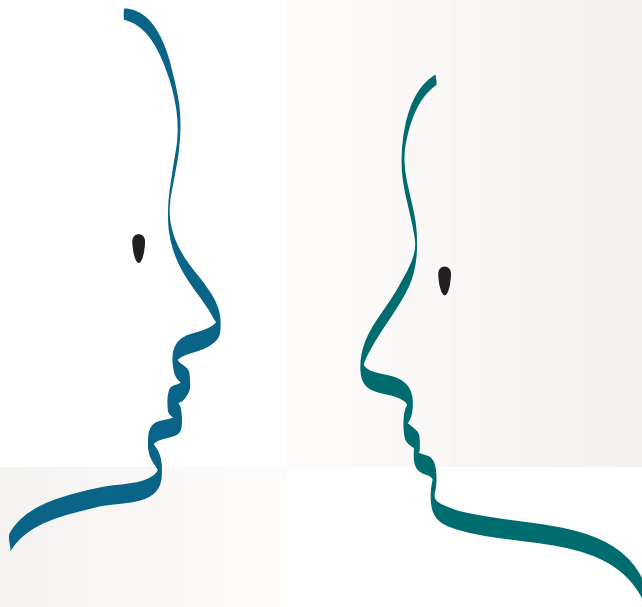


## Talking with Your MS Patients about Difficult Topics



**Rosalind Kalb, PhD, Editor**

### Introduction

This booklet is designed to facilitate conversations with your patients about family issues. MS intrudes just at the time in life when decisions are being made about marriage, children, and careers. From the time of diagnosis, the disease can affect the life cycle of the entire family, compounding and confusing the normal transitions and stresses of everyday living. It has often been referred to as the ‘uninvited guest’ who arrives one day, complete with baggage, and never leaves. It enters the household, taking up space in every room of the house and taking part in every family activity.

Discussions about the impact of MS on family relationships may be particularly difficult to initiate if time is limited or if either you or they feel uncomfortable raising the topic. The physician and nurse have an important role to play—in initiating the discussion, providing helpful information, and referring patients and their families to counseling professionals.

### 1. Why should I talk to my patients about family issues?

- Families living with MS usually find themselves in uncharted territory. Guilt, anger, sadness, and a sense of burden can become part of the family fabric, creating barriers to communication, intimacy, growth, and family unity.
- While many families are able to find a place for MS in their lives without allowing it to take over, other families give MS so much time and space that it dominates every aspect of their lives.
- In response to fears about disability and the unknown, some young adults abruptly change marriage, childbearing, and/or employment plans; others may not consider MS in their plans at all, denying the possibility that MS might have an impact on the future.
- Families differ markedly in their responses to the diagnosis of a chronic illness.
  - ▲ In some families, the person with MS may be discouraged from carrying out his or her usual household chores and participating in previously enjoyed activities for fear of making the symptoms worse. This overprotective approach can leave the person with MS feeling marginalized and undervalued.
  - ▲ In other families, the MS may be denied or ignored, particularly if the person has primarily invisible symptoms like fatigue, pain, or cognitive changes. Some family members may ignore and/or question the validity of MS.
- Cumulative disability can interfere with the performance of a person’s roles within the family. For example, a primary breadwinner may need to give up working; a parent may need help with childcare activities; a homemaker may be unable to manage

household tasks. As with every other loss brought about by MS, these major life changes need to be grieved before the individual and family can begin to make constructive adaptations.

### **2. What are some red flags that I need to look for in assessing the impact of MS on the family?**

- Every interaction with patient and family whether in person or by phone provides an opportunity to observe how a family is coping with MS. Keep an eye out for the following signs of possible dysfunction:
  - ▲ A spouse or other family member accompanies the patient to the office but the patient does not want the person to participate in the visit.
  - ▲ The patient or family members exhibit overt hostility during the visit.
  - ▲ One family member opts for openness about the MS while another is adamant about maintaining secrecy.
  - ▲ You notice signs of possible abuse during your interview and physical exam, such as passive, fearful behavior or bruises that are unaccounted for.
  - ▲ Your patient reports long periods of being left alone.
  - ▲ Your patient regularly runs out of medications, calls your office frequently for unclear reasons, misses appointments without calling.

