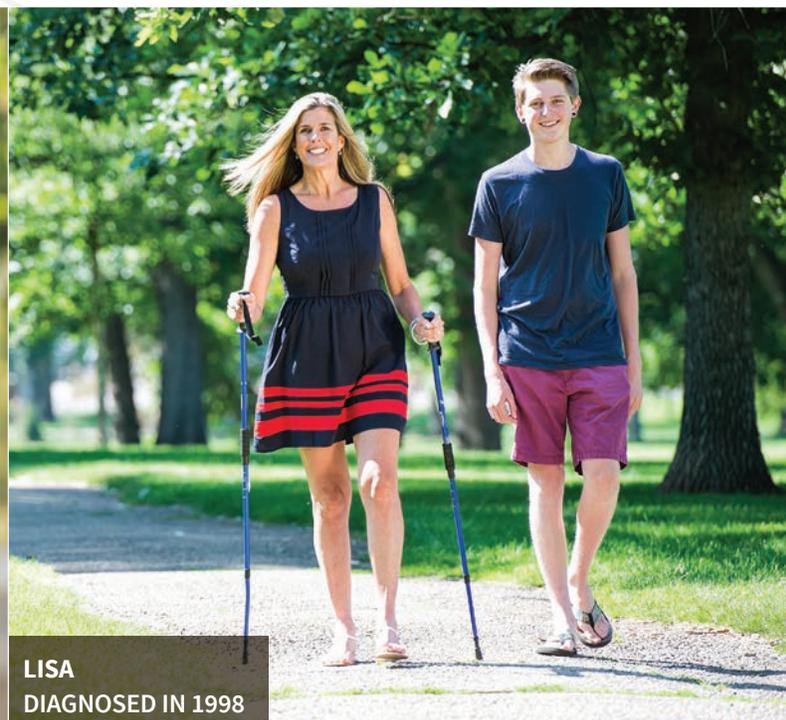


Knowledge Is
POWER

For Family Members of Someone Newly Diagnosed with MS



KAREN (LEFT)
DIAGNOSED IN 2007



LISA
DIAGNOSED IN 1998



JOE (CENTER)
DIAGNOSED IN 2010



ANQUETTE
DIAGNOSED IN 2013

Someone you love — perhaps your spouse or partner, a child, a parent or another family member — has just been diagnosed with multiple sclerosis (MS). At the moment, she or he is the focus of a lot of attention from you, the medical team, and perhaps other family members and friends. But this new diagnosis impacts you as well, and this booklet is **for** and **about you**. It is designed to help you understand what is going on and acknowledge feelings that you may be experiencing, and to give you strategies to deal with your own emotions and challenges while trying to support your loved one.

You probably have a lot of questions: What is MS? How will it impact the person I love and our family? What does this mean for our future? What can I do? What resources are there to help us?

As you may already know, MS is a disease of the immune system. For reasons that we do not yet understand, the person's immune system mistakenly attacks the central nervous system (CNS) — the brain, spinal cord and optic nerves. The targets of the immune attack include the myelin coating around the nerve fibers in the CNS, as well as the nerve fibers themselves. The damage to the myelin and nerve

fibers disrupts communication between the central nervous system and the rest of the body, which gives rise to the symptoms of MS. We do not know what causes MS, and we do not yet know how to cure it, but many treatments are available to help people manage it.

The **Knowledge Is Power (KIP)** book provides more detailed information about the disease (**Taking the First Steps**); describes the disease-modifying therapies used to slow disease activity and progression (**Disease-Modifying Therapies for MS**); and strategies to manage symptoms and enhance wellness (**Treating Yourself Well**).

We encourage you to read these chapters along with your loved one. Becoming familiar with the strategies to manage MS will help everyone in the family to feel better informed and more equipped to deal with the challenges of this disease.

