

Life with MS:

Mastering The Essentials



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,

MS is a chronic condition that can impact many aspects of your life. Although the disease affects everyone differently, nearly everyone experiences similar fears and concerns about what it means to now be living with a chronic disease.

Will my friends and family see me differently? Will I still be able to go hiking, skiing or enjoy any of my normal activities? Can I still be productive at work? What if I can no longer work – how will my family and I pay the rent or buy groceries? Will I still be able to carry my baby or play with my children?

Such questions are common and natural for people diagnosed with a chronic disease like MS. Having the right resources and information about MS will help you and those closest to you adjust to life with the disease. This brochure provides some useful facts about MS, as well as advice that can help you continue living an active, fulfilling life.

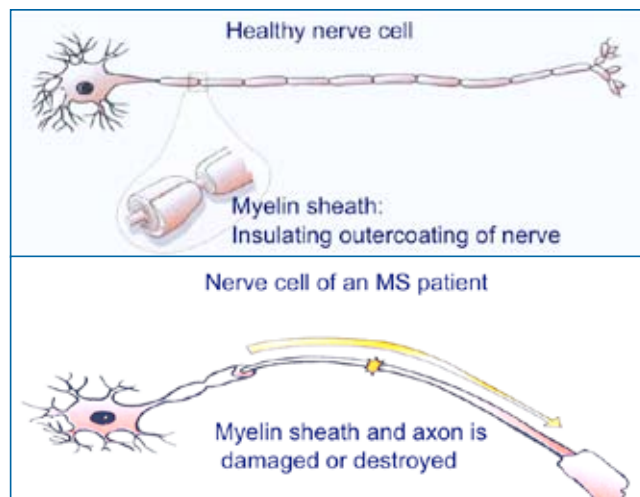
Always remember, you are not alone!

Michele Wahler Denise K...
Bann

Living with a Chronic and Unpredictable Disease

MS is a disease of the CNS, which consists of the brain, spinal cord and optic (eye) nerves.

It is thought to be an autoimmune disorder, which means your body's own immune system attacks healthy cells and tissues. During an MS attack, cells that normally fight off infections and other "foreign" invaders in the body instead attack myelin – the protective covering surrounding nerve cells. When myelin is damaged or destroyed, nerves are unable to function correctly, which can affect, for example, your ability to walk and see.



"The symptoms of MS can come and go, often disappearing for long periods of time. But that doesn't mean you don't need treatment. Even if you look or feel fine on the outside, inside the disease is causing nerve damage that cannot be reversed. This damage can lead to serious disabilities later in life signs of MS is the best way to slow the progression of the disease."

- Dr. Karl Baum, Hennigsdorf Hospital, Germany

Potential Causes of MS

The exact cause of MS is unknown, though research suggests that a combination of genetic and environmental factors is involved.

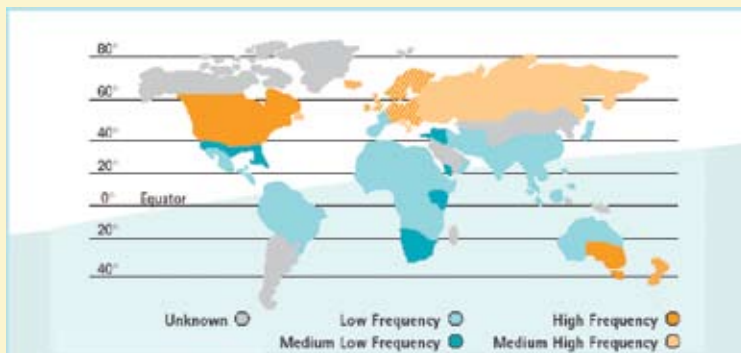
- Environmental factors: The highest frequency of MS occurs in temperate climates, away from the equator and more commonly in economically developed areas.
- Some research suggests that certain bacteria or viruses might contribute to MS, though specific ones have not yet been identified.
- Genetic factors: MS is not simply an inherited condition. Certain individuals may be more susceptible to environmental triggers based on their genes. If you have MS, your child has only a 2% – 3% chance of developing the disease.

Did you know?

- You are not alone: There are up to 2.5 million people with MS worldwide.
- More women have MS: The ratio of women to men suffering from MS is 3 to 1.
- MS strikes when you're young: The average onset of MS is around age 30, but in rare cases it can first appear at a younger or older age.
- MS doesn't mean life in a wheelchair: After 25 years, even without treatment, two out of three people with MS won't need a wheelchair to get around.

Incidence and Prevalence of MS

- MS occurs with much greater frequency in higher latitudes (above 40°) away from the equator, than in lower latitudes (closer to the equator).



Impact of MS Symptoms

Fatigue, cognitive impairment, pain, vision problems, sleep difficulty and other common symptoms of MS can greatly affect your personal and work life. The stress of these symptoms can take a physical and emotional toll on you.

Listen closely to the signals your body is giving you. Take frequent breaks, eat well, and prioritize your activities, focusing on the most important tasks first. Also, talk to your doctor or nurse if you are experiencing these symptoms, as there are medications that can help you manage them.

