



Building and Maintaining

INTIMATE RELATIONSHIPS

BROOKE, DIAGNOSED IN 2009



All of us are familiar with the complexities involved in building and maintaining intimate relationships. We have each experienced the self-doubts and personal insecurities that can make meeting new people so difficult. We are also well aware that long-term, committed relationships face significant challenges.

The diagnosis of a chronic, unpredictable illness like MS often adds additional concerns: How will MS affect my closest relationships? Will others find me attractive and desirable? Will MS affect my sexual feelings and sexual responses? When and how will I talk to others about my MS? This chapter focuses on these personal concerns.

“Who am I now that I have MS?”

At the heart of most people’s concerns about their ability to love and be loved with MS are doubts about who they are and what they have to offer now that they have a chronic illness. Particularly in the early months following the diagnosis, you may be feeling uncertain about yourself. You may be so preoccupied with the symptoms of MS, or your concerns about its potential impact on your life, that you have trouble remembering the “old you.”

As you gradually learn how to make a place for MS in your life, you will be relieved to discover that although the illness is now a part of your life, it is certainly not the whole of it. Remember that as you think about relationships — both new and old — in your life. In order to help others understand and accept MS as part of who you are, you must do the same. In other words, deal with whatever changes MS brings into your life, while staying connected with the qualities and interests that have made you the person you are.

This will ensure that the people around you have the benefit of the “whole package” that is you, and not just the MS part.

Meeting new people

People who are single and looking for committed relationships often worry that potential partners will be frightened away by MS. Some become so concerned about the possibility of rejection that they shy away from the social scene altogether. Although meeting new people always involves some risk of rejection, you will find that while some people are put off by the illness, many others are not. You certainly have more to lose by giving up all efforts to meet people than by making the effort and seeing how it goes.

“I’m worried my MS diagnosis will scare people away. How do I decide if and when to tell?”

As discussed in the chapter on **Taking the First Steps**, there are no hard and fast disclosure rules that apply to every relationship, but here is a reminder of some points to keep in mind:

- The first date is an opportunity for two people to decide whether they are interested in getting to know one another better. There is no need to share a lot of intimate details about your life unless you choose to do so, and you do not have a responsibility to disclose anything about yourself or your MS.
- Once you have decided that this is a person with whom you would like to develop more of a relationship, it is time to start sharing more personal information. A good rule-of-thumb is to ask yourself when you would want to know about any personal or health issues the other person might have.
- Believing that disclosure will eventually become easier or more comfortable, some people delay talking about their MS until the

relationship feels closer or more secure. In general, however, it is probably wiser and easier to get MS out in the open earlier rather than later in the relationship. The more invested you become in the relationship, the more painful it could be if the other person is unable to deal with your MS.

- Secrecy is a shaky foundation on which to try and build a successful relationship.

Try to be patient and tolerant of the other person’s initial response to your disclosure. Just as you did, he or she will need some time to react to your news and digest what it all means. Be prepared to answer questions and provide the person with helpful information if it is wanted. And be ready to offer the same kind of support and understanding that you want for yourself.

Most other people will take their cues from you. Unless they know someone who has MS, or happen to have read news stories about it, they will look to you to educate them. Their response to the MS will be, in large part, determined by the way you present it to them. This is the time for you to remind yourself again that MS is a part of your life and who you are, but certainly not the biggest or most important part.

Sexual feelings and responses

For a variety of reasons, MS can affect a person's sexual feelings and responses even in the very early days of the illness. While not everyone with MS will experience sexual changes, many will experience one problem or another over the course of the illness. Although this tends to be a difficult topic for people to talk about, discuss any questions or concerns with your physician or other healthcare provider so that you can receive the help and information you need. The National MS Society can also provide you with helpful information as well as referrals to specialists in this area.

