Beyond RX



Your disease-modifying therapy is essential, but a little extra self-care could make a big difference in easing your symptoms.

by Aviva Patz

In 2005, when she was first diagnosed with multiple sclerosis, Tami Ryan of Flower Mound, Texas, experienced extreme fatigue, diminished eyesight, and paralysis and numbness in her arm. Today, at 49, she's an active mother of three running a home-based business with her husband. You might say she's thriving—and she gives her MS disease-modifying therapy (DMT) only part of the credit.



Tami Ryan, diagnosed with MS in 2005, focuses on healthy habits.

"I decided that if I was going to beat this disease I needed to push myself beyond what is normal to just live," says Ryan, who runs, practices yoga and does weight training. She also watches her carbs and uses aromatherapy. "I am not trying to be a superwoman, but I won't stop trying to do super stuff. It's a daily mental fight to push, but some things are just worth it. I am worth it."

Besides quitting unhealthy lifestyle habits—most notably smoking—research is beginning to show how healthy lifestyle strategies may help to improve management of MS, from taking vitamin D to exercising and practicing yoga to cognitive behavioral therapy (CBT). It's a matter of finding the ones that fit your particular lifestyle and are most effective for you.

"We all want to feel our best, whether we have MS or not—but self-care is even more important when you have a chronic disease," says Debra Frankel, a member of the healthcare access team at the National MS Society. "We're finding that lifestyle strategies in some cases may modify the course of the disease and even your risk of getting MS in the first place."

Lifestyle strategies to consider

New research can help doctors take lifestyle strategies more seriously. "Now we know that physical activity, diet, stress management and more are having an impact across the board," Frankel says. Lifestyle strategies related to MS can be broken down into these areas:

Diet: Certain diets have been proposed as treatments, or even cures, for the signs and symptoms of MS. But most of these diets have not been subjected to rigorous, controlled

studies, and the few that have been evaluated have produced mixed results. That's why doctors advise following general American Heart Association guidelines for heart health, which means eating vegetables and fruits, whole grains, fish and lean proteins, and cutting down on salt, processed foods and alcohol. "We think dietary changes may improve certain MS symptoms such as fatigue, potentially through beneficial effects on overall health and wellness," says Ilana Katz Sand, MD, assistant professor of neurology at the Icahn School of Medicine at Mount Sinai in New York, who is conducting a diet study with funding from the Society.

Dr. Katz Sand says changing our diet works in two ways to impact MS: directly, via the nutrients we absorb, and indirectly, via changes to our microbiota, the community of gut bacteria that influences our immune system as well as brain signals. We help shape our microbiota by the foods we eat. "We think certain dietary patterns may help by decreasing inflammation, supporting myelin, and protecting and nurturing brain cells through these signaling pathways," Dr. Katz Sand says.

Research has been conducted on two dietary supplements with mixed results:

- **Vitamin D**: A 2015 study in the European Journal of Neurology suggests that low levels of vitamin D are a risk factor for developing MS, and taking vitamin D may help protect neurons and repair myelin.
- **Biotin, a form of vitamin B**: In a 2015 study in the journal Neurology, high-dose biotin improved disability in some 12 percent of participants with MS, likely because it contains an enzyme that's key to activating myelin synthesis.

Researchers caution against taking high doses of any supplement because of potential risks. Be sure to discuss the use of all supplements with your neurologist because some supplements may interfere with medications and may not be safe for every medical issue.

Ryan noticed that 30 minutes after eating a doughnut, her energy crashed and she felt allover body pain. Now she eats carbs in small doses. "I still enjoy my favorite foods, including French fries," she says, "only I manage when I'm going to have them."



Keri Link, diagnosed with MS in 2015, says her resilience comes from being active outdoors with her dog. Photo courtesy of Keri Link

Keri Link, 45, of Missoula, Montana, ditched pasta and potato chips right after she was diagnosed with MS in 2015. Though she still experiences balance issues and visual and cognitive slowness, she believes following a modified Paleo diet (meat, fish, fruits and vegetables, and no grains or processed food) helps keep these symptoms under control. "I eat the most nutrient-dense foods I can find," she says.

Physical activity: According to a recent Society report establishing research priorities based on the most promising avenues of treatment for MS, exercise has a wealth of benefits for people with MS. Studies indicate that exercise improves aerobic capacity and muscular fitness as well as the ability to walk and maintain balance, and possibly even cognition. It appears to help alleviate fatigue and depression and enhances overall quality of life. Working out also might reduce the risk of other diseases, including obesity, which has been linked in some studies to increased MS risk and worsening of symptoms. In a 2017 study in the Journal of Neurology, Neurosurgery, and Psychiatry, people with MS who were overweight or had high cholesterol showed increased risks for relapses and annual changes on a scale that measures disability.

