



National
Multiple Sclerosis
Society

Self Advocacy for Family Roles and Responsibilities

Introduction

This guide is intended to assist people with multiple sclerosis address a variety of issues which may arise within the family context. Roles and responsibilities vary from individual to individual and from family to family. The purpose of this guide is not to define these personal relationships, but to anticipate questions and identify appropriate resources to help you navigate the interplay between MS and family dynamics, and advocate for yourself.

The National MS Society's Self Advocacy Worksheet complements this guide. This worksheet is available at <http://staging.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-in-the-family-environment/download.aspx?id=8130>. It is intended to assist you in planning your course of action for self advocacy within the family. Reference it to assess your circumstances, concerns or needs, and to identify your aims or goals. You can also find a sample worksheet at <http://staging.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-in-the-family-environment/download.aspx?id=8140>.

Disclosing your MS diagnosis

Whether someone is newly diagnosed or has been living with multiple sclerosis for years, inevitably the topic of disclosure arises. How, when and to whom to disclose a diagnosis is a personal decision and varies by individual. You may wish to consider these questions to evaluate how, when and to whom to disclose your diagnosis.

Questions to ask yourself

- **Why do you want the person to know?**
To share personal information with an important person in your life? To explain recent physical or emotional changes? To rally assistance and support?
- **What do you want this person to understand about your MS?**
What MS is? How it affects you? How changeable and unpredictable it is? What you're doing to treat it? That it's not contagious? That it's not fatal? That it's not something else?
- **What is the best way to deliver the information?**
In a face-to-face conversation? With a pamphlet that the person can take and read? By reading a book about MS together? By watching an online program together? By attending an educational meeting together?

- **What kind of response do you expect to get?**
Shocked silence? Sadness and tears? Fear? Lots of questions? Stories about other people with MS? Suggestions for what you should do? Offers of assistance? A hug?

To request a printed version of any of the following resources by mail, call an MS Navigator® at 1-800-344-4867.

- **What should I consider before I disclose my MS diagnosis?**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/disclosure/index.aspx>
- **Tips on disclosing to family and co-workers**
<http://www.nationalmssociety.org/download.aspx?id=47>
- **Disclosure dos and don'ts**
<http://www.nationalmssociety.org/download.aspx?id=527>
- **How do I tell my spouse I have MS?**
 - **Relationship Matters: The National MS Society's couples program**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/relationship-matters/index.aspx>
 - Contact the National MS Society at 1-800-344-4867 or e-mail: couplesprogram@nmss.org
- **How do I explain multiple sclerosis to my children?**
 - **Keep S'myelin, the Society's quarterly interactive children's newsletter:**
<http://www.nationalmssociety.org/multimedia-library/kids-keep-smyelin/index.aspx>
 - To receive **Keep S'myelin**, call your chapter at 1-800-344-4867 or e-mail keepsmyelin@nmss.org.
 - **Someone You Know Has MS: A book for families**
<http://www.nationalmssociety.org/multimedia-library/brochures/for-children--teenagers/download.aspx?id=318>
 - **National MS Society video: Timmy's Journey**
<http://www.nationalmssociety.org/multimedia-library/videos--dvds/timmy's-journey-to-understanding-ms/index.aspx>
- **Teens**
 - **When A Parent Has MS: A teenager's guide**
<http://www.nationalmssociety.org/multimedia-library/brochures/for-children--teenagers/download.aspx?id=319>

Roles within the family

In today's world, family roles and responsibilities are as varied as the individuals within the family. As a person living with MS, you may see a need to change the structure of your family as well as the various roles and responsibilities of each family member. Questions and the need for new resources may arise as together all of you tackle new roles and shifting responsibilities.

- **How will our family adjust to new roles within the family structure?**
 - **Multiple Sclerosis: A Guide for Families** (3rd Edition) by Rosalind C. Kalb, PhD. \$24.95, Demos Medical Publishing (2006) ISBN # 1932603107
<http://www.nationalmssociety.org/multimedia-library/books/a-guide-for-families/index.aspx>

- **Family members as caregivers**
 - **[The Comfort of Home, Multiple Sclerosis Edition: An Illustrated Step-by-Step Guide for Caregivers](#)** by Maria M. Meyer and Paula Derr, \$24.95, Demos Medical Publishing (2006) ISBN # 096647676X

 - **[A Family Caregiver Speaks Up](#)** by Suzanne Geffen Mintz, \$14.95, NFCA, (2007)
http://thefamilycaregiver.org/caregiving_resources/a_family_caregiver_speaks_up.cfm

 - **Respite Care**
National MS Society chapters can provide referrals to respite care services. To find your chapter visit <http://www.nationalmssociety.org/find-a-chapter/index.aspx> or call 1-800-344-4867.

