

Life with MS:

Mastering Relationships with Family and Friends



MASTERING



Multiple Sclerosis

Essential Information About MS

Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS). 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 and delay disabilities. People with MS who begin treatment after their diagnosis can also benefit from long-term, consistent treatment.

For more information about MS, visit:

<http://www.ms-gateway.com>

Mastering MS

Mastering MS is a global awareness campaign designed to illustrate how MS can affect a person's personal relationships and work life, whether as a spouse, parent, child, friend or coworker. The campaign shows that with the right tools, people with MS can continue to lead physically and emotionally fulfilling lives. The campaign offers resources to help people with MS manage their condition, as well as to better cope with changes that may occur in their personal and professional relationships.

Dear Friends,

The bonds we have with friends and family are essential 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 can feel strained as each person adjusts. But no matter what you are going through, you always have an opportunity to strengthen and maintain your bonds with your family and friends.

In this brochure, I've included some tips and advice on keeping these relationships strong while coping with MS. These are things I've found to be useful over the many years I've worked with families facing a chronic disease.

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

MS can feel overwhelming at times, for you and those close to you. But the most important thing to remember is that you should all take time away from the daily practicalities of managing the disease to enjoy each other's company.

Denise Knack

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 good enough because I wasn't the same person. So I didn't tell my friends for months what was wrong with me." - Julie, UK

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

The truth is, with some effort, 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 ways you relate with your loved ones will be necessary as all of you learn to cope with the disease. But 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 your 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 from Mexico 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 to move forward with her life, she first needed to acknowledge her feelings, no matter how uncomfortable they were.

“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, Mexico

Learning you have MS can be an emotional experience for you and your loved ones. Being honest about what you are going through is the important part of coping with MS. It will also inspire 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 only way to make sure you get the support you need is by talking openly about what you are experiencing.

Keeping track of your symptoms is also important to ensuring you receive optimal medical care. Medical studies have shown that getting effective treatment at the early stages of MS can significantly slow the progression of disabilities.

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 Ulrike comes home from work and hasn’t told them it was getting too much, I can see it in her face. Her eyes give it away when she’s exhausted. Enough is enough. You have to look after your health. The work will still be there next week.” - Huub, Holland

Research Information Together

When Elena from Spain 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.

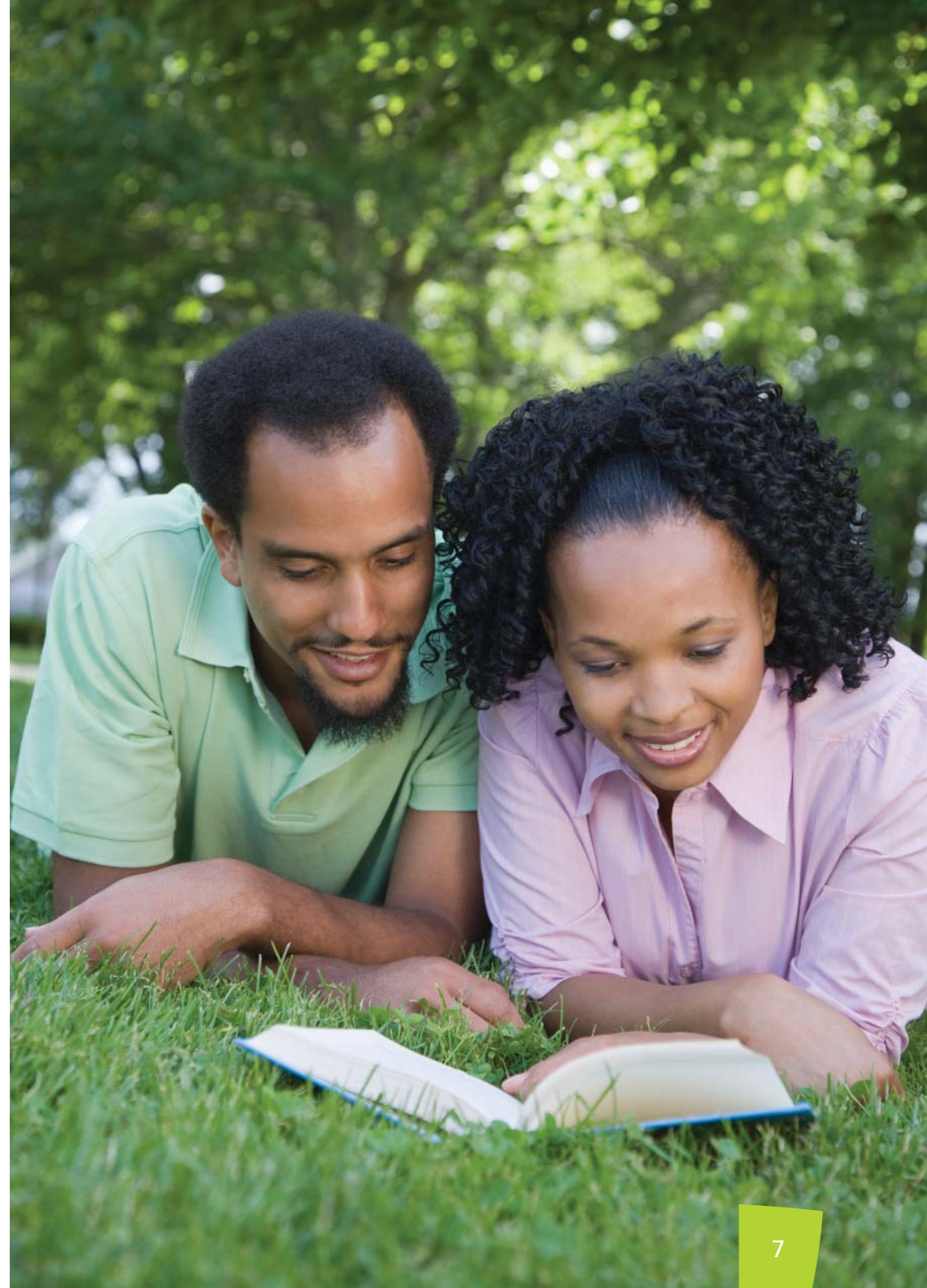
She found that reading books on MS with her loved ones was a good way to start the conversation about the disease.