Maintaining Healthy Relationships is about the impact of MS on the family. Like the individuals who are diagnosed with MS, family members also experience feelings of grief, anxiety, anger and even guilt. Because everyone is different, and likely to have different emotional styles and coping strategies, you are likely to

experience these feelings in different ways and at different times. This chapter may help you understand the ways in which these feelings may be affecting each of you. However, keep in mind that these feelings are a normal response to the unexpected changes and losses that MS can cause on a temporary or permanent basis. Acknowledging these feelings is the first step to being able to talk about them comfortably and productively with one another and with other family members.

Other chapters in the KIP book that you might find valuable cover intimacy, parenting and more.

Why can't anyone give us any answers?

Some questions about MS still cannot be answered. What causes the disease, and how to cure it, are still unknown. However the scientific and medical community's understanding of MS has grown and continues to grow at a rapid rate. As knowledge about the role of the immune system in MS has expanded, several medications have been developed to help slow the disease process. Decades of research show that the earlier a person with relapsing MS

starts treatment with a U.S. Food and Drug Administration (FDA)-approved disease-modifying therapy, the more effective the treatment is likely to be. In addition, a wide range of treatment strategies are available to manage the variety of symptoms that MS can cause.

Your loved one's healthcare provider should be able and willing to discuss what is and isn't yet known about the MS disease process and the strategies available to treat it. Let your family member know if you would like to be included in doctor visits, medical decision-making and other aspects of his or her life with MS. Be sensitive, however, to your loved one's preferences in this regard; people newly diagnosed with a chronic illness may need some time to deal with the information on their own before including you.

Other good ways for you to feel more involved and informed include participating with your loved one in educational programs, self-help group meetings and any other venue where information is provided. We encourage you not to sit on the sidelines — MS is affecting you too. You can also contact the National MS Society by calling 1-800-344-4867 to ask whatever questions you may have.

My partner seems to be pushing me away — it's very hard for me to talk to her/him about this. I'm trying to be involved, but it doesn't seem to be working. What should I do?

Some people respond to a new diagnosis of MS or other medical problems by turning inward — away from people around them. For some, it's a way of taking time and space to deal with their own feelings and reactions. For others it's based on worry about how others will react — “Will they think less of me/feel sorry for me/run away from me because I have MS?” And some people are simply more private than others about issues related to health or their body.

Start by talking about how you feel and reminding your loved one that the diagnosis affects both of you. Let your partner know that you want to learn as much as you can about MS, hear what the doctor has to say and share in whatever decisions need to be made. Armed with accurate information, the two of you can identify ways to help and support each other with the challenges MS may pose for each of you and your family.

What is going to happen to my family member?

Two important characteristics of MS make this question very difficult to answer — even for the most experienced MS clinician. The disease is unpredictable; it is also highly variable from one person to another. This means that each person's experience with MS is unique. So discard any pictures you may have in your head of MS. You may have known someone who was very disabled by MS or someone who had very mild symptoms that seemed to have little impact on the person's life. The experience for the vast majority is somewhere in between.

The list of possible symptoms is pretty long, but most people do not experience all of them. And symptoms can vary from mild and time-limited to more severe or long-lasting. Some symptoms may cause discomfort and inconvenience while others have the potential to be more disabling. Again, each person's MS is going to chart its own, unique path. You can read about the symptoms and their management in the chapter on **Treating Yourself Well**. Most people remain able to walk, although they may need the help of a mobility device like a cane or walker to do so, and most people live very close to a normal lifespan.

I feel invisible. Don't the doctors and other people realize that this affects me too?

In the days following a new diagnosis, it is true that most people — healthcare professionals, family and friends — are likely to be focusing their attention on the person with MS. Doctors and nurses are particularly likely to talk directly to their patient until they are asked to include you as well. Once it is clear that your loved one would like you to be able to hear the information and ask questions, both of you will be included. Make sure your family member knows that you would like to be present and included in these important conversations, and write down your own list of questions and concerns.

With close family members and friends, it may be up to you to let them know how this is affecting you and what kind of support you need. There is nothing selfish about reaching out for assistance or emotional support — people who care about you want to know how they can help.

