in several ways: You will be reassured to learn that other couples are living with, and finding solutions to, the kinds of stresses and strains you are describing. The group can brainstorm together on ways to solve commonly shared problems and find substitute activities for those that you can no longer do because of the MS. You may also find that the group becomes a social outlet as well.

I feel as though my whole life is controlled by MS, and I don't even have the disease. How can I regain my life and still make sure my husband has the care he needs?

When life with MS becomes so overwhelming that you feel you are losing yourself in the disease, it is time to take a step back from the situation and find ways that it can be made more manageable. The first step in this process is to begin to think of yourself as your husband's *care partner* rather than caregiver; the responsibility for managing the MS and the needs that it generates rest on both of you.

In as objective a way as possible, the two of you should make a list of his needs and yours. Try to identify the specific ways in which the MS-related needs have infringed on yours, paying particular attention to those times when you feel especially burdened or overwhelmed. Finally, write down those activities that you personally are missing and want to regain in your life. The goal of this process is to help you think in more specific terms than "MS" and "my whole life." The more specific you are able to be, the more likely it is that you and he will be able to identify strategies for regaining a sense of independence and control in your lives.

While it will not be possible for you to free your lives totally of MS, you will be able to adopt strategies and identify resources to help both of you meet your needs. This kind of problem-solving requires good communication and a lot of creativity. Working with a family therapist can help with the process if you find that, individually or together, you are feeling too overwhelmed or emotionally overloaded to be able to discuss the issues. Also keep in mind that MS support groups can be a helpful resource, particularly those designed for couples.

My wife is desperate to find a cure for her MS. Every time a new treatment is mentioned in the newspaper, she is ready to fly around the world to get it. I get angry when she is ready to spend our retirement money on every quack gimmick that comes along. How can I get her to understand that the money we saved is for both of us and that we need to agree on how to spend it?

This commitment to trying every publicized MS “cure” can be especially frustrating to family members. In addition to making them feel as if their own needs have become unimportant, it tends to keep the entire family on an uncomfortable emotional roller coaster as hope is repeatedly replaced with disappointment. Your wife may be responding more with emotion than with reason to these reported “cures.” To give her some background on the great number of these that have turned out to have no real value, you may want to read together a book entitled *Alternative Medicine and Multiple Sclerosis* (2nd ed.) by Dr. Allen Bowling (see Appendix D). This book describes most of the proclaimed treatments and cures, the ways that each was thought to work, the quality of the scientific research done to evaluate their effectiveness, and benefits and risks associated with each.

Another way to help your wife feel satisfied that she is doing everything possible to treat her MS is to encourage her participation in a *clinical trial* of one of the very promising drugs that are now being scientifically tested (see Chapter 5). If your wife continues to want to use your retirement savings to pursue untested “cures,” the two of you might consider a consultation with an accountant or tax attorney (see Chapter 23) to determine how her spending will affect your retirement and how to establish a financial plan that will protect your retirement funds.

My husband has become quite disabled by his MS, and he doesn't get out of the house much any more. Friends have stopped inviting us to do things because he is no longer able. How can I let them know that

I still need to see people and have a social life even though he can't come with me?

You are wise to take the initiative with your friends rather than waiting for them to take the initiative with you. They may simply need to hear from you that you want to maintain your social relationships and continue to be active. You may start by inviting one friend or couple over for dinner and saying that your husband will join you for part of the evening but excuse himself if and when he becomes too tired. Or, invite them to join you at a restaurant for dinner and let them know that, although your husband won't be coming, he is pleased that you are arranging an evening out. During the evening, after you have had a chance to catch up with one another, ask your friends to tell other members of your circle that you are still looking to socialize with them. You may want to let them know, if it is indeed the case, that you and your husband have talked this over and are both comfortable with the idea that you will continue to make plans even if he is not always able to be with you. It is by your own example that your friends will become comfortable seeking you out for social engagements even if your husband cannot always participate.

I've been able to deal relatively well with my wife's significant physical problems but the cognitive changes and mood swings have been much more difficult for me. At times she seems like a different person, and I begin to feel as though I have lost my life partner. How can I learn to accept this loss?

As painful as it is to recognize the cognitive changes that your wife is experiencing, it is fortunate that you understand their possible relationship to her disease. Many spouses and family members, who don't know that MS can directly cause these memory and behavioral changes, tend to misinterpret the problems and believe that the person with MS is being deliberately difficult or forgetful. With a more complete understanding of the situation, you can begin to deal with it more realistically. Chapters 14 and 16 provide an orientation to the *cognitive impairment* and emotional changes that can occur in MS, and describe how these problems are assessed and managed.