### **3. What is the most appropriate way to respond to signs of family dysfunction?**

- It is important to share your observations with patient and family and express your concerns emphasizing that MS can be a challenging condition that often affects everyone in the family. By doing so, you have indicated your willingness to discuss these issues and opened the door for communication. Although many families will hesitate initially to discuss their problems, it is important to raise the subject periodically so that they feel free to talk about them when they are ready.
- Since coping difficulties are common in MS, you may want to refer your patients to mental health professionals in your community, preferably those familiar with MS. The National MS Society is an excellent source for these referral lists.

### 4. How and when should I include family members in the education about MS?

- Most individuals find that having some family and friends know about their MS from the beginning provides much needed support. They can share their concerns and mull over questions together.
- By encouraging inclusion of others in the educational process from the beginning, you help people feel less alone with their MS. Your patient doesn't have to go home and translate information to them and family and friends can ask their questions directly and feel included in the process. When family members are educated about MS, they are apt to be more understanding and encouraging.
- Encourage patients to bring a family member (or friend) with them to their visits to listen to information and ask questions. One person may ask a question that the other hadn't thought of or was hesitant to mention—yielding information that is useful for both of them.
- There is no right way to learn about MS and it is very common for people to have different learning styles. Point out that there is a variety of mechanisms for learning about MS and most people find a combination helpful. Some people hesitate to attend public education programs because they are uncomfortable being with others who might be more disabled than they are. For them, reading materials about MS may be more appropriate.

### 5. At what point is it appropriate to include children in the education about MS?

- Parents with primarily invisible symptoms may want to take some time to digest the diagnosis and initiate treatment before sharing information with their children. They may also feel that there is no reason to frighten their children by talking about a disease that has no apparent impact.
- Parents need to recognize, however, that children of all ages are sensitive to changes in moods and behavior even when the MS symptoms aren't obvious. Many children know something has happened even before being told; they sense a tension in the household, observe their parent(s) behaving differently, become aware of multiple doctor appointments, and notice that people stop talking when they enter the room.
- Talk with your patients about why educating their children is important. When parents are reluctant to talk about their MS, children can misinterpret the silence as an indication that the problem is so terrible that it can't be discussed. Some children assume their parent is dying and are relieved to hear the truth. Children who have basic information about the disease tend to be less anxious.

- Reassure your patients that most studies show that children of parents with MS do not have significant psychological or behavioral problems and may be more sensitive to the needs of others, more self-reliant, and less likely to take life for granted.
- Guide your patients to the resources at the end of this booklet for help in talking with their children about MS.

### **6. What is the best way for me to introduce information about MS to children?**

- Remember that a child's developmental level influences what he or she can understand about MS. Young children tend to think in concrete terms and have only a limited understanding of the passage of time, while adolescents are able to think more abstractly and consider how the here and now may affect the future.
- It can be helpful to ask children what they already know and what they want to know. School-aged children frequently want to know if their parent is going to die, if they can catch MS, or if they (or their behavior) caused it to happen. With access to the Internet, many children have already researched their parent's symptoms and MS diagnosis.
- It's useful to describe and demonstrate symptoms in a concrete way—for example, by describing MS fatigue as the feeling they would have if they tried to walk around with weights on their arms and legs, or spasticity as the feeling they would have if they walked with an elastic bandage wound tightly around each leg.
- Offer patients the opportunity to bring their older children to an office visit so the children can see what happens during the visit and ask their questions directly. This takes some of the secrecy out of MS and some of the pressure off the parents.