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 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.

Useful Web sites

- Multiple Sclerosis International Federation
http://www.msif.org/language_choice.html
- National MS Society
<http://www.nationalmssociety.org>



Don't Give Up Your Favorite Social Activities

Theresa from Switzerland and her partner Manfred both love to go hiking. But having been diagnosed with MS, Theresa knew she wouldn't be able to keep up. *"Manfred knew that I couldn't go on long hikes anymore, and that he would have to make allowances. For a couple that loves hiking, that wasn't an easy start."*

Sixteen years later, they are married and 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 farther. We've tried lots of different possibilities. Sometimes he climbs up on his own and 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 just because you have MS. With a little planning and some creativity, almost any activity can be modified to fit your changing needs.

- **Plan ahead**

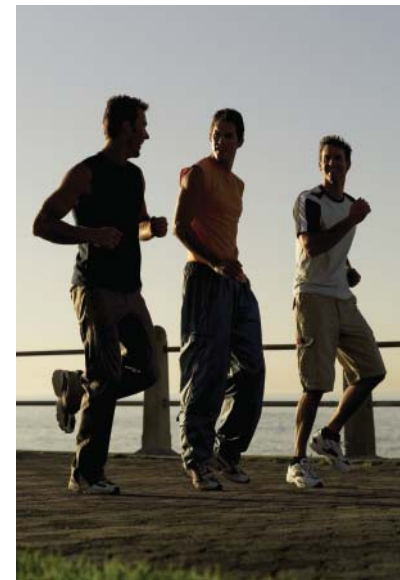
When you are organizing a trip or outing, check to make sure the place you are going has all the resources you need. If you are going to a restaurant or booking a hotel, make sure they have easy access. If you are traveling by plane, make sure to get a note from your doctor so you can take your medical 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 add new life to your relationships. Together, come up with a list of new activities to explore that won't push you beyond what's comfortable for you.



Seek Outside Support

Even if your friends and family are supportive, it can be helpful to talk to other people who have been touched by MS, especially people living with the disease. They may be able to offer useful tips from their own experiences, and help you get perspective on what you are going through.

Betina of Switzerland 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."*

The year after Marion from Germany was diagnosed with MS was very difficult. She suffered many relapses and her marriage ended.

Through founding an MS support group, Marion was able to connect with others in her area who understood what she was going through.



Resources for MS Support:

- Local MS support groups
- MS advocacy groups
- MS nurses
- <http://www.ms-gateway.com/betaplus>

It can be comforting to talk to others who share similar experiences. There are many MS support networks available. If there isn't a local group near you, you might consider organizing one.

Gerald from Austria was stationed as a United Nations soldier in Cypress when he was first diagnosed with MS. In the hospital, he met with an MS nurse through the Betaferon BETAPLUS® Program. She became one of his most important allies. *"Waltraud, my MS nurse, has been my biggest support throughout my experience with MS. She was the first person who really helped me understand the disease, and she has continued to keep me informed of any news about MS."*

Consider Seeing a Family Counselor

Living with MS can pose an ongoing challenge to the emotional equilibrium 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 everyone in the family feels 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 need or want. If your needs are not communicated, it can result in unnecessary tensions and misunderstandings in your relationships.

Julie of the UK would tell her husband, Patrick, to go 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 ok to tell those you love when you need some space. 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 a stressful time as each individual finds their own way of coping. It's an important time for everyone to come together to support their loved one and each other.

"At the beginning, we concentrated a lot on my father [who has MS] and above everything else, we felt strong in our family togetherness. In the meantime, we have become more and more aware of the consequences for every member of the family. I always had difficulties seeing things from my mother's point of view. She tends to dramatise things and I tend to put things in perspective. Perhaps it was my role to keep staying positive."

– Élise, France

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



Supporting Your Family Member or Friend with MS

Understanding MS and Symptoms

MS can affect the way a person walks, sees and thinks. No two people experience the exact 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, grief, guilt and even clinical depression are not uncommon for 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 the health section at your local bookstore.
- **Talk to others.** There are a lot of people that have been in your situation and have experience with supporting loved ones with MS. Talking to these people—including doctors, local MS patient groups, other families or online support groups—will 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 you care.

Contributors



Denise Knowles is a certified relationship counselor, psychosexual therapist and media specialist. She has more than 16 years of experience helping couples and families deal with different life issues, including the challenges associated with the diagnosis of a chronic illness like MS.

Resources

- More stories from friends and families of people with MS can be accessed at www.MS-Gateway.com

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.

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