There are three general types of sexual changes that may be experienced by a person with MS — primary, secondary and tertiary:

- **Primary** sexual problems are the direct result of neurologic changes that interfere with the messages that travel between the central nervous system (brain, spinal cord and optic nerves) and other parts of the body. Examples of these types of problems include changes in level of sexual interest and/or sexual responsiveness. Women may experience changes in arousal, lubrication and ability to achieve orgasm. Men may experience changes in arousal, including problems achieving or maintaining an erection, and an inability to ejaculate. Men and women may also experience sensory changes that make intercourse or other types of intimate contact feel uncomfortable or painful. Your physician can work with you to find helpful interventions for these problems.
- **Secondary** problems are caused in part by other symptoms of MS rather than by the neurologic changes themselves. For example, the fatigue that is so common in MS can interfere with sexual activity; spasticity (stiffness) in the arms or legs can cause certain sexual positions to be uncomfortable; and men and women who are experiencing bladder problems may be concerned about having accidents during sexual intercourse. In addition, some of the medications that people take to manage their symptoms can have side effects that impact sexual functioning. For example, the medications used to treat bladder symptoms can contribute to vaginal dryness; antidepressants can interfere with sexual arousal and orgasm; many medications can increase feelings of drowsiness. Again, your healthcare provider can work with you to identify treatment strategies that manage your symptoms while minimizing the impact of both the symptoms and the treatments on sexual function.

- **Tertiary** problems result from our society's prevailing attitudes about sexuality, illness and disability, and from the very personal feelings and reactions individuals have about MS. For example, a person with MS may feel unattractive or wonder if he or she can still be attractive to others, and a sexual partner may start to feel personally rejected if his or her intimate gestures are repeatedly rebuffed. Sometimes the partner without MS can become concerned about hurting or tiring the person with MS.

“If I notice that MS is affecting my sexual feelings and responses, what can I do to deal with that?”

Many people find it difficult to talk about their sexual feelings, concerns or preferences even under the best of circumstances; trying to talk about the kinds of changes that MS can cause in your sexual feelings and needs can be even more difficult. Should any of these problems occur, your best strategies for dealing with them will include: 1) talking openly with your healthcare provider and learning as much as you can about available

management strategies for the changes and symptoms you are experiencing; 2) learning about your body and any changes that are occurring so that you can communicate them to your sexual partner; and 3) talking with a family counselor or sex therapist if you find that you need help communicating with your partner about sexual issues.

Keep in mind that MS does not affect fertility. Couples in which one of the partners has MS need to make the same decisions and take the same precautions regarding possible pregnancy as any other couple. Likewise, people with MS continue to be susceptible to sexually-transmitted diseases and need to take precautions to ensure safe sex.

Maintaining long-term relationships

Couples in long-term relationships need to weather a variety of storms and stresses over time. Each person brings to the relationship his or her own emotional resources and coping strategies. With some combination of determination, creativity and good humor, they pool these resources to meet the emotional, financial, vocational and social challenges that come their way. Their commitment to each other and to the relationship helps fuel their efforts.

If you or your spouse/partner has recently been diagnosed with MS, you are probably wondering how this may affect your relationship in the future. While it is impossible to predict how MS will affect any one individual, or any particular couple, there are some general points to keep in mind:

- MS is a frightening and unexpected intrusion into people's lives, and no two individuals — no matter how devoted or loving — are going to react to this intrusion in exactly the same way. First, each person brings to the relationship a lifetime of attitudes about, and/or experiences with, illness and disability. Second, no two people are likely to have exactly the same coping styles. One of you may want to read and learn everything there is about the disease, while the other wants to think about it as little as possible. One may need to talk about it with friends, family, colleagues and clergymen, while the other wants to keep it a secret. Since no one coping style is necessarily better than any other, the goal for you is to learn how to recognize and respect each other's feelings and needs, and communicate openly. This will enable you to work together to "lighten the load" of MS.
- The symptoms of MS are difficult to share. No matter how "in tune" you are as a couple, it is difficult for the partner with MS to convey how

a particular symptom feels. This is particularly true of the less visible symptoms of MS, such as fatigue or changes in sexual feelings. As a result, the person with MS may feel misunderstood and alone, while his or her partner feels helpless and confused.

- Partners without MS have feelings too. In addition to being concerned about the person they love, partners often feel frightened about the future and about the extra responsibilities that may fall on their shoulders. They may hesitate to express these feelings and concerns lest they sound selfish or uncaring. Partners without MS also need the support of others. In the days and months following the diagnosis, most expressions of care and concern are directed to the person with MS, leaving the partner to feel that he or she must be strong enough to handle it alone.
- Uncomfortable feelings can cause people to pull away from one another in order to escape the distress or avoid the pain of emotional confrontation. One strategy for dealing with these kinds of communication problems is to talk openly about how you feel, and listen respectfully to your partner's feelings. For example:
 - » "I feel hurt (or angry, or sad) when you ..." will probably work better than an accusatory,

“You don’t care about me ... you’re always so insensitive.” In other words, each person needs to state his or her own feelings, and stick to particulars. Critical statements about the other person’s inadequacies are unlikely to get a positive response.

