

A Remedy Health Guide

Relapsing

Multiple Sclerosis

Feel Your Best!
HOW TO
STAY ACTIVE
AND REDUCE
SYMPTOMS

8

Great Tips
For Caregivers

Multiple sclerosis no longer means a fast progression to significant disability.



Relapsing MS: What to Know

Nerves Under Siege

In MS, your immune system mistakenly attacks myelin, a fatty substance that insulates your nerves and helps them communicate. Over time, this can lead to scarring and hardening of nerve tissue (known as sclerosis) in the spinal cord, brain, and eyes. This, in turn, can cause pain and weakness in the extremities, among other symptoms. Because the location of the damage is so variable, no two individuals have exactly the same symptoms.

Relapsing-Remitting MS: The Most Common Type

There are four types of MS: clinically isolated syndrome, relapsing-remitting, secondary-progressive, and primary-progressive. The vast majority—about 85 percent—of people with MS have relapsing-remitting (RRMS).

Here's what distinguishes RRMS from the other forms of the disease:

► People with RRMS tend to have more brain lesions on magnetic resonance imaging (MRI) scans, and these lesions contain more inflammatory cells. In contrast, people with primary-progressive MS (PPMS) tend to have more spinal cord lesions, which contain fewer inflammatory cells.

► RRMS is diagnosed earlier than the other forms of the illness.
► Most individuals with RRMS eventually progress to secondary-progressive MS (SPMS), which involves a consistent worsening of symptoms. Flare-ups (periods of intensifying symptoms, also known as relapses or exacerbations) may occur, but are less frequent than in RRMS. Recovery is difficult and symptoms may become chronic. The transition to SPMS generally occurs in people who have had RRMS for at least 10 years.

Symptoms and Complications

In the early stages of RRMS, common symptoms may include vision problems; muscle weakness, stiffness, and spasms; limb numbness and tingling; problems with coordination and balance; and fatigue. Many people notice that certain situations, such as a hot bath, feeling stressed, or being feverish, can trigger a flare-up.

As nerve damage progresses, it's possible to develop eye pain, sensitivity to light, and blind spots; depression, possibly triggered by the debilitating nature of the disease; cognitive problems, such as memory and concentration difficulties; swallowing trouble and slurred

speech; urinary and bowel problems; and sexual difficulties.

RRMS can be unpredictable. You may face flare-ups that last for days or months. It's also possible to have a gradual but regular increase in physical and cognitive symptoms over time. Or, you may go for years and years with only mild reminders of the disease.

(Note: Going forward, we will refer to a specific form of MS, such as RRMS or SPMS, only when the issue at hand applies only to that form. Otherwise, we will use the term "MS," which encompasses all forms, as there is overlap in the characteristics of the various types.)

Making Strides

While there's still no cure for MS, recent advances have dramatically brightened the future for people with the disease. Research shows promise for repairing nerve damage and for improved treatments.

"Twenty-five years ago, there were no medications to slow progression of the disease," says Edward J. Fox, M.D., Ph.D., director of the MS Clinic of Central Texas in Round Rock. "Now there's a much greater likelihood of early diagnosis and early treatment, which means the prognosis is a lot better." ▲

0.1 percent

Average American's chance of developing MS

Every hour, someone in the United States is diagnosed with multiple sclerosis (MS), a chronic and progressive disease of the central nervous system. While the severity, symptoms, and course of the disease vary from person to person, one thing remains the same: A diagnosis of MS is not the blow that it used to be.

Women are two to three times more likely to develop MS than men, and most people are diagnosed between the ages of 20 and 50. The prime cause of MS remains a mystery, but risk factors may include ethnicity, family history, exposure to certain viruses, and low levels of vitamin D.



ROBERT GLENN SMITH, M.D., Ph.D., is a neurologist at Houston Methodist Hospital in Texas.

ask the doctor

What are my chances of becoming disabled with MS, and how long does it usually take?

When I was a physician resident many years ago, the average time from diagnosis to being in a wheelchair, and having visual problems or significant cognitive problems, was a decade. That was before disease-modifying drugs were developed.

I'm now in the latter portion of my career, and I'm caring for patients who are as old as or older than I am, who have had this disease for 20- or 30-plus years. They are still walking (some with the help of an assistive device) and still have good vision. There may be some other issues, but they are doing so much better than the patients I saw in my training.

With appropriate therapies, the majority of people with MS do not become severely disabled, and two-thirds remain able to walk, although many end up needing an aid, such as a cane or walker.

However, there is no way to predict any individual's course of disease or that person's likelihood of becoming disabled.

Lisa Emrich's MS doesn't stop her from making beautiful music.