Managing Fatigue

Up to 92% of people with MS experience fatigue, which is an unusual feeling of exhaustion after a short period of time. It can make it considerably difficult to accomplish even the simplest daily tasks, such as dressing or preparing dinner. Fatigue also can impact your performance at work, especially if you spend long hours on your feet or staring at a computer. In fact, it is the leading reason why people with MS quit their jobs.

“At the hospital, I continue to work hard and have made minor adjustments to accommodate my MS. I used to work only night shifts for about a year after my diagnosis, but now I work day shifts too. I am sure my medication has helped me to do this. I just make sure I don’t work too many shifts in a row to avoid becoming overly fatigued.” – Louise, UK

If you’re feeling extremely tired during the day, follow these simple tips:

- **Plan:** Make a list of things you need to do throughout the week, but don’t try to do everything at once.
- **Prioritize:** Perform the most important (and most strenuous) tasks when you have the most energy.
- **Organize:** Whether you’re cooking dinner in your kitchen or working at your desk, it’s a good idea to keep your supplies within easy reach to avoid unnecessary climbing, bending, or walking.
- **Rest:** Make sure you get plenty of sleep each night. And during the day, take short breaks at least once an hour to get re-energized.

Handling Forgetfulness

Up to as many as 65% of people with MS experience some form of cognitive problem. This can be as simple as forgetting where you placed your house key to more serious problems.

Have you missed a rent or credit card payment because of a lapse in memory? How about a deadline or an important meeting at work?

Don’t let cognitive problems impair your daily life. Take time to write things down – in a diary, a notebook or on a hand-held organizer. Keep your work and home space organized so that everything has its place. And take your time. Rushing will only create stress, which will make it more difficult for you to remember the task at hand.

Coping with Pain

Pain is not uncommon for people with MS to experience, which can affect their relationships and even their mood. This pain is very different from the normal pain we feel such as when we walk on hot pavement or touch a cold ice cube.

The pain may be the result of nerve damage caused by MS. This is often called “nerve pain” and is sometimes characterized by shooting or stabbing pain or the feeling of “pins and needles.” And this pain doesn’t seem to be

caused by anything. For example, the touch of a light cotton shirt might cause the same stabbing pain as being stuck with a pin.

Nerve pain can be physically and emotionally stressful. That is why it's important to talk to your doctor or MS nurse if you experience pain. There are medications that are specifically developed to treat nerve pain.

Staying Calm Through Stress

Life can be stressful, whether you're starting a new job, buying a new house, or simply feeling anxious about an upcoming exam or deadline.

When you're diagnosed with a chronic illness like MS, the stress only increases. This might be due to the uncertainty of your diagnosis or the unpredictability of the condition. You might feel nervous about your job and finances, or feeling a loss of control in your life.



The good news is, you can control stress:

- **Simplify your life:** Don't take on too many responsibilities at home or at work. It's okay to say no to things you don't have the energy for or the desire to do. Learn to accommodate your changing needs by being flexible.
- **Plan ahead:** Taking time to map out your day can keep you calm. For example, choose your work clothes and iron them, if necessary, the night before rather than rushing around in the morning.
- **Ask for help:** If you need assistance from people, let them know exactly what you need – be specific. Don't be afraid to be honest and vulnerable.
- **Learn new tricks:** When your old interests become difficult, take on new ones that fit your current needs. Boredom can also be stressful, so stay active.
- **Rest:** Not getting enough sleep can increase your stress level, so make sure you get a good night's sleep, especially before a family gathering or other potentially stressful event.
- **Breathe:** When your heart starts racing and you feel angry and short of breath, stress is getting the better of you. Stop and breathe deeply for a few minutes.



Fears and Emotions are Common

"I felt like my world had collapsed and I burst into tears. I had no idea what the implications of MS were. My head was filled with questions." – Marion, Germany

Emotions are a natural part of adjusting to life with a chronic illness. Often, feelings of loss, anxiety and even depression are common for someone who has just been diagnosed with MS. You may worry that you've lost control of your body, thoughts and feelings. This can lead to changes in self-image and cause feelings of anger and depression.

Learning as much as you can about MS is an important first step toward improving your health and strengthening your relationships and career during this challenging time.

Marion found that talking to others with MS that she met through a local support group, helped her face her fears of living with the disease.

Depression and MS

Feelings of sadness and loss are common in people with a chronic disease, especially as they cope with the changes in their lives and daily routines. The melancholy and grief may resemble depression.

In many cases, the emotions will resolve with support from friends and family, and some positive thinking. However, if these feelings persist, it might be a sign of clinical depression, a more serious condition that requires medical help. Some studies suggest that clinical depression is more frequent among people with MS than in the general population or even in people with other chronic, disabling conditions.

