

Life with MS:

Mastering Relationships with Family and Friends



MASTERING



Multiple Sclerosis

Getting the Support You Need

The bonds we have with friends and family are linked to our happiness and well-being. They bring us joy during good times and support during challenging ones. When you have multiple sclerosis (MS), you need these relationships most of all.

Learning to cope with MS can be a stressful experience for you and your loved ones. Relationships may feel strained as each person adjusts. But no matter what you are going through, you have an opportunity to strengthen and maintain your bonds with your family and friends.

In this brochure, I've included some advice on keeping these relationships strong while coping with MS. I have worked with families facing a chronic disease who have found these tips to be useful.

There also is a section for your loved ones with tips on how they can best support you.

MS can feel overwhelming at times but the most important thing to remember is that you should take time away from the daily practicalities of managing the condition to enjoy each other's company.

Michele Wahlden

About *Mastering MS*

Mastering MS is a global awareness program that illustrates how chronic diseases like MS can affect a person's personal relationships and work life, whether as a spouse, parent, child friend or co-worker. The campaign shows that with the right tools, including early treatment, people with chronic diseases like MS may be able to have physically and emotionally fulfilling lives, despite the condition. *Mastering MS* offers resources people with chronic diseases like MS might need to manage their condition, as well as to better cope with changes that may occur in their personal and professional relationships.

For more information about multiple sclerosis and the *Mastering MS* program, visit:

www.multiplesclerosis.com/masteringms.com

You Are Not Alone

"I used to think my friends would see me differently when they found out I had MS. I worried they would think I wasn't the same person. So I didn't tell my friends for months what was wrong with me." - Julie

It's not uncommon to experience feelings of loneliness or uncertainty when you are first diagnosed with MS. You may worry that people will treat you differently. You may wonder if you will be seen as a burden to your family and friends. These feelings are typical.

The truth is, your relationships can continue to be a great source of comfort and joy when you are coping with MS.

Strengthening Your Relationships

It's natural to wonder how MS will affect your relationships. Some changes in the way you relate to your loved ones will be necessary as all of you learn to cope with the disease. This stress can also be magnified if you don't take steps to strengthen and nurture your relationships during this challenging time.



Tips on How to Strengthen Your Relationships

- Be honest and open with your friends and family
- Help them understand your changing needs
- Research information together
- Don't give up normal social activities
- Ask for the proper support
- Consider seeing a family counselor
- Involve family in treatment decisions

Be Honest and Open with Your Friends and Family

Lucy has lived with MS for about 20 years and has experienced the emotions that can be triggered when facing a chronic illness. She realized that in order to move forward with her life, she first needed to acknowledge her feelings.

*“You have to work through your grief, your anger and your fears so you can stop carrying them with you and see your future.”- **Lucy***

Learning you have MS can be an emotional experience for you *and* your loved ones. Being honest about what you are going through is an important part of coping with MS. It will also encourage others to be open with you.

Help Your Family and Friends Understand Your Changing Needs and Symptoms

Symptoms of MS are often invisible to others. The best way to make sure you get the support you need is by talking openly about what you are experiencing.

Sometimes those closest to you, such as your partner or best friend, may notice changes in your symptoms before you do. Keeping track of your health may also mean listening to others.

*“When Meredith comes home from work and hasn’t told her colleagues it was getting to be too much, I can see it in her face. Her eyes give it away when she’s exhausted. You have to look after your health. The work will still be there next week.” – **Henry, Meredith’s husband***

Keeping track of your symptoms is also important in making sure you receive appropriate medical care.

Research Information Together

When Ellen was first diagnosed with MS, many of her family members found it difficult to provide the comfort she needed because they knew so little about it.

She found that reading books on MS with her loved ones was a good way to start the conversation about the disease.

You may need to help educate your family and friends about MS. The more they know about MS, the easier it will be for them to relate to you and offer you the support that you need.