LIVE
BOLD
LIVE
NOW
STORIES THAT
INSPIRE

Thriving With MS

Lisa Emrich was playing the French horn at a concert in 2005 when two of her fingers on her left hand suddenly went numb. “I couldn’t feel my fingertips and realized I didn’t know where the keys were,” she says. She muddled through the performance, but suspected that something was seriously wrong.

Emrich, 48, who works as a music teacher in Falls Church, VA, was diagnosed with MS. “After the diagnosis, I was very frightened, not knowing what else could happen.” The year that followed was tough. She had several relapses and struggled to come to terms with her weakening body. “There was a lot of crying involved,” she admits. She worried that she wouldn’t be able to keep playing the French horn. In addition to the numbness, she experienced weakness in her left arm. “The left arm handles a lot of the weight of the instrument,” she says.

Help From Others
Emrich’s neurologist invited her to participate in a monthly seminar series for people who were newly diagnosed. The meetings gave participants the chance to ask the doctor questions and meet other people with the disease. “It was a great coping mechanism,” she says.

Initially, she was treated with a course of steroids and began taking an injectable disease-modifying medication, glatiramer acetate (Copaxone). Still, she experienced symptoms of weakness and numbness in different parts of her body for about a year and a half. In 2007, she was also diagnosed with rheumatoid arthritis and began taking medications to treat that condition. In 2009, Emrich had gotten to the point where she was having difficulty standing up. She recounts, “My legs and hip flexors had become weak and I had spasticity in my legs. The numbness was affecting my perception of where I was in space, which affected my balance.”

A Different Treatment
Emrich’s doctor put her on rituximab (Rituxan); her symptoms abated, and her mobility improved. She had physical therapy and balance training and even bought a bicycle. “I’m much stronger now,” she says. “I can cycle for 20 miles.”

Emrich went for four years without a relapse, but in 2016 had a minor one and started a round of steroids. As with other relapses, she felt angry, annoyed, and scared. “However, the fear is not quite the same as the ‘unknown future fears’ that occurred at the beginning,” she says. “By being in touch with so many people with MS who have had a variety of experiences, I am more knowledgeable about the spectrum of possible consequences.” Emrich continues to experience numbness in her limbs, yet she is able to perform, and she teaches French horn and piano, accompanying her students to events. A patient advocate, a disease ambassador, and an MS blogger, Emrich finds meaning in helping others cope. Her advice: “You’ll probably feel like you are on a roller coaster, but you can go through these cycles many times and still be OK. It will get better.” ▲

DOCTOR DISCUSSION GUIDE: Relapsing MS

It is important to take an active role in your care. Don’t hesitate to ask questions, advocate for yourself, and bring a loved one to appointments for support. With so much to discuss, coming prepared to your appointment can help you ask smart questions and record answers so that you and your loved ones can refer to them later. Use this handy guide to help develop a deep understanding of your condition, treatments, and how you can partner with your healthcare providers to achieve your goals.

Since my last visit, I’ve had _____ relapses.
On a scale of 1 to 5, my symptoms have: *(Circle on scale below)*



What information about my symptoms is important to share with you?

Why is my MS relapsing?

How does my medication reduce relapses and lesions?

How will my therapy affect my disability progression?

Benefits	Risks

What is PML and what are my chances of acquiring this rare condition?

How do I discuss treatment options with my family?

Are there lifestyle changes that I can benefit from?

How can we work together to achieve the best results?

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Working With Your Doctor

Try to choose a doctor who is up on the latest research and treatments.

getting the right care can make a world of difference in your treatment for MS and your quality of life. Typically, you will have a team of care providers, which may include a neurologist, nutritionist, social worker, psychologist, neuropsychologist, and physical and occupational therapists, among other providers. Seeing a neurologist who specializes in the treatment of MS is optimal.

MEDIA BAKERY

400 thousand

Number of people in the U.S. with MS

The goal of treatment is to slow the progression of the disease or to halt it entirely. But measuring this is not as easy as it may sound, as symptoms can fluctuate from day to day and visit to visit. That's one reason why your physician will likely want to see you every three to six months in the first one or two years after your diagnosis. After that, your visits may occur anywhere from every six months to annually.

Tests to Expect

Once you are diagnosed with MS, you will need regular tests to monitor how well you are responding to therapies and to determine whether your disease is progressing. These tests may include:

Magnetic resonance imaging (MRI) This produces detailed images of your body. With an MRI of the brain and spinal cord, doctors can spot lesions that are characteristic of MS, as well as other changes.