» “I know that this is a scary time for both of us. Let’s talk about how we can help each other through this,” is probably going to be better received by the other person than, “What do you mean you’re scared? I’m the one with the disease.” Each person needs to acknowledge the sincerity and validity of the other’s feelings.

If you find that your communication strategies are not working, or feel that either one of you is pulling away, you may find it helpful to talk with a family counselor about ways to improve your communication.

- Couples may find that the person with MS has difficulty participating in some of the activities they used to enjoy doing together, such as playing tennis, going camping or taking an evening stroll. You may decide, as a couple, that you will find new recreational activities that you both can enjoy. Or, you may decide that each partner will continue to pursue something that is personally enjoyable. Again, there is no single,

correct way to deal with this problem. Share your feelings, and decide together what works best for both of you. Unspoken guilt and/or resentment can only grow bigger and more intrusive.

Many couples feel overwhelmed by the diagnosis of MS, wondering how it will affect their lives and how they meet its challenges. A valuable strategy is to have a conversation about the ways you have handled problems and stresses in the past, and how these same strategies might help you in the future. Most couples have more coping skills than they realize.

The next step is to identify the particular problems that you need to address; it is always easier to solve the smaller, individual problems than it is to attack the MS itself.

The third step is to make use of all your available resources. Once you have identified the particular problems you need to address, it will be easier to call upon the appropriate resources to help with each problem. For example, the National MS Society can provide you with educational materials and, if necessary, refer you to a professional who is trained to help with a particular problem (e.g., a financial advisor, lawyer, vocational counselor, family therapist, sex therapist, etc.).



Michael, diagnosed in 2004

“Sometimes my partner and I are dealing with so many different feelings, we can’t even begin to talk about them.”

Couples should not wait until they are in a crisis situation to look for help. Learning to live with the intrusive demands of MS is no easy task, and no couple should feel that they need to meet this challenge unassisted.

Becoming educated about the illness and the ways it can impact your lives, learning to communicate openly and effectively, and making use of all the

available resources will enhance your efforts to maintain a satisfying, long-term relationship.

Things to think about

- Although MS is now a part of your life and one aspect of who you are as a person, it is certainly not the “whole package.” In order to help others understand and accept MS as part of who you are, you must do the same.
- Although meeting new people always involves some risk of rejection, you will lose more by giving up efforts to meet people than by making the effort and seeing how it goes.
- A good rule-of-thumb for deciding when to disclose your MS to a person you are dating is to ask yourself when you would want to

know similar kinds of information about the other person.

- It is difficult to build a successful relationship on a foundation of secrecy and half-truths.
- MS can affect a person's sexual feelings and responses even in the very early days of the illness. Do not hesitate to discuss any questions and concerns you have with your healthcare provider.
- Members of a couple, no matter how devoted or loving, may cope with the intrusion of MS into their lives in very individual ways. The goal is to recognize and respect each other's feelings and needs, and communicate openly.
- Most couples have more coping skills than they realize. Try to identify strategies that have worked for you in the past, and put them to work in your efforts to deal with MS.
- Couples don't need to wait until they are in a crisis to look for help. Becoming educated, learning to communicate more effectively and utilizing available resources will help you to maintain a satisfying, long-term relationship.

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 its management, contact the National MS Society at 1-800-344-4867 or visit nationalMSSociety.org or the following topic-specific pages:

- nationalMSSociety.org/bowel
- nationalMSSociety.org/bladder
- nationalMSSociety.org/emotions
- nationalMSSociety.org/intimacy
- nationalMSSociety.org/Living-Well-With-MS/Family-and-Relationships — A relationship enrichment course for couples living with MS, **8 Hours to a Lifetime of Happiness**
- nationalMSSociety.org/KIPintimacy

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)

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).

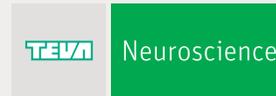
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The National MS Society’s mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through 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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nationalMSsociety.org

1-800-344-4867