Managing relapses

MS flare-ups are unpredictable and discouraging, but you can learn how to cope with them.

34
MAVENCLAD is the first and only short-course oral therapy with no more than 10 treatment days a year over 2 years.†

Talk to your healthcare provider to find out if MAVENCLAD is right for you, and visit mavenclad.com for more information.

MAVENCLAD is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include relapsing–remitting disease and active secondary progressive disease, in adults. Because of its safety profile, MAVENCLAD is generally used in people who have tried another MS medicine that they could not tolerate or that has not worked well enough.

MAVENCLAD is not recommended for use in people with clinically isolated syndrome (CIS).

MAVENCLAD may cause serious side effects.

Treatment with MAVENCLAD may increase your risk of developing cancer. You should follow healthcare provider instructions about screening for cancer. Because of the risk of fetal harm, do not take MAVENCLAD if you are pregnant or of childbearing potential and not using effective birth control.

Your healthcare provider will continue to monitor your health during the 2 yearly treatment courses, as well as between treatment courses and for at least another 2 years, during which you do not need to take MAVENCLAD. Your healthcare provider may delay or completely stop treatment with MAVENCLAD if you have severe side effects. It is not known if it is safe and effective for people to restart MAVENCLAD after the full 4-year period.

*Not taken every day of the year.

I'M READY
FOR AN MS TREATMENT THAT’S
NOT AN INFUSION, NOT AN INJECTION, NOT A DAILY PILL.*

*Depending on your weight.
Read this information carefully before using MAVENCLAD and each time you get a refill, as there may be new information. This information does not take the place of talking with your healthcare provider (HCP).

What is the most important information I should know about MAVENCLAD?

MAVENCLAD can cause serious side effects, including:

- **Risk of cancer (malignancies).** Treatment with MAVENCLAD may increase your risk of developing cancer. Talk to your healthcare provider about your risk of developing cancer if you receive MAVENCLAD. You should follow your healthcare provider instructions about screening for cancer.

- **MAVENCLAD may cause birth defects if used during pregnancy.** Females must not be pregnant when they start treatment with MAVENCLAD or become pregnant during MAVENCLAD dosing and within 6 months after the last dose of each yearly treatment course. Stop your treatment with MAVENCLAD and call your healthcare provider right away if you become pregnant during treatment with MAVENCLAD.
  
  • For females who are able to become pregnant:
    - Your healthcare provider should order a pregnancy test for you before you begin your first and second yearly treatment course of MAVENCLAD to make sure that you are not pregnant. Your healthcare provider will decide when to do the test.
    - Use effective birth control (contraception) on the days on which you take MAVENCLAD and for at least 6 months after the last dose of each yearly treatment course.
    - Talk to your healthcare provider if you use oral contraceptives (the "pill").
    - You should use a second method of birth control on the days on which you take MAVENCLAD and for at least 4 weeks after your last dose of each yearly treatment course.
  
  • For males with female partners who are able to become pregnant:
    - Use effective birth control (contraception) during the days on which you take MAVENCLAD and for at least 6 months after the last dose of each yearly treatment course.

What is MAVENCLAD?

MAVENCLAD is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include relapsing remitting disease and active secondary progressive disease, in adults. Because of its safety profile, MAVENCLAD is generally used in people who have tried another MS medicine that they could not tolerate or that has not worked well enough.

MAVENCLAD is not recommended for use in people with clinically isolated syndrome (CIS).

It is not known if MAVENCLAD is safe and effective in children under 18 years of age.

**Do not** take MAVENCLAD if you:

- have cancer (malignancy).
- are pregnant, plan to become pregnant, or are a woman of childbearing age or a man able to father a child and you are not using birth control. See “What is the most important information I should know about MAVENCLAD?”
- are human immunodeficiency virus (HIV) positive.
- have active infections, including tuberculosis (TB), hepatitis B or C.
- are allergic to cladribine.
- are breastfeeding. See “Before you take MAVENCLAD, tell your healthcare provider about all of your medical conditions, including if you:”

**Before you take MAVENCLAD, tell your healthcare provider about all of your medical conditions, including if you:**

- think you have an infection.
- have heart failure.
- have liver or kidney problems.
- have taken, take, or plan to take medicines that affect your immune system or your blood cells, or other treatments for MS. Certain medicines can increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations. You should not receive live or live-attenuated vaccines within the 4 to 6 weeks preceding your treatment with MAVENCLAD. You should not receive these types of vaccines during your treatment with MAVENCLAD and until your healthcare provider tells you that your immune system is no longer weakened.
- have or have had cancer.
- are breastfeeding or plan to breastfeed. It is not known if MAVENCLAD passes into your breast milk. Do not breastfeed on the days on which you take MAVENCLAD, and for 10 days after the last dose. See “Do not take MAVENCLAD if you:”

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

**How should I take MAVENCLAD?**

- Limit contact with your skin. Avoid touching your nose, eyes and other parts of the body. If you get MAVENCLAD on your skin or on any surface, wash it right away with water.
- Take MAVENCLAD at least 3 hours apart from other medicines taken by mouth during the 4- to 5-day MAVENCLAD treatment week.
If you miss a dose, take it as soon as you remember on the same day. If the whole day passes before you remember, take your missed dose the next day. **Do not take 2 doses at the same time.** Instead, you will extend the number of days in that treatment week.

Your healthcare provider will continue to monitor your health during the 2 yearly treatment courses, and for at least another 2 years during which you do not need to take MAVENCLAD. It is not known if MAVENCLAD is safe and effective in people who restart MAVENCLAD treatment more than 2 years after completing 2 yearly treatment courses.

What are the possible side effects of MAVENCLAD?

MAVENCLAD can cause serious side effects, including:

- See “What is the most important information I should know about MAVENCLAD?’’

- **Low blood cell counts.** Low blood cell counts have happened and can increase your risk of infections during your treatment with MAVENCLAD. Your healthcare provider will do blood tests before you start treatment with MAVENCLAD, during your treatment with MAVENCLAD, and afterward, as needed.

- **Serious infections such as:**
  - TB, hepatitis B or C, and shingles (herpes zoster).
    - Fatal cases of TB and hepatitis have happened with cladribine during clinical studies. Tell your healthcare provider right away if you get any symptoms of the following infection related problems or if any of the symptoms get worse, including:
    - fever
    - aching painful muscles
    - headache
    - feeling of being generally unwell
    - loss of appetite
    - burning, tingling, numbness or itchiness of the skin in the affected area
    - skin blotches, blistered rash and severe pain
  - progressive multifocal leukoencephalopathy (PML).
    - PML is a rare brain infection that usually leads to death or severe disability. Although PML has not been seen in MS patients taking MAVENCLAD, it may happen in people with weakened immune systems. Symptoms of PML get worse over days to weeks. Call your healthcare provider right away if you have any new or worsening neurologic signs or symptoms of PML, that have lasted several days, including:
    - weakness on 1 side of your body
    - loss of coordination in your arms and legs

- **Liver Problems.** MAVENCLAD may cause liver problems. Call your healthcare provider right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - tiredness
  - loss of appetite
  - your skin or the whites of your eyes turn yellow
  - dark urine

- **Allergic reactions (hypersensitivities).** MAVENCLAD can cause serious allergic reactions. Stop your treatment with MAVENCLAD and go to the closest emergency room for medical help right away if you have any signs or symptoms of allergic reactions. Symptoms of an allergic reaction may include: skin rash, swelling or itching of the face, lips, tongue or throat, or trouble breathing.

- **Heart failure.** MAVENCLAD may cause heart failure, which means your heart may not pump as well as it should. Call your healthcare provider or go to the closest emergency room for medical help right away if you have any signs or symptoms such as shortness of breath, a fast or irregular heart beat, or unusual swelling in your body. Your healthcare provider may delay or completely stop treatment with MAVENCLAD if you have severe side effects.

The most common side effects of MAVENCLAD include:

- upper respiratory infection
- headache
- low white blood cell counts

These are not all the possible side effects of MAVENCLAD. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Distributed by: EMD Serono, Inc., Rockland, MA 02370

MAVENCLAD is a registered trademark of Merck KGaA, Darmstadt, Germany.

For more information, call toll-free 1-877-447-3243 or go to www.mavenclad.com
Diversity, equity and inclusion have been a commitment at the National Multiple Sclerosis Society. Our work is evolving as we continue to learn and grow.

After the death of George Floyd in the summer of 2020 and increased public awareness about inequities in the Black community, we renewed our efforts to confront and address the disparities in the healthcare system. We expanded our outreach. We listened — seeking to hear and understand the perspectives and realities of people of color in being diagnosed, finding healthcare partners, and receiving the treatments and support they need.

As we learn, we strive to improve. Creating space for active listening and discussion has become a discipline of ours. At the start of Society meetings, we take turns reading our Diversity, Equity & Inclusion Statement, giving the person reading the statement an opportunity to provide a personal perspective. Each word has been carefully chosen to describe what we stand for:

**Diversity, equity and inclusion statement**

- The National MS Society is a movement by and for all people affected by MS.
- Our voices and actions reflect diversity, equity and inclusion.
- We welcome and value diverse perspectives.
- We actively seek out and embrace differences.
- We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our mission.

Our plans include specific milestones to address disparities in MS healthcare and make space for marginalized groups. We know that diversity, equity and inclusion must permeate everything we do — as a consistent and first consideration, not a one-year, check-the-box activity. We must persist, grow and get better by increasing the diversity and inclusion of our staff and volunteer workforce and ensuring we are an anti-racist organization in everything we do.

The Society is committed to creating a world where everyone — of every race and every ethnic background, as well as members of the LGBTQ+ community — can live a life free of MS. The disparities that keep anyone from receiving today’s care must not keep them from receiving tomorrow’s cure.

What does our Diversity, Equity & Inclusion statement mean to you? As always, I’d like to know what’s on your mind.

Let’s keep in touch.