 - **National Family Caregivers Association**
<http://thefamilycaregiver.org/index.cfm> or call 1-800-896-3650

- **How do we resolve issues and promote communication as a family?**
National MS Society chapters can provide referrals to support groups and professional counselors. To find your chapter visit <http://www.nationalmssociety.org/find-a-chapter/index.aspx> or call 1-800-344-4867.

Intimate Relationships

Intimate relationships are crucial to creating and maintaining a family. Living with MS can bring about a component of uncertainty to those relationships. The following resources will aid you in answering questions that may arise between you and your partner when MS is a factor.

- **How will MS affect my marriage?**
 - **Webcast: Positive Relationships**
Positive Relationships featuring Jude Meyer, Clinical Psychologist
<http://www.nationalmssociety.org/multimedia-library/webcasts--podcasts/positive-relationships/index.aspx>
 - **Relationship Matters: A Program For Couples Living with MS**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/relationship-matters/index.aspx> or contact the National MS Society at 1-800-344-4867 or couplesprogram@nmss.org
- **Does MS affect a couple's intimacy?**
 - **Intimacy and Sexuality in MS: Staying Well**
<http://www.nationalmssociety.org/download.aspx?id=152>
 - **Enabling Romance** by Ken Kroll and Erica Levy Klein, \$5.95, No Limits Communications (2001) ISBN # 0971284202
<http://www.nationalmssociety.org/multimedia-library/books/enabling-romance/index.aspx>
 - **The Sexual Health Network**
Provides information on sexuality for those with disabilities and illnesses.
<http://www.sexualhealth.com/>
 - **The Marriage and Family Health Center**
Offers sexuality education and therapy programs.
<http://www.passionatemarriage.com/> or call: 1-303-670-2630
- **Dating**
 - **Will MS affect my ability to date?**
 - **Real Talk Real Answers: Living with MS in your 20s and 30s**
(National MS Society online program)
<http://www.realtalkrealanswers.com/>
 - **When and how do I tell the person I am dating that I have MS?**
 - **Dating Online: a Guide for Greenhorns**, from **Inside MS**, August-September 2007
<http://www.nationalmssociety.org/download.aspx?id=281>

Family Planning

Some couples may be well along the path of raising children when MS enters their lives. For others, the diagnosis may come before family planning decisions have been made. Therefore, a number of questions may arise regarding whether to have a family when MS is a factor. The following resources and probable questions will help you to become your own best advocate in this process.

To have a printed copy of any of the following mailed to you, call an MS Navigator® at 1-800-344-4867.

- **As a couple with MS, do we still have the ability to have children?**
 - **MS & Pregnancy Kara's Story**, National MS Society video
<http://www.nationalmssociety.org/multimedia-library/videos--dvds/ms--pregnancy/index.aspx>
 - **Reproductive Issues in Persons with Multiple Sclerosis** by Barbara Geisser, MD.
<http://www.nationalmssociety.org/download.aspx?id=168>
 - **Pregnancy and Reproductive Issues**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/index.aspx>
 - **Talking about Reproductive Issues** by Rosalind Kalb, PhD.
<http://www.nationalmssociety.org/download.aspx?id=174>
 - **MS and Pregnancy**, from **Inside MS**, April-June 2003.
<http://www.nationalmssociety.org/download.aspx?id=58>

Fertility and the MS disease-modifying drugs

- **Do the disease-modifying drugs affect contraception, fertility, pregnancy? Delivery or breastfeeding?**
 - **Medical Management During Pregnancy, Delivery, and Postpartum**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/pregnancy-registry/index.aspx>
 - **Pregnancy Registries for the Interferon Beta Products Prescribed for Women with MS**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/pregnancy-registry/index.aspx>
 - **Avonex Registry**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/pregnancy-registry/download.aspx?id=12>
 - **Betaseron Registry**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/pregnancy-registry/download.aspx?id=13>

- **Rebif Registry**

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/pregnancy/pregnancy-registry/download.aspx?id=19>

- **Is there a risk that my children may develop MS?**

Transmitting MS to Children: Possible Differences in Men and Women

<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=90>

Additional Resources

Financial Planning for the Future

- **Guidebook: Adapting: Financial Planning for a Life with Multiple Sclerosis**

<http://www.nationalmssociety.org/download.aspx?id=11>

What types of financial issues should our family plan for?

- **Vehicle Modification (Adapted Vehicles)**

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/mobility-and-accessibility/buying-an-adapted-vehicle/index.aspx>

- **Home Modification (Universal Design/stair lift)**

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/mobility-and-accessibility/affording-stair-lifts-ramps-and-wheelchairs/index.aspx>

- **How will having MS affect my family's health insurance?**

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/health-insurance/faqs-health-insurance/index.aspx>