Neurological exams Your doctor will test your reflexes to see if nerves are firing in a normal way. Checking your coordination can reveal problems with the cerebellum. Since MS is likely to affect your gait, your doctor will see if you can walk normally up and down a hall, on your toes and heels, and heel-to-toe, as though you were being given a sobriety test. You will also do simple tests of balance.

Vision tests It's not unusual for people with MS to experience vision problems, such as blurred vision, blindness in one eye, or double vision, so your doctor will look for signs of damage to your optic nerve.

A gauge of your senses Your doctor may test your ability to feel pain and other sensations, along with your senses of smell, taste, and hearing.

Cognitive tests MS can affect the way your brain functions, so you may receive tests that focus on processing speech; learning and memory; reasoning and planning; visual perception and spatial processing; and language.

Preparing for Your Visit

It can help to collect your thoughts and questions about topics such as new treatments or research ahead of time so you don't forget anything during the visit. Use these tips to assemble information to bring to your appointment.

Keep a log of your symptoms Describe any changes (both good and bad) that have occurred with regard to your symptoms and health since your last appointment. "A weekly log is helpful," suggests Bianca Weinstock-Guttman, M.D., professor of neurology at the State University of New York at Buffalo and director of the Jacobs MS Center for Treatment and Research.

Ask for prescription refills List the medications you need and, for each, note whether it's a monthly or three-month prescription.

After the Visit

Ask for a printed copy of any instructions your doctor gives you. Be sure to set up your next appointment, since attending to symptoms promptly can make a dramatic difference in disease progression. ▲

5 QUESTIONS to ask your doctor

Why should I keep track of my MS symptoms?

By documenting symptoms and body functions that might be affected by MS, it becomes easier to recognize disease progression. Aim to keep a running list of new symptoms, continuing symptoms, and symptoms that may have resolved. Rate each on a scale of 0 to 5 (0=absent, 1=mild, 3=moderate, 5=severe). Bring this list to doctor appointments.

What symptoms should I watch out for?

The most common problems people with MS experience are vision issues, vertigo, weakness or numbness in the limbs, balance and coordination problems, falling or trouble walking, speech problems, memory loss, confusion or hallucinations, decreased concentration, poor judgment or reasoning, fatigue, bladder or bowel problems, and sexual difficulties.

How does a doctor know if a drug is working?

If you continue to have exacerbations of symptoms after starting a medication, then that drug may not be working for you. An MRI is generally recommended before starting a new therapy, six months later, and then on a yearly basis. If you have a relapse after being on a drug for six months to a year, your doctor may consider a new therapy.

How do I know if I'm having a relapse?

A relapse meets these criteria: new symptoms appear or old ones worsen; the episode of new or worsening symptoms lasts more than 24 hours; symptoms do not occur within 30 days of a previous relapse; you have no active infection; and there is no other explanation for your symptoms. If you are in doubt, call your doctor. Only a doctor can determine the best course of action.

Why should I consider seeing an MS specialist?

A specialist can help you navigate increasingly complex treatment options. "With the extensive battery of treatments available today, I recommend that patients seek a referral to an MS center through the National Multiple Sclerosis Society (nationalmssociety.org) or the Consortium of Multiple Sclerosis Centers (mscare.org)," says Dr. Weinstock-Guttman.

Promising treatments for multiple sclerosis are constantly in development.

How Is MS Treated?

When James Bowen, M.D., a neurologist in Seattle, began practicing medicine more than 20 years ago, there was not a single approved medication for treating MS. Today, there are 14 that can treat the relapsing-remitting form of the disease, with an additional treatment for relapsing MS and the first ever for primary-progressive MS expected to receive approval this year. “Multiple sclerosis is one of the fastest moving areas of medicine,” says Dr. Bowen.

Even so, MS can be challenging to treat. Depending on the nature of your illness, how severe it is, and your symptoms, your doctor will determine what treatment is best for you. Disease-modifying therapies focus on slowing the progression of

the disease and changing the course of MS so you have fewer and less severe attacks. Other medications aim to keep symptoms, such as fatigue, depression, spasticity (muscle stiffness and spasms), and bladder and bowel problems, under control. There are also a few nondrug therapies that can help with some MS symptoms.

Modifying the Disease

Disease-modifying therapies (DMTs) fall into three types: injectable, oral, and those that are administered by intravenous infusion. None of these medications will cure MS—as yet there is no cure—and they don’t prevent symptoms, but they do reduce the accumulation of lesions in the brain and spinal cord and, therefore, the frequency and severity of attacks.