Cyndi Zagieboylo
features

thrive

Summer at home
Have a sensational and safe summer with these stellar staycation ideas. 22

Managing relapses
MS flare-ups are unpredictable and discouraging, but you can learn how to cope with them. 34

departments

forward 4
Diversity, equity and inclusion

@momemntum 7
Readers sound off

move 55
Meet the Inspiration Award winners

impact 62
Sylvia Lawry: Tireless crusader

fired up 69
A small window

this is me 72
From visual to visionary

Michelle Droll’s artwork helps her see each day as a starting point.

A story on page 28 of the Spring 2021 Momentum magazine contained an incorrect link for information about minorities in research. The correct link is: ntimss.org/MinoritiesInResearch

Look for these icons throughout Momentum.

CALL  BROWSE  CLICK  EMAIL  DOWNLOAD  WATCH

nationalMSsociety.org/momentum 5
Vocational rehabilitation: How to make the most informed decision about whether to keep working. PLUS: People with MS and their pets, 5 tips to boost your immunity and how to be more grateful.

Contact Momentum

nationalMSsociety.org/momentum

Address drop, add or change
Email: mailinglist@nmss.org
1-844-675-4787

Momentum Editor
National MS Society
900 S. Broadway, Suite 200
Denver, CO 80209

editor@nmss.org
Letters to the editor must include your name, your home state and a way for our staff to contact you. Letters should be no more than 100 words and may be edited.
**Issue spoke to me**

As a Black woman over 60 diagnosed with primary-progressive MS (PPMS) in 2010, I was thrilled with the Spring 2021 edition of *Momentum*. It really spoke to me. The article on foot drop gave me more ideas for stretches. I use a cane and have serious spasticity in my right leg and arm. I also am glad to know that the inequities in healthcare have finally been acknowledged. My first neurologist dismissed my concerns, but the second doctor happened to be an MS specialist and took time to explain things with my diagnosis. Living with PPMS, though, I had research to find helpful information and other ‘MSers’ with our progressive form. Very few therapies are available; most articles focus on relapsing-remitting MS forms. Because I can’t easily rebound from a fall, exercises on the floor (I try to stay away from) obviously can’t work for me. Disease-modifying therapies aren’t made for older PPMS patients. I look forward to new drug therapies being tested now. The need for diverse patients (race, age, MS type) in clinical trials is essential. This magazine made this very clear. Thank you.

Constance Chevalier, California

---

**Cruise control**

After reading the article “5 tips for managing foot drop” (Spring 2021), I thought back to my experience when, after receiving two speeding tickets, I faithfully began using the car’s cruise control. Never associated my foot drop to my later diagnosed MS!

John McMullen, Massachusetts

---

**Good health helps everybody**

Thank you for the article, “Exercise minimizes MS symptoms, preserves brainpower” (Spring 2021). It really helped me with something I’ve been struggling with. As a woman and activist with MS, I feel an overwhelming pressure to have a positive impact on our world, and fatigue means I can’t do it all. (Really, who can?) Using my limited energy for exercise can feel selfish. However, the article helped shift my perspective. The researchers shared how exercise increases brain and body function, and this got me thinking — it’s not just about me. By making time and energy for exercise, I can serve my community, remain a productive employee, be a true partner to my spouse and enhance my quality of life in the long term. Making health a priority serves us all.

Mia Ocean, Pennsylvania

---

**Favorite issue**

The Winter 2020–2021 edition of *Momentum* was my favorite, and I’ve been getting the magazine since being diagnosed almost 10 years ago. This issue was especially informative and inspiring. “Free to be fit” was fantastic, and Robert Paskus is my new inspiration. I’m a swimmer, too. The article on mindfulness and meditation was wonderful. I have been doing it for over five years, and it has changed my life. My favorite article was “In the beginning.” The first month, quarter, year is definitely the hardest. The National Multiple Sclerosis Society was a lifeline for me during that time. The organization was a key part of navigating the first two years, really. The myriad forms of help turned terrible to bearable.

Lisa Donnelly, California
“To you, it’s the perfect lift chair. To me, it’s the best sleep chair I’ve ever had.”

— J. Fitzgerald, VA

The Perfect Sleep Chair®

1-888-919-0968

Please mention code 114605 when ordering.

You can’t always lie down in bed and sleep. Heartburn, cardiac problems, hip or back aches – and dozens of other ailments and worries. Those are the nights you’d give anything for a comfortable chair to sleep in: one that reclines to exactly the right degree, raises your feet and legs just where you want them, supports your head and shoulders properly, and operates at the touch of a button.

Our Perfect Sleep Chair® does all that and more. More than a chair or recliner, it’s designed to provide total comfort. Choose your preferred heat and massage settings, for hours of soothing relaxation. Reading or watching TV? Our chair’s recline technology allows you to pause the chair in an infinite number of settings. And best of all, it features a powerful lift mechanism that tilts the entire chair forward, making it easy to stand. You’ll love the other benefits, too. It helps with correct spinal alignment and promotes back pressure relief, to prevent back and muscle pain. The overstuffed, oversized biscuit style back and unique seat design will cradle you in comfort. Generously filled, wide armrests provide enhanced arm support when sitting or reclining. It even has a battery backup in case of a power outage.

White glove delivery included in shipping charge. Professionals will deliver the chair to the exact spot in your home where you want it, unpack it, inspect it, test it, position it, and even carry the packaging away! You get your choice of Genuine Italian leather, stain and water repellent custom-manufactured Duralux™ with the classic leather look or plush MicroLux™ microfiber in a variety of colors to fit any decor. New Chestnut color only available in Genuine Italian Leather. Call now!

Genuine Italian Leather
classic beauty & durability

Long Lasting Duralux™
stain & water repellent

MicroLux™ Microfiber
breathable & amazingly soft

Footrest may vary by model

Because each Perfect Sleep Chair is a made-to-order bedding product it cannot be returned, but if it arrives damaged or defective, at our option we will repair it or replace it. © 2021 first STREET for Boomers and Beyond, Inc.
Summer — MS style

Stay cool this season in light layers and sun-friendly basics. There are a variety of products available that can help you stay cool while easing MS symptoms in the summer heat, and many come in fun patterns and colors:

- **Cooling scarves and neck wraps** can be worn around the neck.
- **Cooling bandanas** can be wrapped around the head or neck.
- **Cooling wraps** can be tied around the wrist or ankle.
- **Cooling inserts** are small cooling packs that can fit inside a bra.
- **Cooling vests and torso wraps** can be worn around the upper body or over or under clothes.

Below are additional recommendations from Dave Bexfield, founder of Active MSers, who lives with MS and has tested many cooling products.

- **Cooling cushions** can be placed on chairs, beach towels, car seats and more.
- **Sun-protective umbrellas** can block UV rays to keep you cooler while you sit outside.


Practical ideas for living well with MS
in the know

7 tips for getting through an MRI

Ready to lie stock-still in a loud machine for 45 minutes with no bathroom breaks? Relax. We’ve got you covered.

by Aviva Patz
Meredith O’Brien won’t soon forget the magnetic resonance imaging (MRI) scan she had in 2014. “I didn’t know my head would be locked down in a hard plastic ‘face cage,’” she says. When she told the technician she was claustrophobic, he directed her to a mirror she could use to see around the room. “I know he was trying to be kind, but I had a panic attack,” says O’Brien, 51, a Boston-based writer with relapsing-remitting multiple sclerosis (RRMS). She ended up removing the blankets given to her and getting out of the machine to calm down before trying again.

For people like O’Brien, MRIs might never be pleasant, but they play a crucial role in diagnosing and monitoring MS. “MRI has long been the gold standard for imaging in MS because it shows subtle changes in disease activity that you can’t see with other tests, like conventional X-rays and computed tomography (CT) scans,” says Derrek Tew, an MRI technologist with the Cleveland Clinic. “With MRIs, we can see if a lesion is actively demyelinating — it’s the best way to see disease activity.”

Read on to learn what an MRI is, what to expect when you get one and advice on managing the experience.

What is MRI?

MRI is a non-invasive imaging technology that produces detailed three-dimensional images — especially of the soft tissues of the body, according to the National Institutes of Health. “It’s the same radio frequencies used in radio transmissions,” Tew explains. “You’re becoming slightly magnetized, and we’re pinging you with a radio frequency and listening for an echo back, like radar. Depending on where the signals are coming from in the body and other various factors — that’s how the machine makes images.”

MRIs can detect when MS has damaged the fatty myelin layer that protects nerve cells because normally, that layer repels water. Where MS has stripped the myelin away, there’s more water, and that shows up on an MRI.

What’s it like to get an MRI?

After you fill out a health screening form, you’ll remove any jewelry and change into a hospital gown to avoid any metal that could blur the MRI image. There’s also a safety issue. The scanner has a powerful magnet and will pull any metal toward it, which can cause an injury.

If you’re getting gadolinium — a contrast agent made of metallic salt that shows up extra bright on the MRI — you might get an IV beforehand or a shot halfway through the MRI. “About 95% of the time MS patients will get contrast,” Tew says. Up to 7% of people will get a metallic taste in the mouth; about 1 to 1.5% might feel nauseated.

Next, you’ll lie down on the MRI bed and be moved backward into a magnetic tube. If you’re having a brain scan, you’ll be fitted with a receiver. You won’t need a receiver with an MRI of the spine because the receivers are built into the table.

During the scans, which can take 15 to 45 minutes per body part, you’ll need to remain very still so as not to blur the images. The scans can make loud clanging sounds, but you can wear ear plugs or a headset to dull the noise. Relaxing music or mindfulness meditation can help calm nerves and facilitate stillness.

Making it through your MRI

MRIs are technically painless, but these tips can make them feel more manageable.
Know what to expect. A 2019 analysis in the journal Neurologica found that MRIs caused anxiety in people with MS, in part because they fear the unknown. To help quell any fears you may have, talk with your healthcare team about exactly what to expect. What areas will be scanned? How long will that take? Will you be using contrast?