What if my family member becomes unable to work?

Because MS is such an unpredictable disease, it is wise for families to ask themselves this kind of question. Finding answers to the 'What if?' questions that worry you is the best strategy for feeling less vulnerable and more prepared. Many people with MS face challenges in the workplace. For some, the problems are temporary, during a relapse (the appearance of new symptoms or the aggravation of old ones — synonymous with attack, exacerbation, flare-up or worsening — that lasts for at least 24 hours), but require no major career changes. For others, their MS symptoms require them to alter their career path or retire from the workforce altogether.

The Society can help people remain in the workforce as long as they want to and are able; many resources are available at [nationalMSSociety.org/employment](https://www.nationalMSSociety.org/employment). However, planning for the worst, while hoping for the best, can help you feel more prepared and secure no matter what the future brings. With that in mind, the Society offers resources and services to help individuals and families with financial planning. [nationalMSSociety.org/financialplanning](https://www.nationalMSSociety.org/financialplanning)

What should I do about my job? I really can't miss any more days of work.

Beginning with a loved one's first MS relapse and periodically throughout the disease course, a family member may want or need to be available to provide assistance and support, transportation to medical appointments, or other types of help. Having to take days off from work can be very stressful, especially if your employer is not particularly flexible. The good news is that the Family and Medical Leave Act (FMLA) can help. The FMLA requires employers with 50 or more employees to hold workers' jobs open and continue paying health insurance premiums while employees take unpaid time off to treat and/or recover from illnesses or injuries, or while employees take time off to attend to the healthcare needs of their family members. With some restrictions, employees are eligible for this protection if they have worked at the job for at least one year (no fewer than 1,250 hours within the 12 months preceding the requested leave date) and have (or have a family member who has) a serious health condition. Learn more about the FMLA at dol.gov/whd/fmla/employeeguide.htm.

I feel so helpless — what can I do?

Family members experience many different feelings as they support their loved one through a new diagnosis of MS. You may find yourself feeling frightened, angry, sad or even a combination of all those feelings. Many family members also describe a feeling of helplessness — particularly individuals who pride themselves on their ability to solve problems, fix things, take care of family issues, and meet any and all challenges head-on. Watching someone you love go through a difficult time, experience uncomfortable symptoms, and face new and sometimes daunting challenges can be difficult and painful. But there are many ways in which you can participate, provide support and be proactive — as long as you're mindful of your loved one's wishes and needs. If you move too fast or try to push too hard, you may feel the person keeping you at a distance as s/he needs to find a comfortable pace for moving ahead.

Family members have found a variety of ways to learn more and feel effectively involved:

- Gathering information about the disease and available resources particularly around any areas where they have particular concerns (for example, financial or employment issues, insurance, etc.)
- Joining their loved one at medical visits, educational opportunities, self-help group meetings or an MS event like Walk MS[®], Bike MS[®] or another Society event.
nationalMSSociety.org/get-involved
- Becoming an MS activist.
nationalMSSociety.org/advocacy

My family member with MS lives far away. I want to be supportive and involved but the distance makes it difficult. I know that s/he doesn't want to worry us with too many details, so I don't really know what's going on or how best to help.

Helping from a distance is always more challenging. A good place to start is with a conversation about how the two of you can best connect

and support one another. Different families handle this in different ways: some agree to talk regularly and share status reports; others agree to connect whenever there is major news to report. The important thing is to agree on a plan that works for both of you. And many families now take advantage of video conferencing in order to be able to see each other while talking long distance.

Even though you may not be able to offer assistance in person, there are other important ways to help. Searching out resources on the internet can save your family member time and effort, and sending occasional cards, photos or small gifts can boost morale. You can also show your support by learning about MS, joining a local Walk MS team or other fundraising activity, or becoming an MS activist or Society volunteer.

And perhaps most importantly, let your family member know that you care about how s/he is doing and want to provide help and support. Sometimes just asking what you can do that would be most helpful will give you all the ideas you need for ways to stay engaged and involved.