MS organizations and medical Web sites can be a good place to start. Reading books by MS experts or patients can provide valuable information about the disease and insight into how to best cope with it.

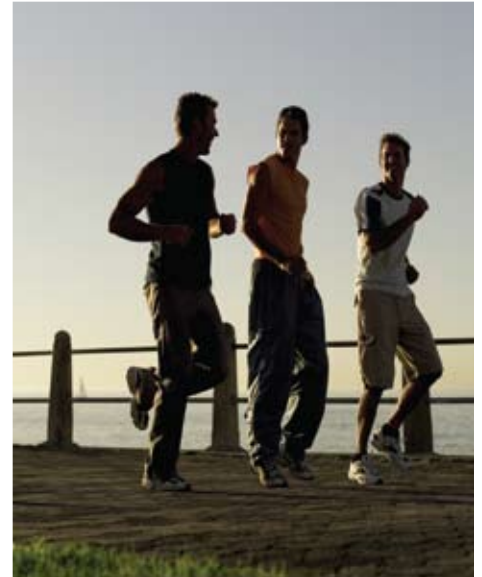


Don't Give Up Your Favorite Social Activities

Theresa and her husband Matthew both loved to go hiking. Having been diagnosed with MS, Theresa knew it would be difficult to walk at the same pace. *“Matthew knew that I couldn't go on long hikes any more, and that he would have to make allowances. For a couple that loves hiking, that wasn't easy.”*

Sixteen years later, they are still exploring mountains together. *“We choose routes where I can walk a shorter distance than him and we arrange to meet somewhere. Or we take routes that you can reach by car so that he can pick me up if I can't go any further. We've tried lots of different possibilities. Sometimes he climbs up on his own, I go up in the cable car and we meet at the top.”*

Like Theresa, you don't have to give up your favorite activities because you have MS. With a little planning and some creativity, many activities can be modified to fit your changing needs.



- **Plan ahead**

When you are organizing a trip or outing, check if the place you are going has the services you need. If you are going to a restaurant or booking a hotel, make sure they have easy access. If you are traveling by plane, remember to get a note from your doctor so you can take your medical supplies through security.

- **Get creative**

Together, you and your loved ones can come up with ways to meet your needs while participating in the activities you enjoy together.

- **Try new things**

Trying new things can be fun and can add new life to your relationships. Make a list together of new activities to explore that won't push you beyond what's comfortable for you.

Seek Outside Support

In addition to your friends and family, it can be comforting to talk to others who share similar experiences. They may be able to offer useful tips from their own experience and help you get perspective on what you are going through. Additionally, there are many MS support networks available. If there isn't a local group near you, you might consider organizing one.

Bethany attends a monthly support group with other people with MS. *"We get together and share our experiences. I also found a colleague with MS, and it is great to be able to discuss things with her. I would recommend to everyone that they look for someone to talk to. Don't become resigned to your condition – try to motivate each other."*

Gary was a soldier when he was first diagnosed with MS. In the hospital, he met with an MS nurse. She became one of his most important allies. *"Wanda, my MS nurse, has been my biggest support throughout my experience. She was the first person who really helped me understand the disease, and she has continued to keep me informed on any news about MS."*



Consider Seeing a Family Counselor

Living with MS may pose an ongoing challenge to the emotional balance of the family. A trained therapist can help you and your loved ones face MS in a healthy way. Counseling can help each family member discuss different coping strategies, since everyone is unique.

Finding a Good Family Counselor

- Ask your doctor for a referral to a family counselor who specializes in chronic diseases
- Local MS societies or patient support groups often provide a list of recommended family therapists
- Make sure family members feel comfortable with the counselor you choose. It's ok to visit a few before making a final decision.



Ask for the Proper Support

Your family and friends may offer you advice and support in ways that you don't want. If your needs are not communicated, it may result in unnecessary tensions and misunderstandings in your relationships.

Julie would tell her husband, Patrick, to do an errand or take the dog for a walk when she was feeling moody. He understood that this meant she wanted some time alone. Invariably, by the time he got back, she had a smile on her face.

