



## Resources for Parents Living with MS and Their Families

As a parent you may struggle with how to talk to your children about MS and the ways it may affect your family. You may also be seeking information on parenting and MS.

You may be wondering:

- How much should I tell my children about MS?
- Will talking about it make it more confusing, frightening or burdensome for them and me?

Children are far less fragile than you think. It is natural to want to protect them by hiding painful issues, but open and honest communication is valuable and important. Finding comfortable ways to talk about MS can be an important step in that process.

Improving or maintaining family functioning is key to helping you and your children adapt to life with MS. The National MS Society provides children and parents with accurate information about a complicated disease, in a way that is easy to understand and fun to use.

For more information or on any of the resources discussed here, please contact an MS Navigator® at 1-800-344-4867 or visit [www.nationalMSSociety.org](http://www.nationalMSSociety.org).

## Publications and DVDs

### Publications

#### *Keep S'myelin®: A Newsletter about MS for Children*

A newsletter for children ages 5-12. Each issue addresses a different topic related to MS. Chapters are provided with new issues each quarter. Interactive versions are also available on the web at [www.nationalmssociety.org](http://www.nationalmssociety.org). To register call 1-800-344-4867 or email [keepsmyelin@nmss.org](mailto:keepsmyelin@nmss.org).

Also available is the *Keep S'myelin Activity Book*. The 24-page activity book is a colorful, engaging, informative, and reassuring publication to help parents and their children talk and learn about MS together. The book features information on a variety of MS-related topics, such as: what is MS, who treats people with MS, feelings, and communication strategies, along with games and activities. The activity book is available in English and Spanish.

#### *Someone You Know Has MS: A Book for Families*

For children, ages 5-12. A story about Michael and his family explains MS and explores children's fears and concerns. Adapted by Martha King from original material by Cyrisse Jaffee, Debra Frankel, Barbara LaRoche, and Patricia Dick.

#### *When a Parent Has MS: A Teenager's Guide*

For older children and teenagers who have a parent with MS. Discusses real issues brought up by real teenagers. By Diane O'Connell with the Programs staff of the National MS Society.

*How to Talk About MS with Your Children*, a publication of the MS Society of Canada. Available for download at <http://mssociety.ca/en/pdf/talkChildren.pdf>.

### DVDs

#### *Timmy's Journey to Understanding MS*

A 15 minute cartoon featuring a young boy named Timmy and his trusted guide, Captain Kip S'myelin. When Timmy becomes frustrated by his dad's MS, he is visited by his new friend, Captain S'myelin, who takes Timmy on an exciting trip through the human body to learn about MS. Through his journey, Timmy gains a better understanding of MS and becomes more accepting of the unpredictability

MS can bring. The cartoon is available in both English and Spanish on the same DVD.

### *MS & Pregnancy*

This DVD covers the Kara's journey through her own decision to become pregnant while answering many of the questions associated with pregnancy and MS, and includes interviews with experts in the field of pregnancy and MS. Ideal for doctors, neurologists, people with MS and, of course, women with MS who are thinking about becoming pregnant and their partners.

*Talking with Your Children about Multiple Sclerosis: A Place to Begin*, a product of Direct Health Media.

## **Programs**

### *Relationship Matters: A Program for Couples Living with MS*

The Relationship Matters program exists to help couples minimize the impact of MS on their lives by:

- Improving communication and learning to resolve conflicts
- Learning how to have greater fulfillment in their partnership
- Learning how to manage MS as a team
- Developing skills for life
- Helping their partnership thrive

Couples participating in the program have the opportunity to engage in a relevant and creative course curriculum designed to deal with challenges related to MS. Couples choose the format of learning that best suits their lifestyle and approach to learning, whether it is in person, online, on the phone, or a combination of the three.

### *Knowledge is Power*

The Knowledge Is Power (KIP) program is as an at-home educational series for people newly diagnosed with MS and their families, but could be adapted for use in the group setting. Knowledge Is Power provides information about dealing with one of the greatest challenges presented by MS - the unpredictability and uncertainty of the future.

The volumes offered as part of the KIP program are:

- Taking the First Steps: What is MS? Dealing with Your Diagnosis & Disclosure
- Disease-modifying Treatments for MS
- Maximizing Your Employment Options
- Treating Yourself Well
- Maintaining Healthy Relationships: Family, Friends, and Colleagues
- Working with Your Doctor
- Building and Maintaining Intimate Relationships
- Parenting with MS

### *Scholarship Program*

MS shouldn't stand in the way of an education. This is why the National MS Society's scholarship program exists - to help highly qualified students who have been diagnosed with MS or who have a parent with MS achieve their dreams of going to college. The scholarship program is open to:

- High school seniors who have a parent with MS who will be attending an accredited post-secondary school for the first time.
- High school seniors who have MS and will be attending an accredited post-secondary school for the first time.
- High school (or GED) graduates of any age who have MS and who will be attending an accredited post-secondary school for the first time.
- High school (or GED) graduates of any age who have a parent with MS and who will be attending an accredited post-secondary school for the first time.
- Applicants must be United States citizens or legal residents living in the U.S., Puerto Rico, U.S. Virgin Islands, Guam or any other U.S. territory and plan to enroll in an undergraduate course of study at an accredited two-or four-year college, university, or vocational-technical school located in the U.S., PR, VI, Guam or any other U.S. territory. Applicants must be enrolled in at least six credit hours per semester in course work leading to a degree, license, or certificate.