What does the National MS Society have to offer a family like ours?

The Society offers a wide range of resources to help every member of the family. An MS Navigator® can answer your questions, provide referrals, point you to valuable resources, and offer support to you, your spouse/partner, and other family members. Contact us at 1-800-344-4867 or contactusnmss@nmss.org.

Things to think about

- The National MS Society offers you a variety of ways to learn more about MS — including the KIP book, a resource for people newly diagnosed with MS — online at nationalMSSociety.org/aboutMS, or by talking with an MS Navigator® at 1-800-344-4867.
- Become familiar with the Family and Medical Leave Act (dol.gov/whd/fmla/employeeguide.htm). It may come in handy if you need to take time off from work to assist your family member.
- Family members have found many ways to provide support and be proactive — gathering information about resources available from the Society and other organizations, participating in education and

support programs, fundraising, or becoming an MS activist or volunteer. There's no need to sit on the sidelines.

- A new diagnosis of MS is a lot to take in all at once. The National MS Society can be a valuable partner as you and your family learn how to live with the disease. None of you need to face the questions and challenges alone.

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

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

- nationalMSSociety.org/educationalvideos (also at youtube.com/nationalMSSociety)

- **nationalMSSociety.org/ brochures** (or see the Catalog of Informational Resources mailed with the KIP book if you received it by mail)

- **Connection Programs for everyone affected by MS** (nationalMSSociety.org/connectionprograms)

The Society helps all people affected by MS connect with others to share experiences and provide support. Connection programs include traditional, in-person self-help groups, telephone or email one-on-one support, online communities and other means of bringing people together. To connect directly to other support partners via the online community, please visit **msconnection.org/groups/CarepartnerSupportGroup**

- **Financial Assistance** (nationalMSSociety.org/financialassistance)

The Society is engaged in a range of initiatives that support independence, safety, health and quality of life for people living with MS, as well as their families. We offer guidance and resources to help with the financial impact of MS. The Financial Education Partners program provides pro bono financial planning

and education to individuals with special health or financial circumstances.

- **Employment**

- » **Career Crossroads** (nationalMSSociety.org/employment)

This video program focuses on the legal rights of employees with MS and examines ways to mitigate the effects of MS on work performance. A self-study companion workbook is also available.

- » **Employment Matters: Managing MS in the Workplace** (nationalMSSociety.org/employment)

Finding and maintaining employment when one has MS can sometimes be challenging; this six-part video series is designed to provide tips to help a person succeed. Topics include: thinking proactively, the ADA, disclosure, managing fatigue and cognition, and assistive technology. The companion toolkit provides additional information on resume writing, searching for a job, preparing for an interview and navigating government assistance programs.

- **Resources Specific to Families**
(nationalMSSociety.org/familymatters)

- » **Timmy's Journey to Understanding MS (DVD)**

A 15-minute animated cartoon that follows a boy's journey to learning about MS. To request the DVD, call 1-800-344-4867.

- » **Keep S'myelin Activity Book**

For younger children with a parent or loved one with MS. Discusses MS through stories and activities. Call 1-800-344-4867 to request.

- » **Scholarships**
(nationalMSSociety.org/scholarship)

The Society's Scholarship Program helps highly qualified students who have been diagnosed with MS, or who have a parent with MS, achieve their dreams of going to college.

- **Spanish Resources**
(nationalMSSociety.org/espanol)

A variety of resources are available for people who speak Spanish, including: Spanish-translated brochures, videos, and 'Café con Leche,' a monthly telephone support group for Spanish-speaking people living with MS.

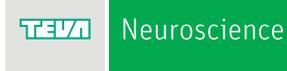
The National MS Society gratefully acknowledges the generous educational grants from our sponsors for their support of this project.



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The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient’s use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSSociety.org** or 1-800-344-4867.



National
Multiple Sclerosis
Society

The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.



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1-800-344-4867