The changes your wife is experiencing are undoubtedly having a major impact on you and your relationship. First, you are probably assuming more of those household responsibilities your wife used to manage, as well as providing more care and supervision for her. Finding the time and energy for this can be a challenge given the many responsibilities you already have at work and at home. Even more importantly, the changes your wife is experiencing are literally taking her away from you. You may be missing her sense of humor, her intellect, her interest in your work and the comings

and goings of your children, or her ability to participate with you at social gatherings with family and friends. In very fundamental way, she is not the person you married.

This idea of having “lost” your spouse while she remains in your home and under your care can be very difficult to accept, and requires a unique kind of grieving process. It is important that you begin to think of your relationship as being very different from most marriages. This grieving process will help you acknowledge the help your wife needs, while allowing you to let go of the woman you married and accept the wife who is now so dependent on your care. The grieving process will also help you shift your expectations for the relationship and prepare for your new responsibilities.

Although family, friends, and support group members can be helpful and sympathetic, few will have any experience with the loss you are experiencing in your marriage. For that reason, it is very useful to work with a mental health professional experienced in dealing with the grief of your ever-changing relationship with your wife. The therapist can help you deal with the losses you are experiencing, the paradox of having to care for that person who is in many ways no longer your spouse, and in sorting out how you and the rest of your family can continue with your lives.

There is no one correct way to manage this situation that suspends you between being partner and nurse. A mental health professional can be an important ally as you find your way in managing this very difficult situation. This can include exploring ways to maintain relationships and activities that you used to share with your wife, or developing new ones. Just as importantly, working with a therapist can help you identify and hold on to those parts of your relationship with your wife that remain intact.

My husband insists on driving a car even though some of his MS symptoms are making him an unsafe driver. We added hand controls to the car two years ago, when leg weakness was his major problem. But now his vision is very bad, and I’m afraid that his concentration is just too poor for him to be safe. He has already had one accident, and I’m afraid that someone will be hurt the next time.

People find it very difficult to give up driving because it represents a tremendous loss of independence. However, as you have indicated, the consequences of severely impaired driving skills can be life-threatening. Trying to convince your husband by yourself that he should stop driving might be difficult. If you are uncertain about his driving competence, or if you believe that your husband will resent your suggestions, you might accompany

him to his next medical appointment and raise the issue with his physician. Explain your concerns to the doctor and ask about the availability of a driving evaluation. This kind of evaluation, which should test both physical and cognitive skills, is often available at *rehabilitation* facilities. With your husband present, ask about the doctor's responsibility for reporting unsafe drivers to the state bureau of motor vehicles (this responsibility varies from state to state). If your husband insists on continuing to drive, and you are certain in your own mind that he is an unsafe driver, let him know that you and your other family members will not ride in the car when he is driving. Help him to make arrangements for rides to those places he is accustomed to going on his own. Many communities have door-to-door transportation services that can help him remain independent. You might also encourage him to consult a psychotherapist for help with the feelings of loss and helplessness that accompany this kind of major life adjustment.

My husband wants our sexual relationship to be the way it used to be. But I am exhausted after a full day of work and taking care of him. It's hard for me to feel romantic after helping him with his personal needs. How can I discuss this without hurting his feelings?

A couple's sexual relationship is important because of both the physical pleasure it provides and the emotional intimacy that it expresses. At different times over the course of every marriage, the sexual relationship is influenced by how the couple is getting along, their family responsibilities, and their physical and emotional health. Remaining close and intimate with each other during these times is an important part of sustaining a good marriage. Before discussing your sexual relationship with your husband, you may want to spend some time sorting out your own feelings. As you have described, your sexual feelings for your husband have been affected by your own physical exhaustion as well as changes in how you feel emotionally. It is also possible that some of your husband's MS-related physical changes are interfering with your sexual activities or your sexual response to him. It will probably make your conversation easier if you have sorted through some of these feelings in advance and perhaps talked them over with a therapist.

The next time your husband talks about your sexual relationship, try sharing some of your feelings with him. As with any important conversation, be sure to put as much effort into hearing him as in expressing yourself. By being honest with him about the way you are feeling and open to his response, you are initiating an important and satisfying form of intimacy. The two of you might also consider talking with a therapist who specializes in sexual relationships. That person can help you talk about your feelings and concerns, explore ways of being sexual that accommodate your husband's disability,

and otherwise enhance the intimacy in your relationship. The sexual relationship in MS is discussed in detail in Chapter 11.

I have always loved my wife and, until her MS came along, we seldom even argued. I would never have believed that I could intentionally be hurtful to her. But now that she is at her most vulnerable, my temper is becoming shorter and shorter. Last night she woke me three times to help her to the bathroom. The second time, at 3:00 in the morning, I found myself shouting at her that I had to be up at 5:30 and she could wait until then. When she called me again a half-hour later, it was because she had had an accident. Even though I knew it was a bowel accident, I let her lay in the soiled bedclothes while I tried to “cool down” and get control before going to help her. I was afraid I might hurt her. These bad feelings and reactions are very frightening to both of us, and they are coming more often and more powerfully. I am frightened for her and for me. What can I do?

