Running Marathons to Beat MS p. 12

Music for Your Mind + Are Vaccinations Safe? + Benefits of a Second Language



WELCOME to the HealthCentral guide to Relapsing Multiple Sclerosis. In these pages, you'll learn about current research, how to make the most of every doctor visit, the latest treatments, and more.

For additional tips and info on MS, go to HealthCentral.com/msguide.

ON THAT NOTE

Cognitive impairment in MS patients can cause a slowdown in processing information, creating problems with speech, memory, and attention.

A small study published in the journal Medicine (January 2020) suggests that neurologic music therapy (NMT) may benefit cognitive and emotional health in people with MS. In the study, music was used to help a group of MS patients identify emotions and recall events from the past in an attempt to boost their mood. Compared with a control group that received cognitive therapy alone, the participants who received cognitive therapy plus NMT showed greater improvement in memory, thought processes, and mood.





Speak Their Language

IMMERSING YOURSELF in a new language can provide a sense of accomplishment. But recent research has demonstrated that learning a second language may have additional benefits for people with MS.

In an eight-week study in Austria, the results of which were published in *PLOS ONE* (December 2019), participants who learned English—both those who had MS and those who didn't—showed an increase in the volume of gray-matter cells in the area of the brain that processes language. Brain cell volume frequently declines in people with MS. Also, those with MS improved their health-related quality of life, as measured by tests administered after the course of study. MRIs of people in both groups indicated that learning a language promotes neuroplasticity, the ability of the brain to rewrite itself in response to new stimuli.

Age at which the incidence of new MS cases peaks

Losing Balance?

People with MS, including those who exhibit little or no disability, are at increased risk of falling. A study funded by the National **Multiple Sclerosis Society** (NMSS) and published in PLOS ONE (March 2020) shows some potential for diagnosing this sometimes hidden problem via virtual reality. In the study, 14 people with MS walked on a treadmill while viewing a virtual-reality hallway; a control group of 14 people without MS did the same. Both groups received slight visual disruptions as they walked in order to test balance, in addition to walking



without such disruptions. The group with MS displayed greater trouble with stability during the visual disruptions than the control group did-significantly more so than when no disruptions were present. The researchers theorized that individuals with MS rely more heavily on visual feedback for balance control. If you've noticed changes in your balance or the way you walk, it makes sense to take fall prevention measures. A guide to doing so, titled "Minimizing Your Risk of Falls." can be found on the NMSS website (nationalmssociety.org).



Is it OK for people with MS to be vaccinated?

Yes. Anyone with MS should receive standard vaccinations, including an annual flu shot, unless there is a specific reason not to, such as an active infection. For the American Academy of Neurology's most recent immunization guideline, our panel of doctors reviewed all of the available clinical evidence and found that preventing infections through vaccines is an important part of medical care for people with MS. If you have MS, you should feel comfortable getting your recommended vaccinations.

■ What is the best timing for administering vaccines, considering that some people with MS may be taking medications that affect their immune response?

Your doctor will check your vaccination status as soon as possible after diagnosis and provide any necessary shots according to the Centers for Disease Control and Prevention's annual recommendations. If you're prescribed an immunosuppressive or immunomodulating medication, you should get vaccinations at least four to six weeks before you begin drug therapy; that will give your body enough time to respond to the vaccine.

You can also be vaccinated if you're already being treated with these MS drugs, as long as the vaccines are not produced with live viruses. (A live vaccine contains a weakened version of a virus, as opposed to an inactivated one.)

Because there's a chance of systemic infection, live vaccines should not be

given when a person's immune system is strongly suppressed by drugs or disease. If you are experiencing an MS relapse, your doctor is likely to delay immunizations until the flare-up subsides.

■ Do vaccinations increase the risk of an MS relapse?

Generally, no. For most vaccines, there's no increase in new MS exacerbations or other complications, except for the circumstances mentioned in the previous response. For some vaccines—such as those for human papillomavirus (HPV) or yellow fever—there have been some occasional reports, but no controlled studies, of MS patients having a greater risk of flares. In counseling you about your options, your doctor will explain the dangers of a certain disease versus the potential risks of vaccinating against it.

■ Are people with multiple sclerosis more likely to develop vaccine-preventable infections?

There's no evidence that MS alone increases the risk of such infections. Instead, anyone who isn't immunized

against a particular preventable disease is at a higher risk of getting it, regardless of whether or not that person has MS. However, there is some evidence that infections may trigger MS relapses and accelerate disease progression.

■ Do MS medications reduce the effectiveness of vaccines?