Injectable The injectable DMTs are interferon beta-1a (Avonex, Rebif), interferon beta-1b (Betaseron, Extavia), glatiramer acetate (Copaxone, Glatopa), and peginterferon beta-1a (Plegridy). “The interferons and glatiramer acetate are overall the safest,” says Vijayshree Yadav, M.D., associate professor of neurology at Oregon Health & Science University School of Medicine in Portland, but they are not as effective as some of the newer drugs.

Oral Some DMTs—teriflunomide (Aubagio), fingolimod (Gilenya), and dimethyl fumarate (Tecfidera)—are taken orally, in pill form. “Oral agents can lead to liver function problems and lower white blood cell count,” notes Dr. Yadav.

Infusion DMTs that are administered by infusion are alemtuzumab (Lemtrada), mitoxantrone (Novantrone), and natalizumab (Tysabri). Infusion time is typically only about half an hour to an hour, and is repeated from every few days to weeks, depending on your condition and which medicine you are on.

Any of these medications may cause potentially serious side effects, and treatment comes down to a balance between a drug’s benefits and its risks. Alemtuzumab, for example, can cause some autoimmune diseases, infections, and cancers; in rare cases, natalizumab can trigger

a potentially severe brain disease known as progressive multifocal leukoencephalopathy (PML).

“We may choose drugs that have fewer side effects but take longer to begin working in a patient who has a very slowly worsening disease,” says Robert Glenn Smith, M.D., Ph.D., a neurologist at Houston Methodist Hospital in Texas. “Or we may choose a drug that’s a lot more aggressive in its beneficial effects, but may have more side effects, for someone with more active disease.”

With so many treatment options, finding the one that’s right for you may take some trial and error. “It’s very important for patients to work with their doctors to find the right drugs for them,” says Dr. Bowen.

Treating Symptoms

You may need medication to control your symptoms during a severe relapse (also called an exacerbation). “Symptoms such as new loss of vision and weakness and numbness of the arms and legs are the result of inflammation,” explains Dr. Yadav. “A short period—usually three to five days—of high-dose steroids will reduce the inflammation, making the relapse both shorter and less severe. Taking steroids for a long time can cause weight gain, osteoporosis, muscle weakness, and a higher risk of diabetes.

Your doctor can suggest other medications that should help with other problems.

Nondrug Therapies

MS symptoms can often be lessened without the use of drugs. “Research has shown that if you improve your diet and lose weight if you need to, it can reduce fatigue,” says Dr. Yadav, “and exercise helps with trouble sleeping.” She recommends physical therapy for balance problems, and mindfulness meditation or psychotherapy for depression and anxiety.

On the Horizon

Research on MS has shown promise. Stem cells may be able to slow disease activity and repair damage to the nervous system (called remyelination). In one study, almost 70 percent of patients treated with stem cells were free of neurological symptoms five years later. Several substances, including an antihistamine, show potential for remyelination. A clinical trial of phenytoin, commonly used to prevent seizures in epilepsy, could protect nerves in the eye from damage and also has the potential to slow the progression of disability in MS. While all of these—and many more—are still in trials, researchers hope they’ll be available before too long. ▲



fight
fatigue

FATIGUE IS one of the most common symptoms of MS, affecting about 80 percent of people with the condition, according to the National Multiple Sclerosis Society. The following advice may help:

► **Prioritize** Decide which activities are most important and save your energy for them. By prioritizing, you can be both realistic and responsible.

► **Pace yourself** It is important to learn what your body can and cannot handle and plan accordingly.

► **Delegate** Call on your support team, whether it’s family, friends, or coworkers. You may be surprised at how asking for assistance can help you conserve your energy.

► **Evaluate your environment** Consider ways

to make your surroundings less taxing on you, such as avoiding too much heat, which can aggravate fatigue.

► **Sleep** Managing symptoms that interfere with sleep—such as sleep apnea, bladder dysfunction, restless legs syndrome, or muscle spasms—is crucial in helping you have more energy during the day.



Caring for the Caregiver

“I brought her to my house so I could give her the care she needed,” Volin, 63, says. “Since I’m a freelancer, I am able to be around to provide adequate hydration, take her to doctor appointments, and get her out to a movie when she feels up to it.”

It’s a challenge for everyone—family, partners, friends—when a loved one has a chronic illness. While it can be rewarding to be a caregiver, it can also be physically and emotionally exhausting. These tips from the National MS Society (NMSS) and from Volin may help you better handle the pressures:

► **Be flexible** Realize that fatigue, weakness, and pain can overtake a person with MS at any time. Plans may be canceled at a moment’s notice. Volin suggests having backup activities that take little energy, like playing games on a tablet or watching shows on streaming services, to pass the time while the person gets through fatigue or an exacerbation.