Fortunately, you have begun to recognize your need for help in managing the reactions you are having to your wife and her care needs. We know from research and clinical practice that couples who have no history of domestic violence can become hurtful to each other in the course of living with a chronic disease like MS. This hurtfulness is often a reaction to the physical stress and emotional strain of living with the illness. We also know that this kind of aggressive behavior is more likely to occur when the illness involves personality and behavioral changes or bowel or bladder incontinence. This is by no means an excuse for becoming either emotionally or physically abusive. It is an alert that anyone can become abusive and that income, gender, and level of disability are no protection when the stress of the situation becomes too much.

You are right to be worried about your reactions. This is the kind of situation that will only become more stressful and dangerous if you try to manage it on your own. Counseling with a mental health professional is a useful and essential strategy for dealing with emotions that are beginning to feel out of control. The professional can help you and your wife to develop a short-term plan to relieve the immediate pressure related to her care, and a long-term strategy to prevent future occurrences. If you do not know a therapist, ask for a referral from your physician or the local chapter of the National Multiple Sclerosis Society.

It is important to let your wife's doctor know immediately that the caregiving has become too much for you, and that you need help in caring for her.

You can also ask the National Multiple Sclerosis Society (800-FIGHT-MS; 800-344-4867) for information about local options for respite care, in-home nursing care, and a variety of other strategies (see Chapter 22). It is fortunate that you have had the courage to recognize the danger that you and your wife are facing. It is now essential that you find the strength to get professional help to correct the situation.

I know that elderly couples have to face the possibility of nursing home placement when they can no longer care for each other any more, but my husband and I are in our 40s and facing that possibility now because of his severe disability. How can we begin to talk about this frightening topic?

One of the most difficult aspects of facing nursing home placement at this time in your lives is that it is such an unanticipated event. Few, if any, people in your immediate circle can appreciate the practical, emotional, and financial issues you are facing. You may be feeling guilty that your husband's care needs have become overwhelming in spite of any assistance you have been able to enlist from friends, relatives, or professionals. In addition, you are probably concerned about the likelihood of finding a facility that has other young adults. You may also be concerned that your family and friends will think you are "abandoning" your husband.

To deal with these issues, it is important to step back from the jumble of overwhelming thoughts and feelings and take an objective look at your situation. The fact that you and your husband are considering residential care for him means that you feel you have exhausted all the other long-term care options. You can refer to Chapter 22 for a detailed discussion of long-term care to determine if this is indeed the case. As you and he examine the positive and negative aspects of each long-term care strategy, you can choose the one that best meets the needs of everyone in the family.

Your husband's ability to participate in this discussion, and the subsequent planning involved, will depend on his cognitive abilities—in particular, his ability to recognize and appreciate his care needs. Because this is a decision that will significantly affect both of your lives, it is important that he be included in this decision to the greatest extent possible.

The starting point for this kind of planning and decision-making is the acknowledgment that you, your husband, and your children each have needs that must be met, and each person's needs are just as real and valid as everyone else's. Much of the anxiety and guilt surrounding this difficult issue results from the mistaken belief that family members ought to be able to care for a loved one at home no matter what. However, research has demonstrated that the physical and emotional health of caregivers can be

severely compromised by the extra-ordinary demands of caregiving. The goal is to arrive at a plan that ensures the health and well-being of the entire family, and allows family members to love and care for one another in the most comfortable way possible.

If your husband is not able to participate meaningfully in this decision because of cognitive impairment, you may want to discuss your options with members of his family. Family members, friends, a clergyman, and a caregivers' support group can all be valuable sources of help and support during this difficult time. It may also be helpful to work with a mental health professional who can provide a "reality check" concerning the options you are considering, guide your efforts to select a facility and arrange placement, and be a source of support as you advise family and friends about your decision.

RECOMMENDED READINGS

Kalb R. *Multiple Sclerosis: A Guide for Families* (3rd ed.). New York: Demos Medical Publishing, 2006.

Chatman L, Chatman C. *The Art of Living with Multiple Sclerosis: Six Secrets for Managing MS as a Team*. Two Hearts Publishing, 2006.

Selected publications available from the National Multiple Sclerosis Society, (800-FIGHT-MS (800-344-3867), or online at www.nationalmssociety.org/Brochures:

- *What Everyone Should Know about Multiple Sclerosis*—An overview of MS, suitable for the whole family (available only in a print version)
- *Someone You Know Has MS: A Book for Families*—For children 5–12
- *Keep S'myelin*—A colorful newsletter for children ages 5-12, available in a print version or interactive, online version at www.nationalmssociety.org/KS
- *Keep S'myelin Activity Book*—For children 5–12 (available only in a print version)
- *Teen InsideMS Web-zine*—A quarterly, online magazine for teens, available at www.nationalmssociety.org/TeenInsideMS
- *When a Parent Has MS: A Teenager's Guide*—A booklet designed for teens