### **7. What resources are available to families who are feeling overwhelmed with caretaking responsibilities and have few personal resources?**

- Refer patients and families to the local chapter of the National MS Society for information and resources such as family counselors trained in MS, group programs where they can share concerns and with other individuals and families dealing with similar issues, and community agencies that may be able to provide home care.
- Of equal importance is respite for caregivers who sometimes just need a few hours out of the home to complete errands or participate in enjoyable activities such as exercise or church. The NMSS may also be able to provide referral to and financial assistance for respite care.

- Stress the importance of creating and maintaining a balanced care partnership where both the person with MS and his or her partner continue to contribute to family life.
- Sometimes families need specific types of assistance—such as medical equipment, services in the home, or financial assistance—which may be available through the National MS Society or other community organizations.
- Social workers who work with medically ill patients can evaluate patient and families needs and identify community-based programs for which they may be eligible, as well as assist them in completing the application process.

### **8. What can I do if it comes to my attention that children are providing personal care for their parent or taking on responsibilities beyond their years?**

- This situation is more likely to occur when a parent is more physically and/or cognitively impaired, socially isolated, single, or in a community where few services are available.
- Although helping around the house in age-appropriate ways is a reasonable expectation for all children, providing personal care is not.
  - ▲ Some children are permitted or asked to assist with the parent's injections as a way of helping them feel more involved. While an older teen may be ready to assume this responsibility for a severely disabled parent, younger children are not—particularly those who feel overwhelmed or frightened by the responsibility but are reluctant to upset their parent by saying “no.”
  - ▲ The kinds of physical contact that are required for personal care activities like bathing and bowel and bladder care often result in significant discomfort for both the child and the parent. In addition to emotional distress, these children may be absent from school more often, fall behind academically, and miss out on other important age-appropriate activities.
- When possible, encourage parents to identify another responsible adult such as a family member or friend who could help them with their care. In many cases, patients haven't asked for help because of pride, anticipation of being turned down, or expected cost.
- The National MS Society can provide referrals for community services. Additional resources include other MS organizations and the local Department of Human Services. Referral to a social worker with experience in MS can be very helpful in identifying and accessing needed services.

### **9. How do I handle family members who call me to express concerns about their loved one but don't want their family member to know?**

- In many cases, family members have valid concerns for the welfare of their loved one but communication difficulties and/or relationship problems make it difficult for them to discuss this directly. In other cases, there is concern for the safety of the person with MS because he or she is not sharing important information about their health with you.
- It is important for family members to know that trust between you and the person with MS is an essential ingredient of the doctor–patient relationship. When they don't want the patient to know they have called, it places you in a difficult situation and potentially jeopardizes your relationship with the patient.
- With your support, concerned family members can be encouraged to share their concerns directly with the person with MS. By doing so, they show respect and potentially strengthen their relationship.
- From the beginning, it is helpful to encourage patients to sign a Durable Power of Attorney for Healthcare so that a trusted individual can be designated to have access to medical information. By doing so, health-related information can be shared as needed.

### **10. What can I do if patients and families do not seek help in spite of my recommendation?**

- It is important to respect a patient's and family's wishes particularly when the situation is stable and no obvious harm is coming to anyone. You might start by expressing your concern about not seeking help and asking them to share their thoughts about this. Within many families there are strong opinions about the need to keep family business within the family as well as a distrust of mental health professionals, sometimes based on prior negative experiences.
- Many patients are more willing to see a mental health professional that you know and who has knowledge of and experience in MS.
- Stressing the relationship between physical and mental health and giving generic examples of how professional help has been of benefit to others of your patients can also be useful in encouraging patients to access mental health care.

