

Knowledge Brochure Series

# MS & BUILDING A SUPPORT NETWORK



# The right network makes all the difference

Living with multiple sclerosis (MS) can motivate individuals to connect. Whether it is meeting an individual with a similar MS experience or talking about MS with your child, this booklet can help guide you through building your support network. Inside you will find tips for having productive conversations with your doctor, different ways to support your CarePartners, and a variety of opportunities for individuals to connect with you and the MS community. Strengthening your support team should be an enjoyable and fulfilling process. This booklet aims to ensure that.



\*Peers with relapsing forms of MS.  
MS Peers are compensated by Teva.

# An opportunity to give back—become involved in your MS community

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Being engaged—not just in your MS management but in your MS community—can be extremely rewarding.

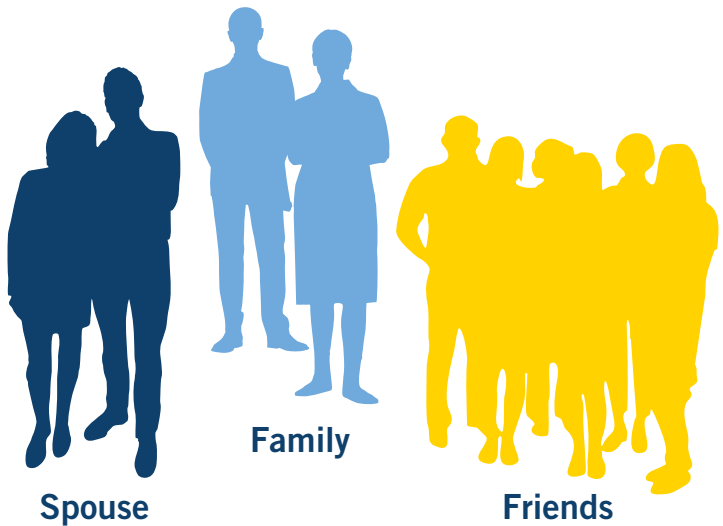
- Attend local programs
- Volunteer for MS patient events
- Learn how to raise funds for MS research
- Get to know your peers—be inspired and feel connected
- Reach out to your local National Multiple Sclerosis Society (NMSS) chapter about volunteering opportunities
- Join online communities
- Be an MS activist—visit the Get Involved section of the NMSS website to determine how you can best influence government policies and programs

# CarePartners—your trusted circle

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CarePartners are individuals who work closely with you to manage your MS on a daily basis. Through patience and open communication, there's a lot you can accomplish with the help of your CarePartners:

- Learn about MS together
- Research tips and techniques for managing daily activities
- Educate your family and friends—including your children—about your MS
- Stay proactive and positive
- Find ways to get involved with the MS community



# Maintain a healthy lifestyle as a CarePartner

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While CarePartners provide emotional and physical support to others, it is also important that their own needs are not neglected. An essential part of being a reliable CarePartner is tending to one's own health. Here are some tips for your CarePartners to help them maintain healthy lifestyles and build their own support networks<sup>1</sup>:

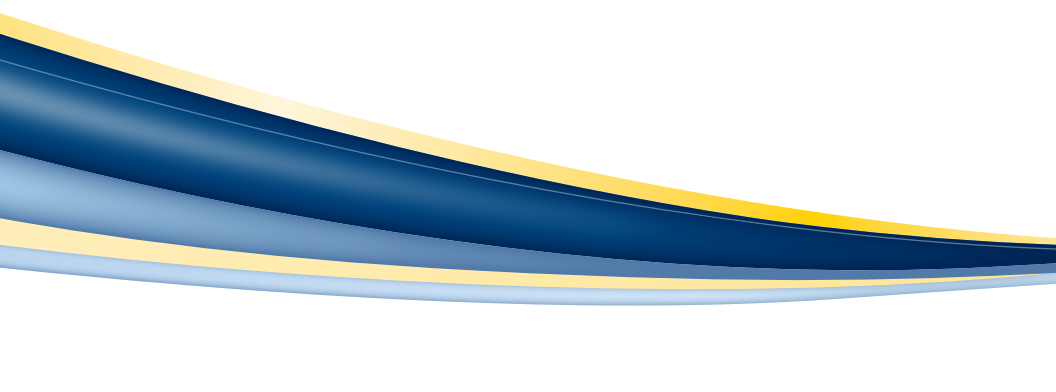
- Recognize that everyone has a limit and acknowledge when you hit yours
- Develop and maintain emotional and social outlets
- Reach out for support and ask others to help with daily tasks when needed
- Contact your local MS chapter and find a self-help group for emotional support as well as practical information
- Take the time to exercise, eat healthy, and sleep at least 7 hours each night to help maintain overall wellness

**Work together toward optimal health.**

# Speaking with your children about MS

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In order to get your child more involved in your MS support network, it's important that your child understands your MS. An honest and thoughtful conversation can help ease your child's worries and foster more open communication. For a balanced, focused conversation<sup>2</sup>

- Find a place where you both feel comfortable and a time when you both feel relaxed
  - Connect with your child by beginning with what he or she knows about MS
  - Allow your child's questions to guide the conversation
  - Ease into the discussion and avoid overwhelming your child with worst-case scenarios and complex details of medical procedures
  - Encourage your child to share his or her concerns. Dissolve any fear or anger your child may have toward the disease by reassuring him or her that his or her behavior does not cause your MS symptoms
  - Share educational resources that can support your child's understanding of the disease
  - Discuss advances in MS research and treatment and MS advocacy
  - Ask your child if he or she is interested in getting involved with the MS community
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# You, your child, and MS: Nurturing the relationship

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There are many benefits to involving your child in your support network. With a positive relationship and open communication there are many opportunities for growth<sup>3</sup>:

- Age-appropriate chores can help your child become a reliable source of support at home
- Helping a parent with MS may motivate your child to help others
- Understanding a parent's experience with MS can encourage your child to respect everyone's differences
- Maintaining a close network of support can help your child value his or her family and seek support when he or she needs it

**Helping a parent with MS can teach children valuable life skills.**

# Partnering with your doctor and staying proactive

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Your treatment decisions are made with careful consideration by you and your doctor, so establishing and maintaining honest and effective communication can make a difference in managing your MS.

