Parenting with MS

- MS does not determine a person’s parenting skills.
- There is no single correct way to be a parent; love and security can come in a variety of packages.
- As a parent with MS, you may need to do things a bit differently than you would have otherwise.
- Accurate information about MS can be very reassuring to children.
- Communicating openly about the challenges that MS brings to your life, and the coping strategies you are using to meet those challenges, gives children the important message that family members can work together to meet life’s challenges, whatever they may turn out to be.

It will be important for you to let your children know whom they can talk to about your MS (e.g., mom, dad, grandparents, and Aunt Karen) and who doesn’t have any need to know about it (e.g., strangers, kids at school or neighbors).

In deciding whether or not to talk openly with children about the MS, each family must evaluate the potential consequences. For example, a parent might not want the MS to be talked about outside the family if it poses a threat to employment. Balanced against this concern is the fact that children sense very clearly when one or another parent is ill or distressed and may develop their own worries about what is going on. As you sort out your own priorities and concerns in this area, stay alert to your children’s signals. While they may not come right out and ask what is wrong, they may demonstrate in other ways that they are curious, worried, or upset by changes in Mom or Dad.

Over time, information about MS is useful to children in a variety of ways. The information can:

- Provide reassurance and help them feel more secure.
- Create a boundary around their fears so that overactive imaginations don’t make things more frightening than they need to be.
- Provide children with a vocabulary for asking questions.
emotional climate in the household. When children are not given the information they need to explain the changes they sense, their imaginations simply fill in the gaps — usually with less-than-accurate information.

Fourth, by talking openly and honestly with your children about MS, you set the stage for effective parent-child communication about other issues that may arise in your life or theirs.

**Disclosure Is a Multi-Stage Process Involving People in All the Different Areas of Your Life**

The decision to disclose your diagnosis is not a simple one. In general, you will base disclosure decisions on your own needs and priorities while also taking into account the needs and priorities of these other important people. You will want to consider what is to be gained — and lost — in your various personal and professional relationships by sharing this information.

Keep in mind, as you begin to talk with others about MS, that people will generally look to you to guide them in their response to your MS. Your ability to educate them about the disease and reassure them that MS is now a part of your life, but not the whole of it, will tend to minimize the impact of this new information about you.

**Taking the First Steps**

- While each person with MS has a chronic, neurologic disease, no one person’s MS is exactly like anyone else’s.
- Over the course of your MS, you may experience some of the symptoms described in this volume and not others. Being knowledgeable about MS is your best strategy for dealing with the unpredictable nature of this disease.
- As you experience new or changing symptoms, take time to educate yourself about them — what they are, how they affect your life — and management strategies for dealing with them.
- It is very important that you learn about your MS, not everyone else’s.
- Keep in mind that your reaction is just that — your reaction. It may differ not only from what was discussed in this volume, but from the reactions of others around you. And it may well change over time.
- Flexibility and creativity will be your keys to managing the day-to-day challenges of MS. When MS interferes with your ability to do something when and how you want to do it, look for alternative strategies and tools to get the job done.
There are no set “stages” to a person’s reactions to MS. Your feelings will reflect the changing ways in which MS affects your life and the lives of people close to you.

Remember that you do not have to handle your feelings alone; there are a variety of resources available to help you.

In making the decision(s) to disclose your diagnosis, think about:

- Whom you are telling
- What you are going to tell them
- Why you are telling them and what you expect in the way of a response

You need to be prepared to educate people about your MS, and be ready to hear different responses.

In general, people will be looking to you to let them know how to respond to your news.

It’s never too early to consult a financial planner about how to plan for an unpredictable disease like MS. Call 1-800-344-4867 to learn about the free financial information and advice available through Financial Education Partners, the National MS Society’s collaborative program with the Society of Financial Service Professionals.

Additional 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 the Society’s website at nationalMSsociety.org or the following topic-specific pages:

- Information for Those Newly Diagnosed
  nationalMSsociety.org/newlydiagnosed

- General Information about MS
  nationalMSsociety.org/aboutMS

- Exacerbations
  nationalMSsociety.org/exacerbation

- Treatments Used in MS
  nationalMSsociety.org/treatments
Disease-Modifying Treatments for MS

- According to MS experts, initiation of treatment is now advised for any person with a confirmed diagnosis of MS who has active symptoms or evidence of disease activity on his or her MRI scans. Treatment may also be considered for people who have experienced their first clinical episode and have MRI-detected brain lesions consistent with MS (clinically-isolated syndrome).

- By educating yourself about the route of delivery, possible benefits and potential side effects of each of these medications, you can be an informed partner in making treatment decisions.

- Your best sources of additional information about these medications are your healthcare providers, the National Multiple Sclerosis Society and the pharmaceutical companies who distribute the medications.