Jessie Ace, who was diagnosed with MS in 2013 at age 22, didn’t even know what an MRI was until she “had to go into this huge white box” and “freaked out a lot.” It was scary the first time, she adds, “particularly as nothing was explained to me beforehand.”

Prepare physically. Remove all your jewelry. “I had a team of nurses pulling my piercings out on that first one,” says Catherine Weston, 26, of Richmond, Virginia. She now avoids all hair products and makeup, which could contain tiny metallic particles. Because she prefers her own clothes to the hospital gown, Weston wears pants with an elastic waist and a sports bra under her top. She skips her morning coffee to minimize bathroom breaks.

Prepare mentally. Some people use pep talks. Ace tells herself: “It’s for a very short time, and all you have to do is lie still. That’s all. It’ll be OK. It’s no big deal. It’s totally safe, and it’ll be over before you know it.” She also imagines the treat she’ll pick up on the way home or what she’ll eat for dinner that evening.

O’Brien, who has claustrophobia, takes a mild sedative that her doctor prescribed for situational anxiety. She also keeps her eyes closed the whole time. It may help to know that there is a panic button you can press if you need to.

“Don’t stay in there to the point of terror or tears,” Tew says. “If it’s really bothering you, we’ll let your doctor know and talk about other options. While you may bail at this moment, being able to come back on your own terms lets you know you’re in control of the situation,” he adds.

Choose your soundtrack. Weston has enjoyed listening to Metallica on Sirius XM radio, but O’Brien prefers to focus on something calming, like going to a specific Cape Cod beach. “Or I tell myself a story or challenge myself to remember a movie from beginning to end,” she says.
Get comfortable in your space. “I actually feel safer in small spaces,” says Weston, who snuggles in with blankets during her MRIs. O’Brien tends to feel constricted, so she skips the blankets.

Decide: To look or not to look. “The MRI helmet has a mirror that allows you to see outside the machines, so I look around the room or watch my care team at work,” Weston says. O’Brien keeps her eyes shut for the duration.

Pass time on your terms. Weston allows herself to nap, but others prefer to mark the time. “Some patients believe that if they know how long each scan is, they can get through it,” Tew says.

Don’t sweat the results
Don’t try to interpret the MRI yourself. “Processing the results is one of the biggest challenges of MS,” Weston says. “It’s going to be either a celebration because the MRI showed no new progression or lesions, or it’s going to be disappointing because it did.” She likes to stay optimistic: “We are living in an incredible time when there are so many different treatment options for RRMS — and new ones for progressive MS as well — that there will be something that works for you.”

Aviva Patz is a writer in Montclair, New Jersey.
Scroll through Christina Roach’s @mybalancedstyle Instagram and Facebook pages, and at first, you may think it’s simply a place to discover ways to harmonize your wardrobe, beauty routine and home with posts like “3 ways to rock a moto jacket” and “My favorite patio set.” But dig deeper, and you’ll learn that the willowy mother of three with the megawatt smile works hard to balance much more.

In 2016, Roach, of Niagara Falls, New York, was diagnosed with multiple sclerosis. The middle-school teacher balances life with MS, a husband, her children and a rapidly growing influencer community of 20,000-plus followers. Key to that balance is her home — with décor she strategically designed to help manage her fatigue. “It’s my oasis,” says Roach, 40.

Two weeks after giving birth to her third child, Roach began experiencing numbness and tingling in her fingers and feet and tightness in her chest. Doctors’ initial thoughts were postpartum depression. “But I had been a health and wellness freak since I was a teenager,” Roach says. “What I knew more than anything was what I was feeling — and the difference between anxiety and numbness and tingling.”

Even with a newborn and two small children, Roach quickly became her own best advocate, initiating more testing, seeing different doctors and conducting endless hours of online research. She was confident of her MS diagnosis weeks before her doctors made it official.

She struggled through being in a “deep dark place” mentally and physically for about eight months after her diagnosis, but through expert insight and tons of research, she found a route to balance. She’s motivated by the love of her husband, Bob, her “rock,” and her children, Gavin, 9, Stella, 7, and Shae, 5. She follows the Wahl Protocol diet, works out regularly with a trainer, walks 4 to 7 miles a day, takes “a million” supplements, receives monthly infusions and takes a disease-modifying drug.
Christina Roach, diagnosed with MS in 2016, balances family, work and blogging with grace and style.
Every morning, Christina Roach walks down from her bedroom and opens the French doors that lead to a room walled mostly by glass. “It’s my happy place,” she says. With views straight out to the backyard and pool, the room offers “calmness and sanity.”

While she hasn’t had a relapse in close to four years, she “has slowed down,” though it may not appear that way online. “That’s the beauty of social media,” she says with a laugh.

A lesion in her neck caused permanent neuropathy in her left leg that has been difficult to manage. “It’s extremely painful. I feel weakness, and I feel I’m losing movement in my toes.”

Fatigue, however, is the symptom that affects her daily life most. In fact, “On the day we were moving into our new house, I was unable to get out of bed and maintain my balance to walk.” Fortunately, family and friends were there to help.

About a year ago, her fashion blogging hobby began to grow into a nearly full-time job as an online influencer. “I started it out of pure joy, just posting outfits and inspiration, then grew it into a savings and deals page,” Roach says.

Today, she has 20,000-plus followers of her Facebook group alone. “It’s grown huge in a year.” The emotional payback through the dark days of the pandemic has been just as valuable, she says. “It’s been such an amazing escape. The community of women is so uplifting and inspiring.”

Roach is developing a website that will allow her to expand her online presence to include more blogging about wellness and living with MS (she’s raised close to $50,000 so far with her Too Inspired to Be Tired Walk MS team). “I knew very early on in my diagnosis that I wanted to help motivate and inspire those with MS or any kind of disease to stay active and positive, physically, emotionally and even socially — regardless of physical limitations,” she says. In addition to raising funds and awareness in her local community, she speaks regularly with newly diagnosed people who reach out to her through social media or friends and family.

A teacher for 19 years, Roach took a hiatus when she contracted COVID-19. She said her anxiety and MS symptoms were worse than the
COVID-19 symptoms. Being home full time with three young children has brought an even deeper appreciation for how she designed her home, which the family moved into in 2019.

Roach describes her home décor style as similar to her fashion style: “classic with a little bit of an edge.” While that’s the flavor, the overarching theme is “minimalist,” she says. The challenge was to decorate and to keep maintenance to a true minimum.

**Simple, streamlined**

“To me, ‘minimalist’ means not a lot of clutter, simple, streamlined, modern and easy to clean,” she says. “I have the energy to be a teacher, a wife and mother, work out and be a blogger, but something’s got to give — and that something is the house. The less clutter, the easier it is for me.”

Roach and her husband turned a room that had been an office into a play and storage room for the kids. Keeping toys in that room does wonders for keeping the rest of the house clear. “I have a robot vacuum that can run for two hours, and because there’s no clutter, it doesn’t get stuck in corners or between things,” she says. To fight ever-encroaching clutter, “We make it a point to go through the toys every couple of months and donate things,” she says.

When she decorated, she chose classic over trendy. “That way, we won’t have to waste energy changing the décor to keep in style.” Greys, whites and blacks run through the home. Each room, however, has a “pop of edginess,” she says. Just as she personalizes a classic outfit with a unique or bright accessory, she tries to put one thing in each room that adds personality. In her bedroom, it’s two artsy canvases above the headboard. One says, “I like her butt.” The other says, “I like his beard.” The girls’ room have 3-D butterflies climbing a wall. Gavin’s room has a giant image of a hockey player on the wall.

**Three seasons room**

Nearly every warm morning of the year, Roach walks down from her bedroom and immediately opens the French doors that lead to a room walled mostly by glass. “It’s my happy place,” she says. “It’s the reason we bought the house.” With views out to the backyard and pool, the room offers “calmness and sanity.” It also brings light into the home. “Lighting for me is huge,” she says. “This room is like being outdoors.”

Christina Roach decorated her daughters’ bedroom with 3-D butterflies.
Functional and fashionable style

MODERN INDUSTRIAL-STYLE LIGHTING AND LAMPS
“We don’t get a lot of light in Buffalo winters,” Christina Roach says. “Like a lot of people with MS, I’m deficient in vitamin D. And really, I just like to have lighting that illuminates a clean, crisp style.” She and her husband swapped out all of the light fixtures and lamps and installed new ones with funky industrial metal and vintage-inspired glass. They add mood-boosting light and “a fun edge to the modern style,” she says.

THE INFLUENCER ROOM
Roach transformed the spare bedroom into the headquarters for her @mybalancedstyle blog. Shelves of shoes line the walls. Racks hold clothes to be reviewed from collaborating retailers. The full-length selfie mirror commands a place of honor on the wall. “This room is my source of inspiration where I find peace of mind,” she says. One of the keys to its allure? “No kids allowed,” she adds with a laugh.

WALL ART
Roach treasures two framed classic photos hanging on the wall of her influencer room — one of Coco Chanel’s designs and one of Louis Vuitton’s designs. “They’re my style icons, my inspiration,” she says.

Shara Rutberg is a writer in Evergreen, Colorado.
Motor-Assisted Therapy Bike
Helps Improve Mobility and Reduce Symptoms

“My wife Sarina has had MS for 25 years. She tried regular physical therapy exercise equipment, but she had no strength. She always feels better after she rides her Theracycle. By all means, get this machine.”

Joe C., North Stonington, CT

The Perfect Home Therapy
in the comfort and safety of your own home!

PROVEN RESULTS
A TheraCycle, different from a traditional stationary bike, uses “Forced Exercise” technology to work with your body, providing motorized assistance as needed with a whisper-quiet 15-speed smart motor. This allows you to maintain a faster speed for a longer duration, increasing your heart rate with repetitive movement, shown to reduce symptoms and improve mobility for MS and other neurological conditions. A TheraCycle also provides low impact, full range of motion exercise for upper, core and lower body with both cycling and rowing combined into one unit.