Not enough clinical evidence is available for all MS drug treatments to say whether or not this is the case. In some studies aimed at answering this question for specific MS drugs, adequate protection has been observed after vaccination. But bear in mind that with some other MS drugs, the immunological response after vaccination is a bit lower. That's why it's important to discuss the benefits and risks of vaccination with your doctor.



JORGE CORREALE, MD, is an author of the American Academy of Neurology's 2019 Practice Guideline Update Summary: Vaccine-Preventable Infections and Immunization in Multiple Sclerosis.

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The good news: A better understanding of multiple sclerosis progression and newer, more effective treatments have made the condition easier to live with for many people.

Percentage of people with MS who are female

f you're sitting in an MS infusion center as you read this, you already know that multiple sclerosis is a chronic, progressive disease of the central nervous system in which the immune system mistakenly attacks myelin, a fatty substance that insulates your nerves and helps them communicate. Over time, these attacks can

cause scarring (known as sclerosis or lesions) and hardening of nerve tissue in the spinal cord, brain, and eyes. The lesions can cause pain and weakness in the extremities, vision issues, and cognitive problems. Because the exact locations of MS damage vary from person to person, so do the severity, symptoms, and course of the disease.

913,900 Estimated number

of MS cases in the United States Who's at Risk

For first-timers at the infusion center, you may still be wondering how and why you ended up with MS. Here are some possible risk factors:

- Female gender; estimates vary, but about three times as many women as men have MS.
- Where you live or grew up; MS is more prevalent farther from the equator.
- Northern European ethnicity
- Family history of the disease
- Certain genes
- Exposure to certain infections, including Epstein-Barr, human herpes virus 6, and Chlamydia pneumoniae
- Low levels of vitamin D
- Smoking
- Obesity (a recently identified risk)

Diagnosing RRMS

Four forms of the disease have been identified: clinically isolated syndrome (CIS); relapsing-remitting MS (RRMS); primary-progressive MS (PPMS); and secondary-progressive MS (SPMS).

With CIS, you have a first episode of neurological symptoms lasting at least 24 hours, caused by inflammation of or damage to myelin in the central nervous system. Some people who experience CIS go on to develop MS of one form or another, and some don't.

About 85 percent of people with MS are initially diagnosed with RRMS. Here are factors that distinguish RRMS from other forms of MS, according to the National Multiple Sclerosis Society:

- Diagnosis at an earlier age
- More brain lesions, with more inflammatory cells, as seen on magnetic resonance imaging (MRI) scans; in contrast, people with PPMS tend to have more spinal cord lesions than brain lesions, with fewer inflammatory cells.
- Some people with RRMS develop SPMS, which entails a steady, sustained worsening of symptoms over

time. Without treatment, the transition generally occurs after 10 to 20 years, but early, aggressive treatment may slow the progression.

Symptoms of RRMS

In the early stages of the disease, such symptoms as blurred or double vision, muscle weakness, stiffness, spasms, tingling and numbness in the limbs, coordination and balance problems, and fatigue are common.

Many people with RRMS notice that certain activities or situations, such as taking a hot bath or being under a lot of stress, seem to trigger flare-ups—periods of intensifying symptoms (also commonly referred to as relapses or exacerbations).

If damage to your central nervous system progresses with RRMS, you may develop health issues ranging from depression and mood changes to difficulties with memory and concentration, urinary urgency and frequency, bowel problems such as constipation, and sexual difficulties.

The ways in which people experience RRMS vary widely. Some have flare-ups, lasting anywhere from days to months before easing up, while others notice gradual but steady physical and cognitive decline over time. Still others live for years with only occasional, small reminders they have MS.

There's no way to predict what course the illness will take, but with the appropriate therapy, most people with MS don't become disabled, says Brian R. Apatoff, MD, PhD, associate professor of neurology and neuroscience at Weill Cornell Medical College and director of the Multiple Sclerosis Institute in New York City. "We have some amazing therapies."

The outlook is much better than it used to be, Dr. Apatoff notes. "Research in MS is one of the most active areas in the field of neurology, with several new therapies in the pipeline. MS is one of neurology's bright, shining areas of investigation." ■

For more info on multiple sclerosis, go to **HealthCentral.com/msguide**.

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Doctor Discussion Guide:

RELAPSING MULTIPLE SCLEROSIS"

Monitoring your symptoms and receiving the right care can make all the difference when managing your multiple sclerosis. You can take an active role in your health by not only asking questions, but also presenting your doctor with a complete picture of what you're experiencing. Toward that end, fill out the guide below so that you're prepared to have a detailed discussion with your doctor. Doing so will help your doctor to best help you.