### 11. What other resources are available to help my patients with family issues?

- Chapters of the National MS Society (1-800-FIGHT-MS) offer:
  - ▲ Educational programs and support groups
  - ▲ Referrals to professionals in the community who specialize in the counseling families and are familiar with MS
  - ▲ Printed materials specifically for children whose parent has MS are available from the National Multiple Sclerosis Society by calling 1-800-FIGHT-MS or on the website at [www.nationalmssociety.org/Brochures](http://www.nationalmssociety.org/Brochures)
    - *Keep S' myelin*, a quarterly newsletter for children who have a parent or other loved one with MS. Also available on line at the NMSS website.
    - *Teen Inside MS*. A special edition of Inside MS, the NMSS quarterly magazine.
    - *Someone You Know Has MS*
    - *Plaintalk: A Booklet about MS for Families*
    - *When a Parent Has MS: A Teenager's Guide*
    - *Timmy's Journey to Understanding MS*
    - *MS and Intimacy*
    - *A Guide for Caregivers*
- National MS Society website ([www.nationalmssociety.org](http://www.nationalmssociety.org)) offers information on a wide variety of topics (e.g., disease-modifying therapies, symptom management, research), as well as access to local resources and events.
- Additional recommended websites:
  - ▲ Multiple Sclerosis Society of Canada. [www.mssociety.ca](http://www.mssociety.ca)
  - ▲ Multiple Sclerosis International Federation. <http://www.msif.org>
  - ▲ Pharmaceutical Company Support Programs
    - Betaseron—MSPathways. [www.mspathways.com](http://www.mspathways.com)
    - Avonex—MS Active Source. [www.msactivesource.com](http://www.msactivesource.com)
    - Copaxone—Shared Solutions. [www.sharedsolutions.com](http://www.sharedsolutions.com)
    - Novantrone. [www.novantrone.com](http://www.novantrone.com)
    - Rebif—MS Lifelines. [www.mslifelines.com](http://www.mslifelines.com)



- ▲ Clinical trials
  - CenterWatch Clinical Trials Listing Service™. <http://www.centerwatch.com>
  - National Institutes of Health (NIH) Clinical Trials Listing Service. <http://www.ClinicalTrials.gov>
  - Infosci Selected Links on MS. <http://www.infosci.org>
- ▲ Family support
  - [www.nfcacares.org](http://www.nfcacares.org). National Family Caregivers Foundation. NFCA is a grass roots organization created to educate, support, empower and speak up for the millions of Americans who care for chronically ill, aged, or disabled loved ones.
  - [www.msworld.org](http://www.msworld.org). MS World provides global Internet community support to people with multiple sclerosis. Offers chat rooms for caregivers and monitored bulletin board for children teens.
  - [www.caregiver.org](http://www.caregiver.org). Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home.
  - [www.wellspouse.org](http://www.wellspouse.org). Well Spouse Foundation is a national, not-for-profit membership organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled.
  - [www.lookingglass.org](http://www.lookingglass.org). Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent, or grandparent has a disability or medical issue.
- Recommended reading:
  - ▲ Kalb R (ed.). (2006). *Multiple Sclerosis: A Guide for Families* (3rd ed.). New York: Demos Medical Publishing.
  - ▲ Kalb R (ed.). (2004). *Multiple Sclerosis: The Questions You Have, The Answers You Need* (3rd ed.). New York: Demos Medical Publishing.
  - ▲ Cohen MD. (1992). *Dirty Details: The Days and Nights of a Well Spouse*. Philadelphia: Temple University Press.
  - ▲ Cristall B. (1992). *Coping When a Parent Has Multiple Sclerosis*. New York: Rosen Publishing Company.
  - ▲ Strong M. (1997). *Mainstay: For the Well Spouse of the Chronically Ill* (3rd ed.). Northampton, MA: Bradford Books.

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Dr. Crawford has conducted research on depression in patients taking beta interferon, group psychotherapy as a treatment modality in chronic illness, and psychosocial outcomes in MS and epilepsy surgery patients. Her publications have focused on issues related to coping with chronic illness and the psychological aspects of MS including depression and the special challenges involved in parenting with MS.

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