Benefits

- Improve Balance
- Reduce Spasticity
- Increase Strength
- Reduce Rigidity
- Reduce Fatigue
- Improve Mobility

CALL FOR PRICING
as low as $59.98/month*

FREE SHIPPING - RISK-FREE 30-DAY TRIAL
INTEREST-FREE FINANCING
*Includes equal payments of $59.98 for 48 months with 20% down

www.theracycle.com
TOLL FREE 1-866-740-1517

THERACYCLE
The Power to Move You
Bike MS: It’s more than a ride

Because MS doesn’t stop, and neither will we.

Find your ride › bikems.org

Don’t just ride, Bike MS

Thank you to our premier national sponsor: Primal

Thank you to our national sponsor: Left Hand Brewing Co.
Come on in, the water’s fine!

Water activities and sports, such as swimming and gentle water aerobics, are great ways to exercise and stay cool in the summer. Below are water activities you can incorporate into your exercise routine.

1. WATER WALKING: While standing in chest- or waist-high water, walk about 10 to 20 steps forward, then walk backward. Continue for five to 10 minutes. Increase speed or intensity (jogging) to make it more difficult.

2. DEEP-WATER BICYCLE: In deeper water, loop one or two pool noodles around the back of your body and rest your arms on top of them for support. Move your legs as if you are riding a bicycle, continuing for three to five minutes.

3. THE BALL: For this exercise, you will need an inflated, waterproof ball with a diameter of about 20 inches, such as a beach ball. In chest-high water, stand up straight and raise your right leg so it is bent at a 90-degree angle. Keeping your right foot about 11 inches in front of your left knee, maintain an upright upper body. With arms slightly bent, hold the ball with both hands just in front of your stomach. Hold this position for approximately 30 seconds, then switch legs. Repeat this routine five times on each leg for a total of 10 reps.

If you don’t like the water or don’t have access to a pool, try the aerobic activities suggested in the next story to get your cardio kick.
Have a sensational and safe summer with these stellar staycation ideas.

by Matt Alderton

Summer can be the perfect season to travel to locations far and wide. However, health issues, safety concerns, limitations imposed by the pandemic, financial considerations and a number of other reasons might mean staying closer to home this year. A staycation doesn’t have to be boring if travel isn’t an option, though. And multiple sclerosis doesn’t have to be an obstacle. Whether you like to spend time inside or outside, testing your body or resting it, here are a few suggestions to help make the most of your summer.

Play at a national park
Since being diagnosed with MS at age 29, accessible-travel specialist Tarita Davenock of Nanaimo, British Columbia, has been all over the world in her wheelchair. Now 53, she shares her love for travel as founder and CEO of Travel For All, a full-service travel agency specializing in accessibility. When COVID-19 took hold, she could no longer plan elaborate overseas vacations for herself or her clients. Instead, she began engineering dream vacations of the domestic variety — many of which included visits to national parks.

“There are some beautiful spots in the U.S. And depending on where you live, you
can drive to many of them,” says Davenock, who points out that national parks are government-run and therefore subject to the Americans with Disabilities Act (ADA). “The beauty of the national parks, if you have a disability, is that they have to accommodate you.”

There are 63 national parks across 30 states and two U.S. territories. If you don’t live near one of them, consider state parks, which also are ADA-compliant and can be just as enjoyable for socially distant outdoor activities and adventures.

“Pack a picnic, and make it a day,” advises 52-year-old travel enthusiast Dave Bexfield of Albuquerque, New Mexico, founder of ActiveMSers.org. “I’d also recommend zoos and botanical gardens, cycling and hiking trails, and outdoor walking/rolling tours — especially nighttime ghost tours, evening nature tours to take advantage of cooler temps.”

Take a swim

Michael Wentink of San Antonio loves vacationing with his wife and two children. Because he’s extremely sensitive to heat, however, he has to be strategic about where he spends his summer months. Usually, the family heads north. Because that wasn’t an option in 2020, Wentink spent much of his summer in the only place he feels relief from the blistering Texas sun: his local swimming pool.

“We’re blessed with a neighborhood pool that’s right down the street from us,” says Wentink, 44, author of “A Life Less Traveled,” a blog about his life with MS. “We spend a lot of time there in the summer because I don’t feel the sun when I’m in the pool. It’s the most wonderful thing.”
When I’m in the pool, I don’t feel like I have MS.”

Kimberly Conover Dickerson likes water parks for the same reason. “Water parks are one of my favorite summer destinations because it’s something the whole family can enjoy together,” says Dickerson, 50, author of the lifestyle blog “Winter & Sparrow.” “Many of the areas are disability-friendly, and who doesn’t like floating on a rubber tube in a cool stream of water? It requires little energy expenditure, and you get to enjoy time outdoors.”

If you don’t have a pool or water park near you, consider planning a night or weekend at a local hotel, suggests Davenock. Hotels — especially those owned by large national chains — often have wheelchair-accessible swimming pools if you need the assistance of a lift, including indoor pools that provide ample protection from the summer sun, she says.

**Have a ‘grape’ time at a winery**

Oenophiles used to have only a few travel options: France, Italy or California. These days, however, there are prolific wine-growing regions everywhere, from Oregon’s Willamette Valley to Michigan’s Harbor Country to New York’s Finger Lakes region, just to name a few. Because many of them make imbibing accessible, these regions can be great destinations for people with MS, according to Davenock, who says wineries are among her favorite places to visit when she’s looking for a fun, convenient daytrip.

“Many of them do wheelchair-accessible tours, tastings and meal pairings,” Davenock says. “These are fantastic things for people with MS to do because we’re able to participate, but it doesn’t require a lot of physical ability.”

Don’t drink? Many regions offer artisanal food experiences instead. If you live in Wisconsin, for example, you could visit dairy farms or cheese factories. And if you live in Texas, perhaps a barbecue tour is in order. Consult with your local tourism bureau to identify public, private or self-guided tours in your area.

**Build a LEGO empire**

Pool days notwithstanding, Wentink usually spends his summers inside where it’s cool. That means he’s always looking for indoor activities that he can do with his kids. One of those activities is building LEGO projects with his 11-year-old daughter, who collects LEGO Friends building sets — including a hospital that she built with her dad last summer.
“She has built an entire city with the various LEGO products she’s gotten over the years,” Wentink says. “She does most of the work, but I like it because it’s quality time that we can spend together indoors.”

If you don’t have LEGO bricks of your own, other hands-on hobbies include jigsaw puzzles, adult coloring books, baking, crocheting, knitting, calligraphy and origami, for starters.

Paint a masterpiece

Hannah Garrison, also of San Antonio, typically spends most of the summer indoors. Because she’s an artist, she devotes much of that time to painting. In 2020, she experimented with new techniques like acrylic pour art. The artist mixes a latex paint additive with various acrylic paint colors, then adds each color, one at a time, to a container that’s subsequently poured onto a canvas.

“It’s really fun and fascinating to watch because the colors just sort of mix and create a bunch of different textures,” says Garrison, 31, an arts instructor at Hearts Need Art, a nonprofit that provides free art and music lessons to people with chronic illnesses. “I also did a ton of alcohol ink art: You use a dropper to drop ink on a nonporous surface — usually a waterproof paper called Yupo paper — and then you add rubbing alcohol and let the colors mix together.”

What’s great about these techniques, according to Garrison, is that they don’t require any artistic skill. Anyone can do them. Because the result is different every time, it’s a satisfying substitute for would-be travelers who can’t take a trip but still want to enjoy new experiences.

“If you think about it, the reason we travel is that we want to get away from our surroundings and do something different,” Garrison says. “Doing artwork using mediums that you’ve never used before offers the same kind of escape.”

Dickerson agrees. Every spring, she travels from her home in Richmond, Virginia, to Washington, D.C., to see the cherry blossoms bloom. Because she had to cancel her trips in 2020 and 2021, she plans to spend this summer learning how to paint with watercolor, so she can paint cherry blossoms of her own.

“Every summer, I make it a point to try a new craft project or technique,” Dickerson says. Although watercolor will be her focus this summer, past projects have included making wreaths, pillows and body scrubs. “It keeps my mind and hands busy while keeping me cool indoors.”
If you want to learn more formal techniques, consider taking a virtual class via Zoom. Or, if you prefer to view art instead of making it, try using Google Arts and Culture to take a virtual museum tour if your MS allows.

“As someone with MS dizziness and visual issues, I find that too much of a virtual tour can make symptoms flare,” Garrison says. “It’s such an amazing resource and activity idea, but I’d recommend using it with caution.”

Host an alfresco movie night
If you avoid summer days, then you probably love summer nights. A fun and safe way to spend them is watching movies at a drive-in movie theater, according to author Elissa Dickey of Aberdeen, South Dakota, who did just that with her husband and three children last summer.

“For me, it’s crucial to have a cool place and the option of sitting down,” says Dickey, 41, who recently published her debut novel, The Speed of Light. “The drive-in was perfect because we sat in the car and kept the air conditioning going as needed until it got cool enough outside.”

If you don’t have a drive-in near you, consider making your own, Garrison suggests. She spent last summer watching movies with her family under the stars, courtesy of her mother, who fashioned a makeshift outdoor theater using a projector, a Roku digital media player, a bedsheet and a box fan for when it was hot outside.

Or forget the movies altogether and use the money you would have spent on a vacation to buy a firepit. “We have a small firepit on our patio, and that was a source of a lot of fun on cool summer evenings,” Dickey says. “We would sit in front of the fire and toast marshmallows while enjoying theoretical question games (Would you rather live where it’s always dark or always light?) and having karaoke battles.”

Discover bird-watching
Karen Lanzetta of Lebanon, New Hampshire, had to cancel several family vacations because of the coronavirus, including trips to Ireland and her native Netherlands. But that didn’t

“Every summer, I make it a point to try a new craft project or technique.”
— Kimberly Conover Dickerson

Karen Lanzetta’s enjoys bird-watching, which can be done from anywhere — even from a car.
5 tips to manage summer symptoms

Backyard barbecues. Fourth-of-July fireworks. Ice cream trucks. Lightning bugs. Fresh strawberries. Kids running through sprinklers. These are just a few of the things worth smiling about in the summertime.