1. On a scale of 1 to 5, since my last visit my symptoms have: (circle on scale below)



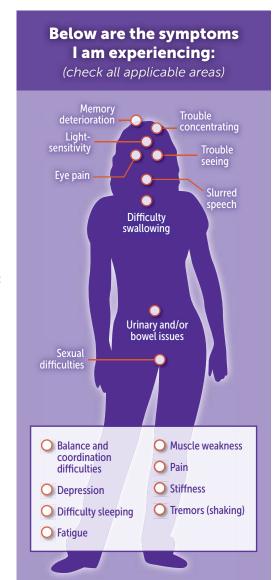
2. Recently, my most noticeable or disruptive symptoms have been:

3. Overall, this is how I feel about my condition and treatment:

4. When I feel overwhelmed with certain aspects of MS, I employ these techniques:

5. I would like advice to help me achieve these goals:









Updating your doctor on your symptoms is key for successful treatment.

hen you're living with multiple sclerosis, your condition may change over time, so your treatment needs may change, too.

But because MS symptoms often fluctuate from day to day, and office visit to office visit, tracking the progression or slowing of the disease is complicated. The best way for you and your doctor to know how well you are responding to your current treatment plan is by spending some time with each other at regular office visits.

Your physician will probably want to see you every three to six months in the first one or two years after your

diagnosis. After that, you'll most likely visit your doctor every six months or once a year. Be sure to follow the recommended appointment schedule, and check in between visits if you're having any new symptoms, medication side effects, or other issues. Monitoring your health over time, getting essential tests, and having your treatment adjusted as needed can make all the difference in living with MS.

What's That Test?

To measure MS progression and your response to treatment, your doc may give you some of the following tests:

Magnetic resonance imaging (MRI):

This technology produces highly detailed images of your body. With an MRI of the brain and spinal cord, doctors can spot lesions characteristic of MS, as well as other changes.

- Neurological exam: Your physician will check your reflexes, coordination, gait (how you walk), and balance.
- Vision: It's not uncommon for people with MS to experience blurred or double vision, so your doctor will look for optic nerve damage.
- Other senses: Some people with MS lose part or all of their ability to taste or smell, develop hearing troubles, or have problems with their ability to feel pain and other sensations. Since such issues can indicate progression of the disease, your doctor will sometimes test these senses.
- Cognitive function: MS can affect the way your brain works, so you may have tests that evaluate speech processing, working memory, reasoning and planning, visual perception, and language. ■

MAKING THE MOST OF YOUR OFFICE VISITS

1. SEE AN MS SPECIALIST

if you can. Check with the National MS Society (nationalmssociety.org/ Resources-Support/ Find-Doctors-Resources) or the Consortium of Multiple Sclerosis Centers (go to mscare.org and click on MS Centers Directory under Connect) to find one.

2. TRACK CHANGES in

your health (positive and negative). Using a journal or app, regularly record anything new going on between appointments. This makes it easier to recognize problems as they occur. Bring your notes to all of your healthcare appointments.

changing symptoms that may indicate your MS is progressing, including vision issues, vertigo, limb weakness or numbness, poor balance or coordination, falling, trouble walking or talking, memory loss,

fatigue, and bladder or

bowel problems.

3. BE AWARE of new or

4. DON'T WAIT for an appointment if you think you're having a flare-up. Call your neurologist. Sometimes the best way to stop a symptom is immediate therapy. Other times, you may just need to ride it out. You and your doc can decide on the best approach for you.





Motivated by her MS diagnosis to start running, Kim Fryling-Resare found new energy in the activity. Now, she conquers marathons.

> n a calendar hanging next to her numerous race medals, Kim Fryling-Resare has a big blue star highlighting the date of the 2020 Boston Marathon—her third time facing a 26.2-mile challenge. Participating in the iconic road race is a milestone for any runner, but for Fryling-Resare—who has relapsingremitting multiple sclerosis (RRMS)it's an even bigger step.

"Training takes a crazy amount of mileage," says Fryling-Resare, who clocks about 120 miles a month in addition to performing her roles as editor, wife, and mother of two boys. "Running has always helped my energy level, but then I upped my mileage and found that, wow, I actually feel great doing this!"

The marathon is being held virtually in September this year because of the COVID-19 pandemic. Although

Fryling-Resare is disappointed she won't be running in Boston, she isn't deterred. "I'll run the virtual race around my town," she says, "And friends and family will be setting up cheering sections."

Fryling-Resare is running as part of the 140-person Brigham Stepping Strong Marathon Team, a group representing the Gillian Reny Stepping Strong Center for Trauma Innovation at Brigham and Women's Hospital in Boston. Funds raised will benefit the center, which was established by the family of Gillian Reny, who was critically injured in the 2013 Boston Marathon bombings and whose life and limbs were saved by a medical team at Brigham.

