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# 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.

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# 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.

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# 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.

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# 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**  
eeoc.gov (800-669-4000)
  - **U.S. Department of Justice ADA**  
ada.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 800-526-7234 or visit them online at [jan.wvu.edu](http://jan.wvu.edu). Learn more about the ADA Technical Assistance Program at [ada.gov](http://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."

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# 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.

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# 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 is 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.



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# Working with Your Doctor

- 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.

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# 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.