

Out-stressing stress



How to identify and manage the tension MS might cause.

by Aviva Patz

Clarisa Walcott, 40, of Portland, Oregon, gets stressed every six months, when she's scheduled to get her infusions of Rituxan, an intravenous drug used for the joint pain and swelling that she experiences along with her multiple sclerosis.

"Most of the time my MS is in the background, but when it's close to infusion time, my anxiety goes up," says Walcott, a mother of three. "All of my symptoms start flaring—the chronic pain in my feet, vibrations in my legs and general weakness. Anxiety is a real trigger for me."

Life with MS is almost like having two diseases: the MS itself and the stress of getting care for the disease.

"One of the things stress does is create anxiety, which can lead to depression, and that makes people with MS feel like they're having a relapse, whether they are or not," says Emily Riser, MD, medical director of the Tanner Center for MS in Birmingham, Alabama. "We don't have all the evidence, but we do know that as with any other chronic disease, like heart disease and diabetes, stress leads to more symptoms and more visits to the doctor."

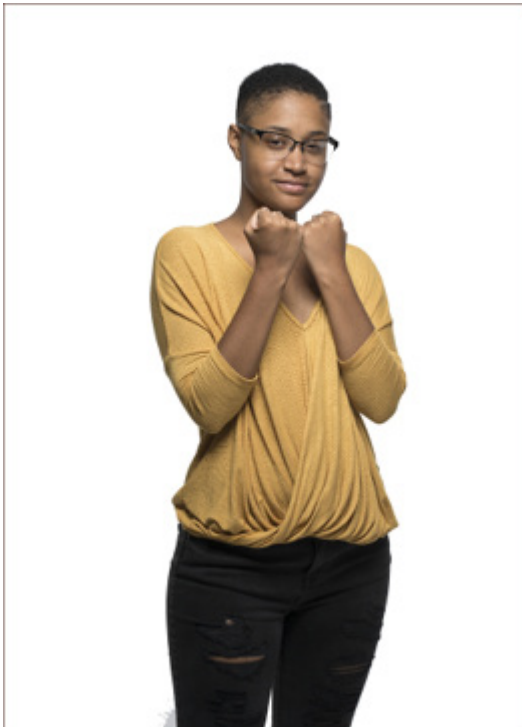
Here are some of the top stressors for people with MS, how to recognize their impact on symptoms and strategies to help cope with stress.

Defining stress

Stress originally meant the chemical fight or flight reaction that prepares the body to face danger, but today it can be the result of anything that causes psychological tension—whether it's a new symptom, a new medication or navigating the complex world of insurance.

Causes of stress

MS is unpredictable. That's the top stressor, according to Rosalind Kalb, PhD, a clinical psychologist who has counseled people with MS for 35 years. "If we could tell people what is going to happen next week with their disease, they could manage it. It's the not knowing that causes the most stress and anxiety."



Jessica Oler says she experienced depression around the time of her MS diagnosis.

Jessica Oler, 31, of San Francisco, says that when she was diagnosed in 2012, "there was fear, there was depression, there was suicide stuff." Walcott wakes up every day "wondering if something else is going to happen today with my MS," and some days she cries about it.

Many symptoms are invisible to the world—and to your health care team. "Unless you tell your doctor, he or she can't tell if you're in a lot of pain, if you're not sleeping at night, if you're struggling at work because of cognitive issues," Kalb says. "Then you leave the appointment with a renewal for your disease-modifying therapy (DMT), but you don't know how to deal with your day-to-day symptoms." Not treating those less-visible symptoms can lead to more stress.

Before attorney Laurie Lee, 71, retired from her law firm in Portland, Oregon, she occasionally had trouble talking and finding words. Her ability to prepare written analyses to clients was impaired, and she developed facial tics because of overwhelming stress. Now when she's stressed, she still has trouble tracking and talking and then becomes irritable because she can't communicate the way she wants to. She discovered she sometimes has aphasia (temporary inability to verbalize an important point or describe an event) only because her symptoms once occurred in front of her neurologist during an appointment.

With MS, choice—ordinarily a good thing—can also be a stressor. Today, thanks to an expanded toolbox of options, there are a variety of treatment decisions to be made.

“Back in the 1980s, people were told to go home and rest, but today we have more than a dozen approved treatments with several different mechanisms of action,” Kalb says. “So if one doesn't work for you, your doctor will recommend another.” But the menu of options can leave people feeling confused and overwhelmed: “What's the best choice for me?” and “What if I don't choose the right one?” are common concerns.