Unfortunately, summer has a way of quickly wiping that smile off your face when you have MS. Heat intolerance often exacerbates symptoms like fatigue, numbness, blurry vision, tremors, incontinence, imbalance and weakness. However, with forethought and planning, you can make summer a lot more comfortable — and a lot more fun.

WEAR A COOLING VEST: Cooling vests can do wonders in warm weather, according to Dave Bexfield, founder of ActiveMSers.org, where he regularly reviews cooling gear. “My best advice: Purchase what you’ll actually wear,” he says. “In my experience, vests that are lightweight and attractive get worn. The rest just get buried in the closet. Inexpensive cooling wraps also are a favorite.”

DRINK COLD, CAFFEINE-FREE BEVERAGES: Dehydration causes an increase in body temperature, so it’s essential to drink lots of water, according to Michael Wentink, author of the MS blog, “A Life Less Traveled,” who never leaves home without a bottle of water.

In the summertime, frozen drinks like slushies and snow cones also hit the spot — as long as they aren’t caffeinated (or too sugary). “Caffeine can irritate your bladder, which may lead to more incidents of urinal urgency and incontinence,” says Kimberly Conover Dickerson, author of the MS blog, “Winter & Sparrow.” She recommends wearing a urinary protection product and carrying extra pads, liners or underwear — just in case.

CALL AHEAD: If you have mobility challenges or need other accommodations, call ahead to hotels, attractions and tour operators to ask about door widths and thresholds, restroom availability and accessibility, shaded areas or other concerns, suggests Tarita Davenock, founder and CEO of accessible travel agency Travel For All, who says a little legwork ahead of time will ensure your comfort later. “Do not go online because the information might not be correct,” she says. “Call them directly ... I even ask them to send me pictures to confirm.”

SCHEDULE AROUND THE SUN: Ultimately, avoiding the heat is easier than managing it, according to Wentink. “Because the heat is so hard for me, anything my wife and I do outside is done, for the most part, either before sunrise or after sunset,” he says.

KNOW YOUR LIMITS: If you venture outside in the summer heat, be realistic about how much of it you can handle, and be prepared to retreat when you’ve hit your limit. “Set a timer for outdoor activity,” suggests Elissa Dickey, author of the new novel, The Speed of Light. “I love working in my flower garden in the summer, so I set a timer for 10 to 15 minutes to make sure I take frequent breaks.”

Be aware of your limits indoors, too, Dickerson advises. “I’m still able to walk short distances, but if I’m going to a place that covers a lot of distance, I’ll rent a scooter or bring my own to conserve energy,” she says. “I find that I enjoy myself more when I do this.”
stop her from enjoying beloved summer activities at home — one of which is birding. All you need to partake, she says, is patience, a pair of binoculars and a burning curiosity about nature.

“I think we all secretly want to fly, especially now that we’re all stuck at home,” explains Lanzetta, 54, author of “Our Carpe Diem,” a blog about living and traveling with MS. Birding, she says, is great for people with MS because it can be done from anywhere — even a car. “I enjoy the thrill of seeing new, exciting and colorful birds. I’ll take pictures of them and look them up when I get home. I enjoy learning new things, and I always find out something surprising.”

Karen Lanzetta hula-hoops for 10 or 15 minutes every morning for fun and exercise.

**Go on a 21st century scavenger hunt**

Another summer activity Lanzetta enjoys is geocaching, a high-tech treasure hunt where you use your phone or a GPS device to explore the outdoors and find hidden “geocaches” — miscellaneous trinkets and sundries that fellow geocachers store and stash in containers for you to find. You can get started using the official Geocaching app, which provides GPS coordinates for geocaches in your area that you must find using a combination of navigation, intuition and observation.

To learn more about heat sensitivity, visit [ntlms.org/heatsensitivity](https://ntlms.org/heatsensitivity).

Explore recreation activities at [ntlms.org/recreation](https://ntlms.org/recreation).
“It’s local and tied to real places, so it’s a fun way to explore [your hometown],” Lanzetta says. “You don’t always find the geocaches, but that’s OK. It’s about the experience.”

Commit to fitness
If you can’t exercise your passport, you can at least exercise your body, Lanzetta says. After she was diagnosed with MS, she joined MS Fitness Challenge Gym, a charitable organization serving people who want to battle MS through fitness and nutrition. Every month, it poses a different exercise challenge, such as planking or wall-sitting. In a private Facebook group, members share their progress and give one another support and encouragement. While she was stuck at home during summer 2020, Lanzetta participated in an eight-week pushup challenge and raised $600 — she did one pushup per $1 donated — for the MS Fitness Challenge program.

“It’s nice to be part of a community where physical fitness is stressed, even for people with MS,” Lanzetta says. “Even without leaving the house, you can have human contact with other people who keep you motivated to exercise and have the same challenges as you.” She recently discovered a fun new activity to do at home this summer, independent of the MS Fitness Challenge Gym: hula-hooping. “Every morning when I wake up, I blast music while hooping and dancing for 10 or 15 minutes. It’s really fun, and it’s good exercise.”

Matt Alderton is a Chicago-based writer and editor.
What is MAYZENT® (siponimod) tablets?
MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults. It is not known if MAYZENT is safe and effective in children.

IMPORTANT SAFETY INFORMATION
Do not take MAYZENT if you:
• have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your health care provider. Ask your health care provider if you are not sure.
• have had a heart attack, chest pain called unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
• have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

MAYZENT may cause serious side effects, including:
1. Slow heart rate (bradycardia or bradarrhythmia) when you start taking MAYZENT. MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of MAYZENT.
   During the initial upprising period (4 days for the 1-mg daily dose or 5 days for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the upprising. Call your health care provider if you miss a dose of MAYZENT.
2. Infections. MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your health care provider should review a recent blood test of your white blood cells before you start taking MAYZENT.

Call your health care provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:
• fever
• tiredness
• body aches
• chills
• nausea
• vomiting
• headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 1 to 4 months after you start taking MAYZENT. Your health care provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your health care provider right away if you have any of the following: blurriness or shadows in the center of your vision, a blind spot in the center of your vision, sensitivity to light, or unusually colored (tinted) vision.

Before taking MAYZENT, tell your health care provider about all of your medical conditions, including if you:
• have an irregular or abnormal heartbeat
• have a history of stroke or other diseases related to blood vessels in the brain
• have breathing problems, including during your sleep
• have a fever or infection, or you are unable to fight infections due to a disease or are taking medicines that lower your immune system. Tell your health care provider if you have had chickenpox or have received the vaccine for chickenpox. Your health care provider may do a blood test for chickenpox virus. You may need to get the full course of vaccine for chickenpox and then wait 1 month before you start taking MAYZENT.
• have slow heart rate
• have liver problems
• have diabetes
• have eye problems, especially an inflammation of the eye called uveitis
2. Infections.

MAYZENT may cause serious side effects, including:

- have certain types of heart block or irregular or abnormal heartbeat
- have had a heart attack, chest pain called unstable angina, stroke or
- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT,

IMPORTANT SAFETY INFORMATION

disease, and active secondary progressive disease, in adults.
multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting

MAYZENT is a prescription medicine that is used to treat relapsing forms

What is MAYZENT® (siponimod) tablets?

review a recent blood test of your white blood cells before you start taking

within 3 to 4 weeks of stopping treatment. Your health care provider should

MAYZENT.

MAYZENT can cause your heart rate to slow down, especially

for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need

During the initial updosing period (4 days for the 1-mg daily dose or 5 days

activity of your heart called an electrocardiogram (ECG) before you take

MAYZENT.

MAYZENT can cause your heart rate to slow down, especially

Call your health care provider right away if you have any of the

Macular edema. Macular edema can

Test your vision before you start taking MAYZENT and any time you notice

You should have a test to check the electrical

MAYZENT.

MAYZENT can cause your heart rate to slow down, especially

MAYZENT.

MAYZENT can cause your heart rate to slow down, especially

Tell your health care provider about all the medicines you take, including

prescription medicines, over-the-counter medicines, vitamins, and herbal

supplements. Especially tell your health care provider if you take medicines to

control your heart rhythm (anti-arrhythmics), or blood pressure (antihypertensives),

or heart beat (such as calcium channel blockers or beta-blockers); take medicines

that affect your immune system, such as beta-interferon or glatiramer acetate, or

any of these medicines that you took in the past.

Tell your health care provider if you have recently received a live vaccine. You

should avoid receiving live vaccines during treatment with MAYZENT. MAYZENT

should be stopped 1 week before and for 4 weeks after receiving a live vaccine. If

you receive a live vaccine, you may get the infection the vaccine was meant to

prevent. Vaccines may not work as well when given during treatment with

MAYZENT.

MAYZENT may cause possible side effects, including:

- increased blood pressure. Your health care provider should check your blood

pressure during treatment with MAYZENT.

- liver problems. MAYZENT may cause liver problems. Your health care provider

should do blood tests to check your liver before you start taking MAYZENT. Call

your health care provider right away if you have any of the following symptoms

of liver problems:

  - nausea
  - vomiting
  - stomach pain
  - tiredness

  - loss of appetite
  - your skin or the whites of your
  - eyes turn yellow
  - dark urine

- breathing problems. Some people who take MAYZENT have shortness of

breath. Call your health care provider right away if you have new or

worsening breathing problems.

- swelling and narrowing of the blood vessels in your brain. A condition

called PRES (Posterior Reversible Encephalopathy Syndrome) has happened

with drugs in the same class. Symptoms of PRES usually get better when

you stop taking MAYZENT. However, if left untreated, it may lead to a stroke.

Call your health care provider right away if you have any of the following

symptoms: sudden severe headache, sudden confusion, sudden loss of vision

or other changes in vision, or seizure.