Sometimes the best help is no help. It's alright to tell those you love when you need some time alone. They will be grateful for the clear guidance.

Tips for Your Family and Friends

When someone in the family or in a circle of friends has MS, it touches everyone. Adjusting to the disease can be stressful as each individual finds his or her own way of coping. It's an important time for everyone to come together to support their loved one and each other.

You should share the following section with your family and friends. It provides a brief description of MS, and offers advice on how they can best support you.



Supporting Your Family Member or Friend with MS

Understanding MS and Symptoms

MS is a disease that affects the body's central nervous system (brain, spinal cord, optic nerves). MS can affect the way a person walks, talks, sees and thinks. No two people experience the same combination or severity of symptoms. The best way to find out what your loved one is experiencing is to ask them directly.

Common Symptoms of MS

- Fatigue or tiredness
- Blurry vision
- Numbness or weakness in the limbs
- Loss of balance
- Dizziness
- Memory loss
- Slurred speech
- Loss of bladder control

Learning they have MS can be an especially emotional time for your loved one. Feelings of fear, grieving, guilt and even clinical depression are not uncommon in someone dealing with a chronic illness. It's important to be patient and compassionate and to provide a safe environment where they can talk openly about what they are experiencing.

Best Ways to Support the Person with MS

- **Do your own research.** The more you know about MS, the more you can help your loved one. Look at MS organization Web sites, or browse the health section at your local bookstore.
- **Talk to others.** There are a lot of people who have been in your situation and have experience with supporting loved ones with MS. Talking to these people - including doctors, members of your local MS patient groups, other families or online support groups – may provide valuable advice on how to give your loved one the support they need.
- **Ask your loved one with MS to tell you what they need.** Each person has different needs, and these may change day to day. The best way to make sure you are giving the right support is to ask for guidance and direction from the person you want to help.
- **Continue to include them in social activities.** You may need to tailor activities to meet their physical needs, but making your loved one feel included is important to their happiness and well-being.
- **Don't pity your loved one with MS.** Feeling sorry for your loved one won't help the situation. Staying positive is a better way to show them that you care.

Resources for MS Support:

In addition to the information contained in this brochure, following are resources that offer advice and support for people with MS:

- *MS advocacy groups*
 - » The Multiple Sclerosis Society of America (MSAA) <http://www.msassociation.org>
 - » Multiple Sclerosis Foundation (MSF) <http://www.msfocus.org>
 - » National MS Society (NMSS) <http://www.nationalmssociety.org>
- *Local MS support groups*
- *MS nurses*
- www.multiplesclerosis.com

ESSENTIAL INFORMATION ABOUT MS

Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS). Approximately 2.5 million people worldwide and 400,000 people in the U.S. have MS. MS occurs more frequently in women than in men, and the onset of MS is typically between the ages of 20 and 50.

MS usually progresses over time, but early diagnosis and treatment may help slow disease progression. It is important that people recognize the symptoms of MS as early as possible. Research has found that starting treatment after the first clinical attack suggestive of MS could slow disease progression. One of the most important things someone with MS can do is start treatment early and then stay committed to it over the long term.

For more information about multiple sclerosis and the *Mastering MS* program, visit: www.multiplesclerosis.com/MasteringMS.

Contributors



Michele Wahlder, a certified life and career coach for more than 15 years, counsels clients on how to deal with life, health, and career issues. As a two-time cancer survivor, she has had first hand experience in dealing with the challenges of a chronic illness and how it affects a person's career.



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All the people with MS mentioned in the Mastering MS brochures have been diagnosed with multiple sclerosis (MS) and are currently receiving treatment for their disease.

The testimonials represent each person's own experience, both with the disease and any treatment history. Statements regarding MS treatment represent the individual's own experience and perspective. Not all people receiving treatment will have the same results.

Mastering MS has financially been made possible by Bayer HealthCare Pharmaceuticals.

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