Laurie Lee uses breathing and meditation exercises to help manage her stress. Photo courtesy of Laurie Lee

It's normal to not know what to do first. Care for MS can involve any number of tasks: keeping up with doctor appointments and physical therapy; obtaining and remembering medications; keeping track of symptoms; filing for insurance claims; and figuring out how to pay for everything. “Many times, the abundance of these disease-specific tasks can feel

overwhelming,” says Meghan Beier, PhD, assistant professor in the division of Rehabilitation Psychology and Neuropsychology at Johns Hopkins University School of Medicine.

Effect of stress on symptoms

Stress manifests differently for everyone. “For some people, it’s hearts pounding, sweaty palms, stomachaches and headaches,” Kalb says. “For others, it’s a chronic feeling of upset and worry and just feeling overwhelmed.” Stress might involve symptoms such as irritability or nervousness; expecting the worst and having difficulty making everyday decisions; constipation or diarrhea; headaches; shallow breathing and fatigue.

Any challenge people with MS face may seem worse when they’re stressed, because it further taxes their already limited reserve of energy. Ultimately, Beier says, stress may play a role in secondary conditions such as insomnia, chronic pain, cardiovascular diseases such as high blood pressure, or even obesity.

Strategies that might help

Treatment decisions and doctors’ appointments aren’t going to go away, but the way a person handles them can help lower the stress they may bring. A variety of stress management techniques might help people become more resilient in general. Among them:

Yoga

Coping strategy: Walcott started practicing yoga when she was first diagnosed and had pain in her feet and the sensation of banding around her knees. “I would do yoga, and for 20 minutes afterward, I felt fairly close to normal.



Practicing yoga can help decrease fatigue and pain.

I don't know if it's the circulation or the breathing or the calming at the end, or some combination," she says. "Now when I do yoga," Walcott says, "I feel mentally, physically and emotionally stronger."

Research shows: A 2016 study in the Journal of Diagnostic Resources shows that yoga is likely to "increase self-efficacy of MS patients through enhancing physical activity, increasing the strength of lower limbs and balance, decreasing fatigue and pain, and finally to promote social functioning and to relieve stress and anxiety."

Mindfulness meditation

Coping strategy: Lee tries to breathe and meditate for about 20 minutes a day using mobile apps like Insight Timer and Calm. She attended two retreats sponsored by complementary-medicine advocate and author Deepak Chopra, MD, where she learned health principles of Ayurveda and was given her own personal mantra. Over those intensive several days and in the weeks that followed, Lee says she was able to gradually cut back on her antidepressants and get off her anti-anxiety medication entirely (under the advice of her physician).

Research shows: In a 2016 study in the journal Caring Sciences, people with MS who received eight two-hour sessions of mindfulness-based stress reduction training (MBSR) saw improvements in physical health, emotional well-being, health distress, health perception, satisfaction with sexual function, fatigue severity and overall quality of life. A 2017 study in the journal Mindfulness adds that MBSR can also help with cognitive function in addition to stress reduction.

Positive affirmations

Coping strategy: Like the famous "I think I can" chant in "The Little Engine That Could," affirmations can help you stay positive and feel in control. "I've found that it really helps me not catastrophize," says Oler, who watches motivational videos on YouTube. "It reminds me that I'm strong and capable and I can handle all of this." She says affirmations when she wakes up in the morning and throughout the day as needed, especially when she has an infusion coming up. "I have to stay strong on all levels," she says.

Research shows: In a 2013 study in PLOS ONE, researchers found that people can boost their ability to solve problems under pressure by using self-affirmation. In fact, study participants who were chronically stressed and completed a self-affirmation activity before a problem-solving task performed at the same level as participants with lower stress levels.

Manage the unpredictability

Coping strategy: If the fear factor is overwhelming, counseling can be a good place to start. In her work as an occupational therapist, Walcott teaches practices based on cognitive behavior therapy (CBT), which involves changing thoughts to change behavior, and incorporates them into her own daily life to manage her anxieties. For example, she was training for a 10K race when she started developing foot drop. "My brain kept ruminating on

this one thing—how it’s going to affect me, my run, my children, my work, everything, so I stopped running,” she says. But then she realized she could ask her doctor to prescribe physical therapy, which allowed her to continue training. “Once I realized that I have a team of people who are there to guide me when I feel like this disease is taking over, I was able to change everything I thought,” Walcott says, “and changing my thoughts helped me change my behavior.”