- severe worsening of multiple sclerosis after stopping MAYZENT. When

MAYZENT is stopped, symptoms of MS may return and become worse

compared to before or during treatment. Always talk to your doctor before

you stop taking MAYZENT for any reason. Tell your health care provider if

you have worsening symptoms of MS after stopping MAYZENT.

- a type of skin cancer called basal cell carcinoma (BCC), melanoma, and

squamous cell carcinoma. Tell your doctor if you have any changes in the

appearance of your skin, including changes in a mole, a new darkened area

on your skin, a sore that does not heal, or growths on your skin, such as a

bump that may be shiny, pearly white, skin-colored, or pink. Your doctor

should check your skin for any changes during treatment with MAYZENT.

Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear

protective clothing and use a sunscreen with a high sun protection factor.

The most common side effects of MAYZENT include: headache, high blood

pressure (hypertension), and abnormal liver tests.

These are not all of the possible side effects of MAYZENT. Call your doctor for

medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the

FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see Consumer Brief Summary on following pages.
CONSUMER BRIEF SUMMARY

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about MAYZENT® (siponimod) tablets, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.mayzent.com.

What is the most important information I should know about MAYZENT?

1. MAYZENT may cause serious side effects, including: Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT. MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (EGG) before you take your first dose of MAYZENT.

During the initial updosing period (4 days for the 1 mg daily dose or 5 days for the 2 mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the updosing. Call your healthcare provider if you miss a dose of MAYZENT. See “How should I take MAYZENT?”

2. Infections. MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your healthcare provider should review a recent blood test of your white blood cells before you start taking MAYZENT.

Call your healthcare provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:

- fever
- vomiting
- tiredness
- body aches
- chills
- sensitivity to light
- fatigue
- headache
- rash
- stomach pain
- confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 1 to 4 months after you start taking MAYZENT. Your healthcare provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your healthcare provider right away if you have any of the following:

- blurriness or shadows in the center of your vision
- sensitivity to light
- unusually colored (tinted) vision

See “What are the possible side effects of MAYZENT?” for more information about side effects.

What is MAYZENT?

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults. It is not known if MAYZENT is safe and effective in children.

Who should not take MAYZENT?

Do not take MAYZENT if you:

- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your healthcare provider. Ask your healthcare provider if you are not sure.
- have had a heart attack, chest pain called unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

What should I tell my healthcare provider before taking MAYZENT?

Before taking MAYZENT, tell your healthcare provider about all of your medical conditions, including if you:

- have an irregular or abnormal heartbeat
- have a history of stroke or other diseases related to blood vessels in the brain
- breathing problems, including during your sleep
- a fever or infection, or you are unable to fight infections due to a disease or taking medicines that lower your immune system. Tell your healthcare provider if you have had chickenpox or have received the vaccine for chickenpox. Your healthcare provider may do a blood test for chickenpox virus. You may need to get the full course of vaccine for chickenpox and then wait 1 month before you start taking MAYZENT.
- have slow heart rate
- have liver problems
- have diabetes
- have eye problems, especially an inflammation of the eye called uveitis
- had or now have a type of skin cancer called basal cell carcinoma (BCC), melanoma, or squamous cell carcinoma
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your healthcare provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
- If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- If you are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take MAYZENT.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements. Especially tell your healthcare provider if you:

- take medicines to control your heart rhythm (antiarrhythmics), or blood pressure (antihypertensives), or heart beat (such as calcium channel blockers or beta-blockers)
- take medicines that affect your immune system, such as beta-interferon or glatiramer acetate, or any of these medicines that you took in the past
- have recently received a live vaccine. You should avoid receiving live vaccines during treatment with MAYZENT. MAYZENT should be stopped 1 week before and for 4 weeks after receiving a live vaccine. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with MAYZENT.

Know the medicines you take. Keep a list of your medicines with you to show your healthcare provider and pharmacist when you get a new medicine.

Using MAYZENT and other medicines together may affect each other causing serious side effects

How should I take MAYZENT® (siponimod) tablets?

The daily maintenance dose of MAYZENT is either 1 mg or 2 mg, depending on your CYP2C9 genotype. Ask your healthcare provider if you are not sure about your daily maintenance dose.

Day 1 1 x 0.25 mg tablet
Day 2 1 x 0.25 mg tablet
Day 3 1 x 0.25 mg tablet
Day 4 1 x 0.25 mg tablet
Day 5 5 x 0.25 mg tablet

How should I store MAYZENT?

MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. If you need to keep it longer, store between 36°F to 46°F (2°C to 8°C) until use.

Bottles that are unopened and stored in a refrigerator between 36°F to 46°F (2°C to 8°C) containing an inner coating containing iron oxides (black and red iron oxides for the 0.25 mg tablets), behenate, lactose monohydrate, microcrystalline cellulose, with a film coating containing iron oxides (black and red iron oxides for the 0.25 mg tablets), may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. If you need to keep it longer, store between 36°F to 46°F (2°C to 8°C) until use.

You may split, crush, or chew MAYZENT tablets; take tablets whole.
Do not split, crush, or chew MAYZENT tablets; take tablets whole.

Start your treatment with MAYZENT using the following titration schedule:

<table>
<thead>
<tr>
<th>For the 1 mg daily maintenance dose:</th>
<th>Tablets a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 2</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 3</td>
<td>2 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 4</td>
<td>3 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 5 and every day after</td>
<td>4 x 0.25 mg tablet</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For the 2 mg daily maintenance dose, use the starter pack:</th>
<th>Tablets a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 2</td>
<td>1 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 3</td>
<td>2 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 4</td>
<td>3 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 5</td>
<td>5 x 0.25 mg tablet</td>
</tr>
<tr>
<td>Day 6 and every day after</td>
<td>1 x 2 mg tablet</td>
</tr>
</tbody>
</table>

- Take MAYZENT exactly as your healthcare provider tells you. Do not change your dose or stop taking MAYZENT unless your healthcare provider tells you to.
- Take MAYZENT 1 time each day.
- Take MAYZENT with or without food.
- If you miss 1 or more doses of MAYZENT during the initial dose titration, you need to restart the medication.
- If you miss a dose of MAYZENT after the initial dose-titration, take it as soon as you remember.
- If MAYZENT treatment is stopped for 4 days in a row, treatment has to be restarted with the titration.
- Do not stop taking MAYZENT without talking with your healthcare provider first.

What are the possible side effects of MAYZENT?

MAYZENT may cause serious side effects, including:
- See “What is the most important information I should know about MAYZENT?”
- Increased blood pressure. Your healthcare provider should check your blood pressure during treatment with MAYZENT.
- Liver problems. MAYZENT may cause liver problems. Your healthcare provider should do blood tests to check your liver before you start taking MAYZENT. Call your healthcare provider right away if you have any of the following symptoms of liver problems:
  - Nausea
  - Loss of appetite
  - Vomiting
  - Your skin or the whites of
  - Stomach pain
  - Your eyes turn yellow
  - Tiredness
  - Dark urine
- Breathing problems. Some people who take MAYZENT have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems.
- Swelling and narrowing of the blood vessels in your brain. A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your healthcare provider right away if you have any of the following symptoms:
  - Sudden severe headache
  - Sudden confusion
  - Sudden loss of vision or other changes in your vision
  - Seizure
- Severe worsening of multiple sclerosis after stopping MAYZENT. When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping MAYZENT.
- A type of skin cancer called basal cell carcinoma (BCC), melanoma, and squamous cell carcinoma. Tell your doctor if you have any changes in the appearance of your skin, including changes in a mole, a new darkened area on your skin, a sore that does not heal, or growths on your skin, such as a bump that may be shiny, pearly white, skin-colored, or pink. Your doctor should check your skin for any changes during treatment with MAYZENT. Limit the amount of time you spend in sunlight and ultraviolet (UV) light. Wear protective clothing and use a sunscreen with a high sun protection factor.

The most common side effects of MAYZENT include:

- Headache
- High blood pressure (hypertension)
- Abnormal liver tests

Tell your healthcare provider if you have any side effects that bother you or that do not go away.

These are not all of the possible side effects of MAYZENT. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store MAYZENT?

Unopened Containers
MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. If you need to store MAYZENT tablets for more than 3 months, containers should remain unopened and stored in a refrigerator between 36°F to 46°F (2°C to 8°C) until use.

Opened Containers

Bottles
MAYZENT 0.25 mg and 2 mg tablets may be stored at room temperature between 68°F to 77°F (20°C to 25°C) for up to 3 months. Do not refrigerate after opening. Store in original calendared blister wallet container.

Keep MAYZENT and all medicines out of the reach of children.

General information about the safe and effective use of MAYZENT

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use MAYZENT for a condition for which it was not prescribed. Do not give MAYZENT to other people, even if they have the same symptoms you have. It may harm them. You can ask your pharmacist or healthcare provider for more information about MAYZENT that is written for health professionals.

What are the ingredients in MAYZENT?

Active ingredient: siponimod
Inactive ingredients: colloidal silicon dioxide, crospovidone, glyceryl behenate, lactose monohydrate, microcrystalline cellulose, with a film coating containing iron oxides (black and red iron oxides for the 0.25 mg strength and red and yellow iron oxides for the 2 mg strength), lecithin (soy), polyvinyl alcohol, talc, titanium dioxide, and xanthan gum.

Distributed by: Novartis Pharmaceuticals Corporation, East Hanover, New Jersey 07936

For more information, go to www.novartis.us or call 1-888-669-6682.
Managing relapses

by Vicky Uhland

MS flare-ups are unpredictable and discouraging, but you can learn how to cope with them.

In December 2017, Antonia Juarez fell off her horse. That wasn’t unexpected for the avid 27-year-old equestrian, but the residual effects were. Juarez was used to recovering quickly from the bumps and bruises resulting from her falls, but three weeks later, she still had numbness in her left leg.