There's no one-size-fits-all workout for MS, so do what you love and can handle physically. Ryan says that doing yoga three times a week has made an "amazing difference" in her balance. She also runs.

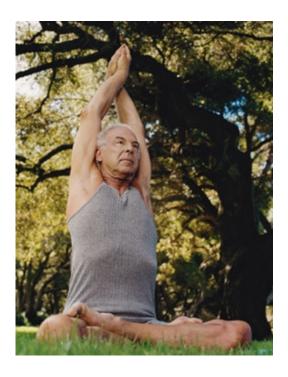
Link has found that hiking makes her feel better—she hikes outside with her dog and does yoga and stretching.

For adults with mild to moderate disability, the MS Society of Canada recommends 30 minutes of both moderate intensity aerobics and strength training exercises for major muscle

groups twice a week. Get a personal recommendation from a physical therapist or a fitness professional with experience in MS.

Emotional well-being: Depressive disorders are common among people with MS—and they're often underdiagnosed and undertreated. Promising remedies for emotional changes include:

- **Therapy.** Depression often goes hand in hand with fatigue and sleep problems, according to Amy MB Sullivan, PsyD, director of Behavioral Medicine, Training and Research at the Mellen Center for MS at the Cleveland Clinic in Ohio. Sullivan coauthored a small study showing that cognitive behavioral therapy (CBT)—a kind of talk therapy that helps you identify and replace thoughts and behaviors that trigger sleep issues and teaches healthy sleep habits—improves insomnia, increases total sleep time, and reduces fatigue and depression. "The benefits of working with a therapist are significant, and can substantially improve mood, sleep, fatigue and even your MS," Sullivan says.
- **Social support.** Research has linked social support to better mental health and less stress among people living with MS, so call friends, spend time with family and join support groups: The Society's Peer Connections program connects you to a trained volunteer for tips, suggestions and support; MSFriends is a telephone help line for MS questions (1-866-673-7436); and you can join a local MS support group (call 1-800-344-4867 or enter your ZIP code at nationalmSsociety.org/SHG). When Link discovered there were no MS support groups in her town, she worked with the Society to start one and has been running the Missoula MS Healthy Active Lifestyle Support Group for two years.



Eric Small, diagnosed with MS in

1951, practices yoga, which can help lessen depressive symptoms common among people with MS.

- Mind-body approaches including mindfulness and meditation, plus yoga and tai chi, can help lessen mild to moderate depressive symptoms, anxiety and stress. Link uses mindfulness and meditation, along with deep breathing, lavender oil and a gratitude practice. "A sense of gratitude carries me through the tough times, because it could always be worse," she says.
- **Stress-management strategies.** According to a 2012 study in the journal Neurology, a stress management program reduced measures of disease activity.

Ryan has incorporated essential oils like black spruce, frankincense, blue tansy and ylang ylang into her bedtime routine. "I was skeptical at first, but then I was amazed at how well they work to help me relax and sleep," she says. Managing stress can involve reducing things that cause you stress, but it's also about finding ways to cope with unavoidable stressors. That might mean getting organized, asking for help and viewing stressors as challenges rather than life-enders.

Complementary therapies

If you're going to experiment with nontraditional therapies, use them wisely. And always check with your doctor. "Just because a supplement is herbal doesn't mean it can't still be dangerous or interact with a drug you're taking for MS," Frankel warns. "I'm not saying you shouldn't explore complementary therapies—you just have to be smart about it."

- **St. John's wort** is an herbal supplement that may help treat mild to moderate depression. Talk to your doctor first to avoid interactions with other medications.
- **Acupuncture** may help relieve MS-related symptoms, including pain, spasticity, numbness and tingling, bladder problems and depression.
- **Cannabis (marijuana)** might ease symptoms like MS-related pain and spasticity, but there's no hard evidence that it works—and smoking it likely has the same negative health consequences as cigarette smoking. No matter how you ingest it, cannabis can also impair balance, coordination and cognition.

Considerations to keep in mind

When choosing methods of self-care, it makes sense to consider factors like your physical ability, time, schedule and budget. But in the end, it's important to set realistic goals. "If you've been eating an unhealthy diet, maybe say, 'Tomorrow I'll replace dessert with a fruit,'" instead of trying to go from pasta to Paleo, Frankel says. "Also manage your expectations. You can't think, 'I'm going to take vitamin D every day and MS is going to go away."

Ryan adds, "Find what makes you happy first, then focus on healthy ways to keep that

feeling. Start small, as one little change can make all the difference."

Finally, she says, "Try something new. Amazing things happen when we choose to try."

Aviva Patz is a freelance writer in Montclair, New Jersey.

Learn more about how self care can help ease symptoms. Visit <u>Living Well with MS</u> or <u>Complementary & Alternative Medicines</u>.