Call 1-800-344-4867 for a list of support groups near you or visit nationalMSSociety.org/supportgroup.

Experts say: “When people get diagnosed, they immediately picture themselves sitting in a wheelchair and it’s terrifying. How can we get over that?” Dr. Riser asks. Her approach involves assembling a team that might include a medical care provider whom the person with MS can trust, family members and perhaps a dietitian, an exercise physiologist and a psychologist. She also encourages access to research and resources. Having this team in place and access to information helps people feel more in control with the support they need.

Other strategies

Advocate for your priorities: Bring a list of your concerns to your appointments. “If your fatigue or sexual problems or mood or pain are at the top of the list, that’s what you need to present to your provider,” Kalb says. Schedule a follow-up appointment if necessary to get all your concerns addressed.

Seek out resources: Visit nationalMSSociety.org/wellness to learn about wellness strategies, consult the MS Society brochure on Taming Stress and hear how other people are getting their MS needs addressed by joining an MS support group. Call 1-800-344-4867 for a list of groups near you or visit nationalMSSociety.org/supportgroup. You can also join the MS online community (MSconnection.org) to trade tips.

Make decisions for today and course-correct as needed: Work with a health care team you trust to sort out the best treatment option for you today, knowing that if it's not effective, you can switch. "It's not a personal failure," Kalb says. Keep an open line of communication with your providers to assess your treatments as you go along. One way to track your symptoms is by downloading an app such as one from the MS Association of America (mysaa.org/msaa-community/mobile).

Break down your to-dos into bite-sized chunks: Beier recommends taking one step each day. For example, if you start to experience a new symptom or sensation, there are steps you can take to name and address it:

1. Don't panic. Document your experience. How often does it occur, what time of day, in reaction to something specific? Writing things down can help bring clarity. You can also track the frequency or severity with a symptom tracker, which is a beneficial resource for your doctor when deciding on a treatment plan.
2. Try to understand whether what you're experiencing is from MS, a side effect of a medication or something completely unrelated. You may need your nurse's or doctor's help with this—don't spend too much time attempting to self-diagnose on the internet. Make an appointment to see your doctor.
3. Gather (and continue) your documentation, and prepare a list of questions for your upcoming appointment. Talk to a trusted friend or family about it, if it feels good to talk.
4. If you're feeling overwhelmed or stressed, consider talking with a counselor. An MS Navigator at the Society can refer you to a professional in your area. Call 1-800-344-4867.
5. Once you and your doctor have agreed on a plan of action or treatment, it may be helpful to continue documenting your experience. Check in with your health care providers as scheduled, and move on with life.

"The tasks and steps will be different for each person, but breaking them down always reduces the stress of getting them done," Beier says.

What doesn't work

Some types of online research are counterproductive. "People get on the internet and start freaking out," says Dr. Riser. "Don't get into chat rooms [with someone making negative remarks] because it's just going to make you more depressed and more anxious." Instead, look for trusted sources of information online, and limit your time on social media if you find you feel more depressed afterward instead of connected and affirmed.

Untreated depression and anxiety may also lead to alcohol and drug use and smoking, which can make MS symptoms worse. “Smoking impacts the disease, and alcohol increases neuropathy and affects the liver, cognition and balance,” Dr. Riser says.

When Oler would try to “drown her sorrows” with alcohol, it just made her feel more lonely and depressed, she says. It also threw off her balance and heightened her pain and other symptoms.

Today, Oler says she has learned the importance of self-care and being an advocate for herself. She goes to talk therapy, and she meditates and repeats affirmations every morning to stay positive. “Now instead of dreading the day,” she says, “I’m excited to see what it holds.”

Clarification: Please note that rituximab (Rituxan) is not FDA-approved for the treatment of multiple sclerosis, but has been used off-label in an effort to limit new MS disease activity in some patients. Rituximab does have an FDA indication for the treatment of rheumatoid arthritis where clinical trials demonstrated a reduction in joint pain and swelling, according to Kathleen Costello, associate vice president healthcare access with the Society.

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[Join a local support group](#) or call 1-800-344-4867 for a list of groups near you.

Read more about [stress and emotional well-being](#).