## Online Learning

### *MS Learn Online*

MS Learn Online is the National MS Society's online educational webcast series. New webcasts are debuted bi-monthly, but past webcasts can be viewed at any time from the Society's website ([www.nationalmssociety.org/MSLearnOnline](http://www.nationalmssociety.org/MSLearnOnline)). Anyone interested in receiving the email notification of new programs can register for the mailing list by emailing [mslearnonline@nmss.org](mailto:mslearnonline@nmss.org).

### Online Courses

#### *My Life, My MS, My Decisions*

*My Life, My MS, My Decisions* is a program to help people with MS make medical decisions about all aspects of their health. The program includes a DVD and four online classes:

1. Teaming Up with Your Healthcare Providers
2. Navigating the Medication Maze
3. Considering Clinical Trials
4. Achieving Optimal Wellness

The DVD follows three different people through the medical decision-making process:

- Annie is a woman in her twenties, who has been recently diagnosed. Her doctor would like her to begin taking a disease modifying medication, but she is feeling a bit reluctant. She researches the medications, talks with her doctor, and decides to start. During her decision-making process, she explores clinical trials, addresses her depression and overall good health.
- James is in his thirties and has had MS for 10 years. It is affecting his walking and his physical relationship with his partner. James talks with his doctor and his partner, researches possible medications, talks with his pharmacist about side-effects of medications, and decides to try an ED medication. James explores clinical trails, works on his relationship with his partner, and finds new ways to stay healthy.
- Joann is in her forties and uses a wheelchair to get around. She feels that her MS is getting worse and her current doctor isn't willing to try some of the newer therapies. She decides to change doctors. Her new

doctor encourages her to explore a clinical trial and she decides to participate.

The online courses provide more in-depth information and decision making tools.

#### *Adapting: Financial Planning for a Life with MS Together*

MS can be an expensive disease. Participants can learn how to plan for their financial future as a couple through classes in budgeting, debt management, and building savings.

#### *Intimacy: Enriching Your Relationship*

Participants in this class can learn how to talk about the tough issues that can get in the way of true intimacy. The class presents creative ways to address and overcome those issues in a relationship.

#### *Career Decisions: Relationship Matters*

Employment concerns can add strain to any relationship and MS can make these issues even more challenging. Through participation in this class couples can learn strategies to manage employment choices together.

To access any of these online classes go to

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/society-programs-and-services/online-classes/index.aspx>.

## **Support and Connection**

National MS Society connection programs bring together people who share a common life experience for support, education and mutual aid.

Benefits of participating in a connection program include:

- Learning new information and strategies for managing your MS
- Finding support from others
- The opportunity to help others
- New power and confidence in facing the challenges of living with MS

Connection programs are available in a variety of formats including:

- In-person
- On the phone
- Online
- Group settings
- One-on-one opportunities

Connection programs are based on the belief that positive personal change happens through individual efforts with the support of others.

The Society recognizes the valuable role these programs play in addressing the informational, emotional and social support needs of our members. For more information about these programs in your area, call 1-800-344-4867.

### *MSFriends Telephone Peer Support*

MS knows no timetable – this is why we offer support when you want and need it.

MSFriends is a telephone-based peer support program for people living with MS. The MSFriends program connects you with volunteers living with MS. The common bond of living with MS creates a unique connection. MSFriends volunteers complete a rigorous screening and training program and are focused on the needs of those who call for support.

What are the benefits of an MSFriends peer relationship?

- Having someone who knows first-hand what it is like to live with MS to talk with and share your story. MSFriends is there to help you deal with the changes brought about by MS.
- Having a relationship that provides you with a sounding board for good decision-making and problem solving.
- MSFriends is just a telephone call away — ready to help you.

Call the MSFriends at 1-866-673-7436. All of your conversations are confidential to the peer relationship.

Please note – Our goal is to answer every call at the time it comes in. However, MSFriends is a network of people living with MS. While we are trying hard to serve everyone as quickly as we can, there may be times when an MSFriends volunteer is not able to immediately answer your call. When that happens, you

will hear a recording in which we will ask you to please leave a message. If that happens, please leave your name and complete phone number with area code and an MSFriends volunteer will contact you within 24 hours. You may also call back after waiting a little while. We are working hard to build our capacity so that every call is answered at the moment it is received, and we appreciate your understanding while we grow.

### Online Communities

The MS Society of Canada offers bulletin boards for children and teens with a parent with MS, as well as parents with MS, are sponsored by:

- [www.msforkids.com](http://www.msforkids.com)
- [www.msforteens.com](http://www.msforteens.com)
- [www.msforparents.com](http://www.msforparents.com)

MSWorld<sup>®</sup>, Inc.

MSWorld provides a global virtual community of support to people living with multiple sclerosis. The site's sole mission is to create a safe, informative, useful, and fun place for people to meet, share ideas and gain useful resources to help manage and cope. MSWorld maintains a well-trained staff of volunteers that moderate live chats, message boards and other resources to provide a safe and useful online community. ([www.msworld.org](http://www.msworld.org))