When that numbness spread up her entire left side, Juarez went to a hospital emergency room near her home in West Hollywood, California. She was diagnosed with relapsing-remitting multiple sclerosis (RRMS) and given a heavy dose of steroids. Two months after Juarez left the hospital, she was sitting on a friend’s couch and realized she couldn’t feel her left arm when she touched it. Even though she had started a disease-modifying therapy (DMT), Juarez’s doctor told her to return immediately to the hospital. An MRI showed that Juarez had a new lesion on her spinal cord, and she was diagnosed with a relapse.

Since she switched DMTs and started monthly intravenous immunoglobulin (IVIG) infusions in April 2018, Juarez hasn’t experienced another relapse, and her MRIs have shown no new lesions. But that doesn’t mean she’s been symptom-free. “A few months ago, I couldn’t get out of bed because I was so fatigued. My legs were shaking,” Juarez says. “The doctors said it wasn’t a relapse, but it felt as bad as a relapse because I was completely affected and hospitalized.”

“I got from my friends with MS about relapses was ‘you’ll know it when you see it.’”
— Emily Zipps

Emily Zipps knows that feeling well. Zipps, who lives in Albuquerque, New Mexico, was diagnosed with RRMS in 2018 at age 30. Since then, she’s had symptoms like constant neuropathy in her hands and feet that sometimes flare up.

Zipps’ situation isn’t unusual. The 2020 Global vs. MS online survey of 1,075 people with RRMS living in Australia, Canada, France, Italy, Spain, the United Kingdom and the United States reported that nearly half — 507 people — hadn’t been diagnosed with a relapse in the last 12 months. About 28% — 300 people — reported one relapse during that period.
Emily Zipps lives in Albuquerque, New Mexico. She was diagnosed with MS in 2018.
Another 134 people had two relapses, and 134 had more than two relapses. But these statistics don’t mean Zipps — or anyone else with RMSS — will go through their entire life without a relapse. A 2011 study published in the journal Neurologic Clinics reported that 85% to 90% of people with RMSS will have at least one relapse, flare or exacerbation at some point in their lives.

Managing expectations
That makes knowledge about relapses a key component in disease self-management. But, like everything else about MS, there’s no one-size-fits-all relapse handbook. And that includes identifying if you’re having a relapse in the first place.

“My first neurologist said you may have a relapse or you may not — we don’t know. Live your life, and let us know if something bad happens,” Zipps says. “The vibe I got from my friends with MS about relapses was ‘you’ll know it when you see it.’”

For some people living with RMSS, however, that’s not always the case. It can be difficult to know when worsening symptoms or even a new symptom is a relapse or due to other factors like an infection, stress or simply staying out in the sun too long. Even doctors — especially emergency room doctors who aren’t well trained in MS — can’t necessarily diagnose a relapse on the spot. As a result, many relapses can go unreported by both patients and physicians.

How to identify a relapse
There are tools that can help you understand how to identify a relapse, what to do if you have one and how to lessen your chances of having a relapse. Along with physical treatment options, there are tools to mentally and emotionally cope with a relapse.

Tool 1: Defining a relapse
MS is an unpredictable disease, and that applies to relapses. There’s no medical protocol — or crystal ball, for that matter — that can determine when you might have a relapse. But there are ways to rule out a relapse.

The standard definition of a relapse includes the following characteristics:

- You have a new symptom or worsening of existing symptoms.
- It’s been at least 30 days since your last relapse.
- This new issue lasts for more than 24 hours.
- Fever or infection doesn’t cause it.

If a suspected relapse doesn’t meet all of these criteria, it’s likely a pseudo relapse and should go away within a day, says R. Alejandro Cruz, MD, who works at the DHR Health Neurology Institute’s Neuroimmunology & Multiple Sclerosis Clinic in McAllen, Texas.

Pseudo relapses are relatively common compared with diagnosed relapses. In 2020, during the first five months Cruz worked at the MS clinic, he saw 104 patients. Three had relapses, and about 10 had pseudo relapses.

To help differentiate between the two, Cruz asks his patients a series of questions. He begins by asking if the patient has experienced the same symptoms a series of questions. He begins by asking if the patient has experienced the same symptoms in the past. While a relapse can cause a worsening of existing symptoms — a new lesion near the same spot as an old one can exacerbate a symptom — if it’s a new symptom or in a new area of the body, that’s a red flag that it may be a relapse.

According to a long-term study of 806 people with RMSS published in 2010 in the journal Brain, the most frequent symptoms involved in a relapse are sensory, including numbness, tingling or pain. Visual symptoms are also fairly frequent, affecting 22% of relapse...
patients. Other common relapse symptoms include balance issues, weakness in extremities, and bladder and bowel issues.

Cruz’s second question involves what the patient was doing at the beginning of the suspected relapse. Were they overheated? Fatigued? Stressed? These metabolic issues can cause a temporary worsening of symptoms that can go away in 24 hours — meaning the patient isn’t having a relapse.

Then, Cruz checks to see if the patient has changes in urination like burning or increased frequency, because urinary tract infections can exacerbate symptoms. Respiratory infections and fever associated with a virus or infection can also exacerbate symptoms. A urinalysis or complete blood count can determine whether fever or infection is causing a pseudo relapse.

Cruz will usually also conduct a neurological exam, assessing vision, strength, sensation, gait and
coordination. Finally, “I can always get an MRI to check for new lesions, but for the most part, I don’t wait for the MRI to determine if it’s a relapse,” he says.

**Tool 2: Treating a relapse**

Relapse symptoms can be different for different people and can last for a few days or several weeks. In general, relapse symptoms gradually worsen over a few days before reaching a peak that’s followed by recovery, says Lokesh Rukmangadachar, MD, assistant professor of neurology in the neuroimmunology and MS division at the Saint Louis University School of Medicine in St. Louis.

Since each relapse is different, a detailed clinical history and a neurological exam are essential. There’s no validated tool or consensus on guidelines for how to assess the severity of an MS relapse, so doctors have to decide on their own. This is important because that decision usually determines the course of treatment.

The standard treatment for a relapse is three to seven days of intravenous or oral high-dose steroids to control the inflammation associated with the relapse. Doctors have differing opinions on which steroid delivery method is better, but clinical trials show outcomes are similar between oral and IV steroids. It comes down to which type you tolerate better.

Cruz points out that oral steroids can be taken at home, and thus are more convenient than going to a hospital or clinic to get daily steroid injections. But some doctors have found that oral steroids may cause more heartburn and gastric issues in patients. The more severe the relapse, the longer the steroid treatment, although five days is the most common. But not every relapse has to be treated with steroids.

“I ask my patient how much their relapse is interfering with their life,” says Harold Moses Jr., MD, associate professor of neurology at Vanderbilt University in Nashville, Tennessee. “Steroids shorten the time you deal with the symptoms of a relapse, so if the relapse isn’t having a significant impact on the patient’s life, sometimes we’ll just keep an eye on how they’re doing and see if we need to use steroids at all.”

That said, Moses notes that steroids work better the earlier they’re given. “It’s OK if you want to wait a day or two to see your doctor if you think you’re having a relapse, but don’t wait too long.”

Moses also cautions against going directly to the emergency room if you think you’re having a relapse. “The doctors there may not be familiar with MS, and your care may be uneven,” he says. “Try to communicate with your neurologist before heading to an ER.”

Cruz says 95% to 99% of the time, a course of steroids will end a relapse. But not everyone can tolerate steroid side effects, including gastric issues, insomnia, blurred vision, restlessness and mood swings. People with diabetes may also have difficulty with steroid-related blood sugar increases.

In those cases, a doctor may prescribe IVIG therapy, like Juarez underwent, or adrenocorticotropic hormone (ACTH) gel injections. ACTH promotes the natural production of steroids in the body, but it’s expensive and difficult to obtain. Another option for severe relapses that don’t respond to steroids is plasma exchange, but this is rare.

If a relapse is severe, a patient may need to go to rehab after the symptoms are stabilized. A 2015 research review published in Neurology found that eight weeks’ worth of weekly physical therapy sessions can help improve balance, disability and gait in people who can walk at least 16 feet without a mobility device post-relapse.
Tool 3: Assessing a relapse’s effects
A review of 180 studies conducted over a 44-year period, which was published in Neuroepidemiology in 2015, found that people who have exacerbations that affect the bladder, bowels, or muscular system tend to have more disability after their relapse than those who have optic neuritis flare-up. Relapses that involve the brain have mixed outcomes.

The review found that women tend to have better recovery from relapses than men. Studies show that women are more prone to visual and sensory relapses, which are easier to recover from than the motor or neurological relapses that more often affect men.

Age also plays a role in relapse recovery. Research shows that people younger than 40 tend to have fewer residual symptoms after a relapse.

“There are different theories why,” says Rukmangadachar. “The brain is more ‘plastic’ when you’re younger and therefore may be better able to compensate after a relapse. The neurological reserve may be less in older individuals. And maybe earlier in life, the repair mechanism, remyelination, may be better.”

Moses says there’s some controversy about how likely relapses are to result in significant disability down the road. There’s evidence that people who have five or more relapses in the first one to two years of their disease have a higher risk of disability progression five to 10 years in the future.

However, he says, many people will have few if any relapses, but will still move into a progressive phase of MS 15 to 20 years after their initial relapse.

And if you continue to have exacerbations in the same body system, such as your optic or motor system, you’re at higher risk of symptom progression in those areas, Moses says.

Overall, 90 days after your relapse began, there’s about an 80% chance that any remaining symptoms will continue for an extended period of time, Moses says. Fewer than 10% of people will see an improvement in some of their symptoms after more than a year, he says.

Tool 4: Reducing your relapse risk
The Neuroepidemiology review found that women are more likely to have relapses than men. People of color tend to have more relapses than white people. And you’re also more likely to have a relapse if you’re younger or earlier in your disease course.

“The chances are higher in your 20s and 30s because the disease is more active then. The relapse incidence comes down in your 50s and 60s,” Rukmangadachar says.

All of these are factors you can’t influence. But there are also relapse predictors you can influence.

The review found that people who smoke are more likely to have relapses than nonsmokers. Stress and mental and emotional trauma are significant factors in relapses, but, interestingly, physical trauma isn’t. Relapses are less common during pregnancy. And your vitamin D levels may influence relapse frequency.