► **Allow extra time** Moving is difficult for many people with MS, and a rushed schedule will add stress. Make sure to leave plenty of time to get to engagements.

► **Enjoy each other** Whether you are the care recipient or the caregiver, it’s normal to experience guilt, resentment, and anger toward the other person. But it’s important to have happy moments as well. “We are companions to each other,” Volin says. “Meg is the funniest person I have ever known. Humor is probably her greatest tool for dealing with her disabilities.”

► **Talk to others** Caregiver support groups can help you keep going

when things are tough, and they allow you a place to vent. If there are no groups nearby, talk to a friend or seek help from a therapist.

► **Accept help** Feeling overwhelmed? This might be the time to call on those friends who have said, “If there’s anything I can do...” Let them fill in for you, and go out for a meal, take a nap, or otherwise attend to your own needs.

► **Keep up with your own health** Do your best to eat well, be physically active, and stay current with medical appointments and medications. Talk to your doctor if you aren’t getting enough rest or sleep.

► **Modify your home to be safe and accessible** Consider having an occupational therapist or a physical therapist make a home visit and recommend measures—such as ramps, widened doorways, or kitchen or bath renovations—to keep the person with MS as independent as possible, as well as reduce the physical strain on you. The NMSS (see nationalmssociety.org) can suggest practical, low-cost modifications and provide referrals to home remodelers and architects. Adaptive devices can help, too. “My sister’s favorite tool is a walker with a basket, which enables her to carry things like her cell phone whenever she’s up and around,” Volin says.

► **Accept that you can’t fix everything** Know, also, that some decisions only the patient can make.

Your medical team can help you find support and assistance—or visit the Caregiver Action Network’s website (caregiveraction.org) or the Family Caregiver Alliance’s website (caregiver.org). ▲

Meg Lane* received a diagnosis of relapsing-remitting MS in 1992, at age 31. By 2013, she was mostly using a wheelchair and no longer working; that year, she experienced an exacerbation due to dehydration that landed her in the emergency room. At that point, she went to live part-time with her sister, Pat Volin*, in Sparta, NJ. Although Meg lives with her husband in Nanuet, NY, when possible, his job limits the amount of time that he is able to spend at home.

*Neither Meg Lane nor Pat Volin is depicted in the photo.



With the diagnosis of multiple sclerosis, you have many questions. MS Focus is here for you, offering programs to assist with the critical needs of people affected by MS and services to help them maintain health and well being.

Our services include:

- A National Toll-free Helpline
- Homecare Assistance Grant
- Assistive Technology Program
- Cooling Program
- Health and Wellness Program
- Support Group Program.

All services are free of charge.

Contact: 888-673-6287

support@msfocus.org

www.msfocus.org.

Let’s Find Better Days

Additional Resources

Get better ZZZs Sleep problems often accompany MS. The National Sleep Foundation (sleepfoundation.org) offers many helpful suggestions for improving the quality and quantity of your shut-eye.



Tools, Tips & Apps

1 Eat to Beat MS
Nerve damage is caused by inflammation, which occurs in MS when the body's own immune cells attack the nervous system. Some diet choices—oily fish (salmon, sardines, tuna), tea, strawberries, almonds, carrots, onions, and broccoli—may help decrease inflammation. The Inflammation Factor Tracker (for iOS and Android) provides recipes and nutrition information for many foods.

2 Use Technology
Assistive devices can improve efficiency and mobility, and help you conserve your energy. Some examples are wheels on a laundry cart, a mobility scooter, a long-handled vacuum cleaner, and countertop appliances that reduce the need to stoop or reach. For more great ideas, check out healthcentral.com/multiple-sclerosis/cf/slideshows/assistive-devices-living-ms.

► **Talk It Over** More than 25,000 people with MS have joined MS Connection (msconnection.org) to find support groups, discussion threads, info on the latest research, and one-on-one volunteer peer support.

3 Manage Everything
My MS Manager (mysaa.org/msaa-community/mobile) is a free app (Android, iOS) you can use to store medical information and track disease activity, including symptoms and treatments.

4 Consider Rehab
Physical, occupational, vocational, and speech-language therapy can improve many functions in people with MS. For more info, check out the National MS Society (nationalmssociety.org).

5 Know Your Rights The Americans with Disabilities Act (ADA) is designed to make sure that people don't face job and other discrimination based on a health condition. The Job Accommodation Network (askjan.org) offers practical suggestions to help your employer determine effective accommodations and comply with the ADA. Some examples are allowing flexible work hours; providing memory aids, such as schedulers or organizers; and designing ergonomic workstations.

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