Speak to your doctor about

- Symptom management
- Therapy goals
- How you are feeling
- How your treatment is working

**It's important to talk to your doctor frequently and honestly about your MS to make well-informed treatment decisions.**





# Making the most of your doctor appointments

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## Plan a productive conversation with your doctor

An open and thorough conversation with your doctor can help you better manage your MS. You can use these guidelines to help facilitate the discussions with your doctor:

- As they occur, record questions, feelings, and concerns you'd like to discuss during your next appointment
- Keep a detailed log of your treatment routine, symptoms, side effects, or any changes you notice between appointments. Make sure to keep your treatment list up to date
- Consider asking a friend, family member, or CarePartner to go with you to your doctor's appointment to help you remember information about your MS, take notes, or help facilitate the conversation
- Don't hesitate to ask questions and say how you really feel. Before your appointment, write down personal information that you'd like to discuss related to both your therapy experience and your daily life with MS
- Schedule and record your follow-up visits as recommended or needed

# Get one-on-one encouragement from your MS Peers\*

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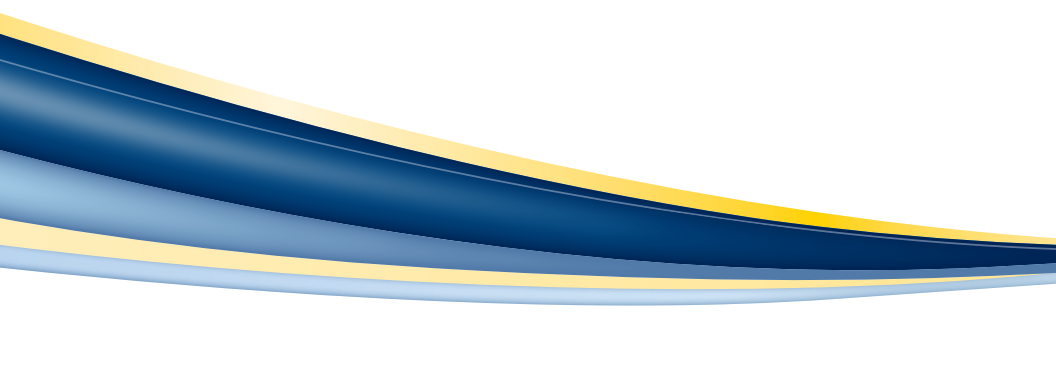
MS Peers are

- Individuals with relapsing MS who relate to your experiences
- People who listen to your stories and share their own
- A source of support, understanding, and encouragement

Call **Shared Solutions**® to request to be connected with an MS Peer. When you call, you will be asked a few questions to help match you with a peer whose experiences are similar to your own.

Curious to find out more about support networks?  
See the next page of this booklet for links to  
information about support networks for people who  
are living with or affected by MS.

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# Trust in the experience of Shared Solutions®

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While there's no substitute for medical advice from your doctor, **Shared Solutions®** is here to help if you have questions about MS-related issues or need therapy support. **Shared Solutions®** is a comprehensive network of free resources available to people with MS, CarePartners, friends, family, and anyone else who has been touched by MS. Contact **Shared Solutions®** at **1-800-887-8100** or online at **[www.sharedsolutions.com](http://www.sharedsolutions.com)**.

## The following websites provide additional MS-related information:

- National Multiple Sclerosis Society: **[www.nmss.org](http://www.nmss.org)**
- Multiple Sclerosis Association of America: **[www.msaa.com](http://www.msaa.com)**
- Caregiver Action Network: **[www.caregiveraction.org](http://www.caregiveraction.org)**
- MS Connection: **[www.msconnection.org](http://www.msconnection.org)**
- Young MS, an interactive resource for children and teens: **[www.youngms.org.uk](http://www.youngms.org.uk)**



Call 1-800-887-8100  
or visit [www.sharedsolutions.com](http://www.sharedsolutions.com)  
to learn more.

**References:** **1.** A guide for caregivers: Managing major changes. National Multiple Sclerosis Society (NMSS) website. [www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-A-Guide-for-Caregivers.pdf](http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-A-Guide-for-Caregivers.pdf). Accessed November 20, 2014. **2.** Phillips L. Kids talk. *Neurology Now*. 2008;4(2):26, 28-30. [http://journals.lww.com/neurologynow/Fulltext/2008/04020/Kids\\_Talk.13.aspx](http://journals.lww.com/neurologynow/Fulltext/2008/04020/Kids_Talk.13.aspx). Accessed November 20, 2014. **3.** When a parent has MS: A teenager's guide. NMSS website. <http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-When-a-Parent-Has-MS-A-Teenagers-Guide.pdf>. Accessed November 20, 2014.

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