Know the warning signs of depression. Talk to your doctor if you experience any of these symptoms:

- Sadness and/or irritability
- Loss of interest or pleasure in everyday activities
- Loss of appetite – or increase in appetite
- Sleep disturbances – either insomnia or excessive sleeping
- Agitation or slowing in behavior
- Fatigue
- Feelings of worthlessness or guilt
- Problems with thinking or concentration

Changing Moods and MS

Some people with MS also experience moodiness, described as unpredictable changes in emotions. Your family may complain that you are easily irritated or prone to fits of anger. Mood swings can strain relationships with your family and friends, so it's important to talk to a family counselor.

But remember, not all mood changes are due to MS and other health conditions may contribute to these changes, so it is also important to talk to your doctor or MS nurse. Medications and counseling can both help you get these feelings under control.

You Are Not Alone

*"I want people to see me as Betina, not as a disease. A lot of people have diseases, but they manage to do things anyway. If I choose to live in fear of it all ending horribly, then my life will turn out that way." – **Betina, Scandinavia***

If you are worried about being less attractive to your partner or becoming a burden on your family and friends, you are not alone.

An international survey of 650 people with MS from 12 countries found that people with MS:

- Fear that they will become a burden to their family (61%) or that their spouse or family will leave them (26%)
- Believe that they will no longer be successful at work (58%) or that they will lose their jobs (39%)
- Worry that they will no longer be able to maintain active lifestyles (54%)

Mastering Your Life with MS

“For people living with MS, the good news is that research shows starting treatment with interferon beta early delays the development of disability. Along with an effective treatment, it is equally important to help patients find ways to cope psychologically with the disease.”

– Dr. Karl Baum, Germany

- **Master your treatment:** Right now, you may be thinking, “I don’t have any symptoms of MS. I feel just fine – why do I need to be on treatment?” But did you know that MS can cause *four times* more nerve damage in the first year of the disease than later on?¹ That damage may eventually affect the way you walk, feel, see, and even the way your brain processes information. Getting effective treatment early may delay this damage and these disabilities.

After going to his doctor about his double vision, Mikael from Denmark was immediately prescribed an interferon beta drug to help control the effects of the disease.

“My symptoms went away within one week of starting treatment. At the time, we were expecting our first child and so I didn’t have time to worry about my diagnosis. Now we have two children and I’ve never had a relapse in their lifetimes.”

¹ Kuhlmann T, Lingfeld G, Bitsch A, Schuchardt J, Brück W. Acute axonal damage in multiple sclerosis is most extensive in early disease stages and decreases over time. *Brain*. 2002;125:2202-2212.

- **Master your relationships:** Fears of abandonment are not uncommon after being diagnosed with a chronic illness like MS. At the time Isabel of Spain was diagnosed with MS, she heard horror stories about couples divorcing and families being torn apart because of MS and worried that this would happen to her. *“I thought my personal life would change completely. My husband and I were just settling down.”*



Relationship expert, Denise Knowles, says that talking openly is an opportunity to strengthen and maintain these important bonds. *“A frank discussion with your spouse or friends will help to ease fears and reinforce your bonds. When it’s difficult to talk openly about how you feel, you may benefit from the support of an experienced counselor. Keeping feelings inside only leads to misunderstandings that can hurt and create resentment.”*

- **Mastering your career**

“For many people, work is an important and fulfilling part of their lives. But once they are diagnosed with a chronic illness like MS, it’s common for them to leave their jobs. This is not always necessary. There are steps you can take to create a comfortable and supportive work environment where you can continue to thrive as a productive employee.”

– Michele Wahlder, career expert

Some simple accommodations might enhance your productivity, such as combining short breaks into one longer break or having a desk closer to the elevator or lavatory. Or there may be an opportunity to find a new role in your company. Before quitting your job or making major decisions at work, consider talking to another person with MS, an MS nurse, a local career expert or your local patient group. They can offer encouragement and support to help you make the best decision for yourself.

Getting the support you need

There are many resources available that can help clear up misconceptions and relieve unnecessary stress for people with MS and their loved ones. Isabel’s husband, Francisco, found a lot of guidance from reading about the MS on the Internet and in books. *“You can learn a lot from books, but they can also be impersonal. I’ve found the best way to learn about MS is to live with the person who has it, and let the books serve as a guide.”*

Other helpful resources include:

- **Your doctor and MS nurse**, who oversee your medical care and ensure that you are getting the right support
- **Local MS support group**, which offers a place to meet other people with MS who share the same experiences
- **Relationship/family counselor**, who can help you manage the impact of MS on relationships with loved ones
- **Career coach**, who will help ensure you are in a supportive working environment. You can find a local coach by visiting www.coachfederation.com
- **Government agencies and programs (INSERT LOCAL INFORMATION)**

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.



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.



PD Dr. Karl Baum is chief of staff at the Neurological Clinic at Hennigsdorf Hospital in Germany, which he founded in 1997 with the associated MS – Center. He is known as one of the thought leaders in the MS field, and is an active member of the Multiple Sclerosis Therapy Consensus Group (MSTCG), a group responsible for a regular updating of MS therapy recommendations.

Resources

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

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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.

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