A typical day for Fryling-Resare includes a morning run along guiet paths near her home in Rhode Island. Afterward, she starts work from her

home office as managing editor for NursingCenter.com, a website featuring peer-reviewed journal articles and continuing education resources for nurses.

Finding Meaning

Always an athlete, Fryling-Resare, now 44, played field hockey in high school and then in college on the Division I team for the University of Richmond in Virginia. She often sails with her husband, David, a yacht broker and owner of a yacht management company. "I used to hate running, but MS made me a runner," she says. "I've found it really helps me, mentally and physically. I can put my music on and get into my head. I can work through things."

Fryling-Resare says she runs to eclipse the challenges of RRMS with her own achievements. "I ran a 10miler in 2013, but I didn't train properly, and it hurt," she says. "But it left an impression on me, and like anything in my life, I couldn't leave running feeling defeated. I kept at it, I researched, and I started to train properly."

In 2016, Fryling-Resare ran her first half-marathon. In the years after, she completed two full marathons, seven half-marathons, and numerous 10milers, 10Ks, and 5Ks. "During races, I'll wear a shirt that says 'MS Warrior' for my own motivation and to raise awareness," she says. "I want to show people what MS can look like."

Fryling-Resare credits her training with helping her stay positive. But she didn't always have a bright outlook, particularly in the early months after her diagnosis, when she was in her late 20s and living in Boston.

"My first symptom was that my left side was not working," she says. "I had maybe 20 percent control of it, but 80 percent was like something else was controlling it. I was basically dragging my left side with me. I was walking my dogs and it just started happening. I thought I must have pinched a nerve or pulled a muscle or something."



Fryling-Resare running the Walt Disney World Marathon in Bay Lake, Florida, on January 12, 2020.

Her symptoms worsened over the next few weeks. She started dropping dishes, and it was taking her almost an hour to shower and get dressed.

Ultimately, Fryling-Resare asked her sister, Gina, to meet her at the ER, where she had an MRI and got a possible diagnosis. "The doctor said. 'Well. the good news is that you didn't have a stroke, and you don't have a brain tumor. We think it's MS, and we're going to admit you to the hospital for further neurological examination," she recalls. "And I looked at my sister and was like, 'What? I just pulled a muscle. What are they talking about?""

After five days in the hospital and more tests, the diagnosis was confirmed. "I was lucky in that respect, that they identified it so early, that it didn't take years," says Fryling-Resare, who quickly began treatment at the Partners Multiple Sclerosis Center at Brigham and Women's.

Another Hurdle

At first, Fryling-Resare had a really hard time emotionally as she faced the uncertainties of a new reality. "I was 20-something and thought I was invincible. I didn't know what this would mean for my life and my family, moving forward," she says. "I was really, really depressed after the diagnosis. It took me a while to work through that."

She credits therapy, family, and friends with helping her weather the difficulties during that period, "I did see a counselor at that time." she says. "I was even on medications for depression and fatigue—they helped me get through the emotion and have a bit more clarity. And now I'm on neither of these. Running helped alleviate the need for them. I eat healthy—everything in moderation—and I take vitamin D and a disease-modifying therapy."

Words of Wisdom

Fryling-Resare has used her firsthand experience to help others. She's blogged for **LiveWiseMS.org** and NursingCenter.com, and volunteered as a peer counselor for the New England chapter of the National Multiple Sclerosis Society.

"I wish I'd had someone back then who was doing well that I could have reached out to." she says. "I had all these dire scenarios in my head of what the future was going to be." So she makes herself available to the newly diagnosed, telling them, "Maybe I can help you sift through it, because I know where you are right now. It's going to get better. Try to take it moment by moment, get information from reliable sources, and don't give up. Keep trying-if one treatment or medication doesn't work for you, there are other options out there."

RRMS is a constant presence in Fryling-Resare's life, but running has helped her make peace with that. "I would love to have times when I forget about it, but it's always there," she says. "It's not a bad thing because it's also motivating for me. I want to stay healthy, so it's a constant reminder that, OK, you need to go for your run. You need to just keep going." ■

For more info on multiple sclerosis, go to **HealthCentral.com/msguide**.

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hirty years ago, not a single drug was approved to treat MS. Today, there are close to 20 meds for relapsing-remitting MS (RRMS). Many of these are also approved for other forms of the disease.

That's good news, but the range of choices can make planning MS treatment a little complicated. Your doctor will consider the nature and severity of your illness, along with your specific symptoms, to determine which medication is best for you.