- As with all medications, it is important for women who are pregnant or wish to become pregnant to consult with their physicians about the use of any of these medications.
Employment and Financial Security

- You can continue to work for as long as you are interested and able.
- Becoming educated about your company’s benefits and your rights and responsibilities under the ADA will help you maximize your options and prepare for the decisions ahead. Recommended websites to explore include:
  - U.S. Department of Labor Office of Disability Employment Policy
dol.gov (866-633-7365)
  - U.S. Equal Employment Opportunity Commission
eecoc.gov (800-669-4000)
  - U.S. Department of Justice ADA
da.gov (800-514-0301)
  - Social Security Administration Office of Employment Support
ssa.gov/work (800-772-1213)
  - National Organization on Disability
nod.org (202-293-5960)

- Become more familiar with the ADA and accommodation strategies that may be helpful to you. Contact the Job Accommodation Network (JAN) at 1-800-526-7234 or visit them online at jan.wvu.edu. Learn more about the ADA Technical Assistance Program at ada.gov.
- Take responsibility for your own job performance; don’t wait for your employer to do it for you. It is your responsibility to identify and request the accommodations you need to function at an optimal level.
- Be proactive. Don’t wait until you are already in a crisis situation to take action. Once your job performance is under review, it can be far more difficult to ask for, and be given, the necessary accommodations.
- When you begin to disclose, it is important to determine who needs to know. Is it your immediate supervisor or someone in the human resources or personnel department? As much as possible, you should be the one in control of what information is shared, with whom, and when.
- Learning to manage life’s stresses is far more effective and satisfying in the long run than trying to avoid them.
- Sound financial planning today can help you feel more prepared for the unpredictability of the future.
- Use the available resources to help you; there is no need to “go it alone.”
Employment and Financial Security

Things to Think About

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  - U.S. Department of Labor Office of Disability Employment Policy
dol.gov (1-866-633-7365)
  - U.S. Equal Employment Opportunity Commission
eeo.gov (1-800-669-4000)
  - U.S. Department of Justice ADA
ada.gov (1-800-514-0301)
  - Social Security Administration Office of Employment Support
ssa.gov/work (1-800-772-1213)
  - National Organization on Disability
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- Use the available resources to help you; there is no need to “go it alone.”
Treating Yourself Well

- While this brief overview of symptoms and treatments may be overwhelming, remember that no two people have identical symptoms. You may or may not experience the symptoms described here.
- By educating yourself about the possible symptoms of MS, you will feel more prepared and less frightened when, and if, you experience one of them.
- You will get a lot of well-meaning advice from friends and relatives. Keep in mind that your best sources of accurate, reliable and up-to-date information about treatments in MS are your healthcare providers and the National Multiple Sclerosis Society.
- People can be healthy and well in spite of having MS.

Additional 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 the Society’s website at nationalMSsociety.org or the following topic-specific pages:

- **Symptoms**
  nationalMSsociety.org/symptoms
- **Treatments**
  nationalMSsociety.org/treatments
- **Healthy Living with MS**
  nationalMSsociety.org/healthy
- **Medications Used in MS**
  nationalMSsociety.org/meds
- **Educational Videos**
  nationalMSsociety.org/educationalvideos
Again, much of the burden for re-establishing contact may land on you. Decide which of the people in your life are most important to you — family members, friends, colleagues, neighbors — and reach out.

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

Maintaining Healthy Relationships

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

- **Urologist** — A physician who specializes in the branch of medicine (urology) concerned with the anatomy, physiology, disorders and care of the male and female urinary tract, as well as the male genital tract.

While you may never need these types of specialty care, it can be very comforting to know that there are a variety of health professionals available to help you manage whatever types of problems may arise.

**A Word About Insurance**

The world of insurance has gotten increasingly complex in the last several years. If you haven’t already done so, it would be well worth your while to familiarize yourself with your insurance plan, particularly concerning what access you have to specialty care in the event that you need it.

The National MS Society can answer questions about health insurance coverage and direct you to additional information or consultation if you are in need of it.

- It is important for you to feel comfortable with your doctor so that you can be an active partner in your health care. Recent changes in healthcare policies have made this truer now than ever before. Effective teamwork is the key to successful management of MS.

- Regular visits with your MS provider are important. Try to prepare for the visit ahead of time so it is productive and informative for you.

- New symptoms can be worrisome, and you will want to inform your doctor about them. Discuss the optimal methods for communication with your doctor so that your questions and concerns are addressed and any worry or anxiety is minimized.

- As you work to establish a comfortable, collaborative relationship with your MS doctor, be sure to pay adequate attention to your general health and wellness. People with MS have the same need for exercise, a healthy diet and regular medical screenings as everyone else.
Nurses, physical therapists, psychologists and other healthcare professionals can be valuable resources for people living with MS. It is important to become knowledgeable about all your resource options.

If you haven’t done so already, now is the time to familiarize yourself with the coverage provided by your health insurance plan. Find out about your plan’s appeals process in the event that coverage is denied for a particular type of treatment or medication.

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 the Society’s website at nationalMSsociety.org or the following topic-specific pages:

- **Having a Good Doctor Visit**
  nationalMSsociety.org/docvisit

- **Health Insurance and Medicare**
  nationalMSsociety.org/insurance

- **Symptoms of MS**
  nationalMSsociety.org/symptoms

- **Educational Videos**
  nationalMSsociety.org/educationalvideos

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

- See the Publications Catalog that was mailed with Volume 1 of this series or visit nationalMSsociety.org/brochures
Building and Maintaining Intimate Relationships

- 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 will need to 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.
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