Treatments known as disease-modifying therapies (DMTs), which focus on slowing the course of the disease, are a key part of MS care. DMTs can't cure the condition, but they can moderate the accumulation of lesions in the brain and spinal cord while lessening the frequency and severity of attacks. They can also help delay the progression of disability. DMTs can be injected, given via intravenous (IV) infusion, or taken orally (see sidebar).

Your treatment plan may also involve medications aimed at controlling

symptoms of MS, such as fatigue, depression, muscle stiffness and spasms, and bladder and bowel problems. There are a few nondrug therapies that have been shown to help ease certain symptoms as well.

Medication decisions come down to evaluating the balance between a drug's benefits and risks. "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," explains Robert Glenn Smith, MD, PhD, 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 has more side effects, for somebody with more active disease."

Like many things in life, there is no one-size-fits-all treatment approach for MS, and finding what works best for you may require a bit of trial and error. Try not to get discouraged if it takes a few attempts before a match is made. With so many options available, eventually something will click.

DMT TYPES



INJECTABLES: The injectable DMTs are interferon beta-1a (Avonex, Rebif), interferon beta-1b

(Betaseron, Extavia), glatiramer acetate (Copaxone, Glatopa), and peginterferon beta-la (Plegridy). "The interferons and glatiramer acetate are overall the safest," says Vijayshree Yadav, MD, associate professor of neurology at Oregon Health & Science University School of Medicine in Portland, but they may not be as effective as some of the newer drugs. The most common side effects of interferons are flulike symptoms and injection-site irritation.



INFUSIONS: The DMTs administered via IV infusion are alemtuzumab (Lemtrada), mitox-

antrone, natalizumab (Tysabri), and ocrelizumab (Ocrevus). Depending on the medication, infusion time can range from as little as five minutes to several hours, and infusions are repeated anywhere from daily to yearly for varying periods of time. The side effects differ by drug, so be sure to ask your doctor about those.



ORAL MEDS: DMTs taken as pills include dimethyl fumarate (Tecfidera), fingolimod (Gilenya),

and teriflunomide (Aubagio). Two newer oral medications, siponimod (Mayzent) and cladribine (Mavenclad), were approved in 2019. Oral drugs are convenient, but like all MS medications, they have various side effects and risks. Work with your doctor to choose your best option.

Insta Advice



Thaiana Sabova





Angie Randall

- **Read the Right Books.** "Don't read too much about the disease—that can trigger anxiety and make you forget that your case is unique. Instead, read books about people who beat autoimmune disease—get inspired by them." —Thaiana Saboya (@thai5aboya)
- start my day with a positive mind-set. I look at MS as my life teacher, rather than a life destroyer. If my symptoms are acting up, I take a deep breath and listen to my body. If I need rest, I rest. I've learned not to take things for granted." —Paige Zender (@ms_p_a_i_g_e_2017)



Paige Zender

- **Seek the Best Care.** "Find a neurologist who specializes in MS, but also be open to other therapies, such as yoga, and improving your diet," Saboya says. "Follow up with a nutritionist who has worked with patients with MS." Consider it a 360 approach!
- Take It a Day at a Time. "Try not to dwell on the what-ifs with this disease because no one knows what's going to happen tomorrow, MS or not. If you have a bad day, acknowledge it and then do something to distract yourself, even if it's just watching Netflix!" -Cat Reed (@avox_v)



Cat Reed

Prioritize Sleep. "I try to really unwind and relax after I put my kids to bed. I know **Build Your Tribe.** "You are going to need I personally need 'me time' before I can a support system. Reach out to the people sleep. I aim to turn off the lights around in your life you trust, and allow them to 9:30 p.m. so I get in at least seven hours. It help you. Don't be discouraged if you feel helps me function better the next day." like your current support system is lacking. -Angie Randall (@angieroserandall) Sometimes you have to rebuild and add new people, as well as let go of people who



Tara Merrell

- Nourish Your Body. "I do my best to eat unprocessed, whole foods to ensure I am providing my body with the nutrients it needs to function at its best," says Randall. "I also aim to drink 8 cups of water a day, and even use my organizational templates to help track my intake!"
- Hold on to Humor. "Laughing things off when you can, instead of emotionally draining yourself by taking it all too seriously, makes it so much easier to cope," says Merrell. "Just remember to laugh at your situation and not yourself. Life is funny, but being self-deprecating isn't."

are not supportive." —Tara Merrell

(@stares_and_steps)



Look for Beauty in Your Day. "Every day, I remind myself that life is beautiful. I try to

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