But more than any other factor you can control, being on a DMT has the most impact.

“DMTs not only help prevent relapses, but they also help prevent the accumulation of disability down the road,” Rukmangadachar says.

A variety of studies equate DMTs with significantly lower chances of having a relapse. A 2013 Cochrane review of 44 studies found that DMTs can reduce the risk of relapse by 36% to 85%, depending on the type of drug. As Juarez discovered, different medications can have different effects on your relapse susceptibility, so it’s best to work with your doctor to find the most effective one.
Tool 5: Finding coping strategies
There’s no getting around the fact that relapses can be scary. Not only do you have no idea if or when they’re coming, but you also don’t know what effect they’ll have on you now or in the future.

But while relapses are serious, doctors are quick to offer reassurances. They note that because of DMTs, relapses are much less frequent than even a decade ago and more treatable. And even if you do have a relapse, that doesn’t mean your disease outlook is worse.

As someone who hasn’t had a relapse, Zipps feels like she’s in a “wait and see” mode. She focuses on her tangible symptoms. “I think about things like what kind of fatigue will I have today? My wife would like to do more backpacking trips, and I worry, what if I have a bad day and can’t hike out?” she says. “I’m a worrier, but it doesn’t seem productive to worry about having a relapse because there’s nothing I can do about it.”

5 fun things to do during a flare-up

by Jessie Ace

Let’s face it. Multiple sclerosis flare-ups are not fun. They often come out of the blue and can last for days on end. When you’re feeling super wiped out, it’s hard to do anything. Is there a way to have a little fun and feel productive when you’re experiencing a relapse?

I’m the kind of person who always has to be doing something, whether I feel well or not. In my years of having MS, I’ve experienced the debilitating fatigue that often comes with a relapse. If you’re not careful, these relapses can stop your plans for living life to its fullest.

So, what can you do during this time? Here are my top five go-to activities to feel productive during a flare-up.

1. MINDFULNESS.
Mindfulness is the practice of being in the present with yourself. Use this time to meditate and connect with your spiritual side. Sit quietly, focus on your breathing, and recall how you feel on a good day. You also could try quiet activities like drawing or playing a game.

2. READING. In the past, during my flare-ups, I found that moving images and bright screens were too much for me. Instead, I read. When I experience a relapse, my mental health can suffer. I start to feel frustrated and angry because my body is not able to do what I want. Reading books helps me kick those negative vibes and focus on the positive.

3. PODCASTS. A flare-up is often the perfect time to listen to podcasts. You can build your knowledge, laugh at stories or listen to inspiring interviews. Podcasts are a great way to feel productive, and you can even listen while sleeping! Alternatively, you could listen to your favorite music to give you feel-good vibes.

4. MARATHONS. Not the energetic, running kind! I mean the movie/TV series binge kind. If your flare-up makes you feel super exhausted, treat yourself to a movie or TV series marathon. Giving yourself a focus takes your mind away from how you are
feeling. Is it possible to watch all the Harry Potter movies in one day? Find out! When you are feeling well, you have something to discuss with others.

5. JOURNALING. Journaling allows you to get all the words, thoughts and frustrations out of your head and onto paper. Once they are on paper, they become tangible. Come back a few hours later and reread what you wrote. You might be surprised at how differently you feel. Moreover, you can look back at past journal entries to see how your thinking has changed.

Jessie Ace is an illustrator, author of the “ENabled Warrior Symptom Tracker,” host of the “DI$abled to ENabled” podcast, and columnist for Multiple Sclerosis News Today. She lives in Swadlincote, Derbyshire, with her husband and dog, Lucy.
As someone who has had multiple relapses, Juarez agrees with that philosophy. “Your body may not feel like it’s yours, but you do have control over your mind. The more you panic about something, sometimes that thing will happen to you,” Juarez says. “You have to learn to calm your mind.”

Juarez does that through meditation and other relaxation techniques. Even though she now struggles to ride her horse, she makes it a priority because the exercise and equine-human connection soothe her both mentally and physically.

Juarez and Zipps also help alleviate their concerns about relapses by learning more about their disease through MS groups, classes and materials from the National MS Society. “I read a lot about MS, and it gives me hope because there are so many different stories,” Juarez says. “My story doesn’t have to be about just waiting around until I [have] another relapse.”

Vicky Uhland is a writer and editor in Lafayette, Colorado.

Learn more about relapses at nationalMSsociety.org/Treating-MS/Managing-Relapses.

Care to comment? Email us at editor@nmss.org.
MUSIC x MS

Music has a wide range of benefits. It can connect us to one another and provide a beat to dance to and console our broken hearts. Now, new studies are examining how music therapy and rhythmic auditory stimulation (RAS) might help people who have difficulty walking. Learn more about the research in progress on the next page.

In the meantime, we have just the soundtrack for you to download. Our Spotify playlist, Music x MS, showcases artists and producers living with MS. These include:

- Art Alexakis (solo artist and from the band Everclear)
- Clay Walker
- Tamia Hill
- Victoria Williams
- Noah ‘40’ Shebib (producer who has worked with artists such as Alicia Keys and Drake)
- Hal Ketchum
- Exene Cervenka (solo artist and from the band X)
- Steven Riccio (solo artist and from the band Horriblyright)
- David Osmond

Visit ntlms.org/playlist or scan the QR code with your phone to listen to the playlist.

PHOTO: ISTOCK/BLACKZHEEP
Wearable sensors

Technology can be used to detect progression in MS.

by Mary E. King, PhD

by Mary E. King, PhD
What if something you wore around your wrist could tell your doctor if your multiple sclerosis is progressing by measuring tiny changes over time in how you move? That technology may be on the horizon.

Catching disease progression earlier could lead to important decisions about disease-modifying therapies before large changes in mobility occur. And reliably detecting very small changes in mobility could also speed clinical trials of new MS treatments.

A new way of sensing

Research on wearable technologies is booming, and it includes looking at their application to MS. For example, two researchers are studying the use of tiny sensors that can measure small but reproducible changes in mobility. Jennifer Graves, MD, PhD, is an associate professor of neurosciences at the University of California San Diego (UCSD) and director of the UCSD Neuroimmunology Research Program. Tanuja Chitnis, MD, is a neurology professor at Harvard Medical School and director of the CLIMB Study at the Partners Multiple Sclerosis Center at Brigham and Women’s Hospital.

The small changes are difficult or even impossible for a clinician to identify with current tests of mobility. The research sensors are like advanced versions of the sensors currently available in smartwatches and fitness trackers. The sensors can even be packaged in a wearable device that wraps onto a wrist, arm or leg, and the data can be sent wirelessly to a computer for detailed analyses.

Graves uses a wearable band that includes tiny sensors and a simple testing approach. The person with MS straps the band onto their forearm and taps a forefinger 20 times, repeating with the other forearm and forefinger. Then the person wears it on one calf, tapping that foot 20 times and repeating on the other side. The process takes less than 5 minutes. Even though it sounds simple, there’s a lot of science involved.

The wearable band, which looks much like a standard fitness tracker worn on a wrist but with a longer strap, contains tiny sensors that measure specific aspects of how the fingers and feet move in three dimensions (up/down, left/right, forward/back). Sensors also measure acceleration, rotation and muscle electrical activity — nerve impulses moving through the arm/leg. All this data is sent wirelessly to a computer that can calculate additional information, like the speed of tapping and patterns of rhythm.
Currently, most MS clinicians use a standard measure of mobility — Expanded Disability Status Scale (EDSS) — that requires a trained observer, often the doctor, to identify much larger changes in walking mobility. This process may be repeated at six-month intervals, and it is only designed to pick up fairly significant mobility changes, like moving from a cane to a walker. This approach can take a year or more to demonstrate reproducible losses in mobility that may lead to adjustments in treatment.

**Detecting changes in mobility**
Graves recently published two promising studies with her experimental sensor device. The first looked at 117 people with MS and 30 control subjects. Researchers compared physician-scored EDSS and patient self-assessments with computer-scored assessments of the information gleaned from in-office tapping tests with the sensors. The sensor data correlated well with both physician and personal evaluations of mobility.

**“Finding more sensitive measures to track disease progression more quickly is a priority for speeding clinical trials in progressive MS.”**

— JENNIFER GRAVES, MD, PhD

In the next study, Graves followed 53 individuals with relapsing-remitting MS and 15 with primary progressive MS for about a year. The results showed two things. First, the sensor data is excellent at distinguishing between relapsing and progressive MS, a clinical need. Second, the year-long study results confirm that the sensors can reliably detect smaller mobility changes that are not captured by the usual clinical tests like EDSS.

As an example of how this new approach might help in the future, Graves describes a pianist with MS who said she could no longer play the fast notes as well as she used to. This small change in physical dexterity is something that current neurological exams can’t measure, Graves says. However, she says, “the experimental wearable device was able to detect very subtle changes in movement that correlated well with the pianist’s self-report.” Graves explains these are precisely the types of small, progressive changes that could be measured and monitored in the future.

She is excited not only for the clinical information this could give doctors deciding on an appropriate therapy, but also for speeding research. Clinical trials to evaluate new treatments typically rely on specially trained observers and clinically verified measures like EDSS that can only identify large mobility changes, Graves says. Trials can take a long time, up to three years, to determine if a possible new therapy is working, especially in a large group of people with different degrees of MS. Something quicker, yet very reliable and observer-independent, would be a great help in speeding research. “Finding more sensitive measures to track disease progression more quickly is a priority for speeding clinical trials in progressive MS,” Graves says.

Chitnis also used research-grade biosensors to measure movement in 25 people with MS. The study participants wore small sensors attached to nine body locations (chest, wrists, thighs, ankles, hip and back) during clinic visits. The sensor array allowed researchers to measure motion in three dimensions and capture rotatory motion — movement as you turn, Chitnis explains. The sensors measured many different aspects of gait, balance and dexterity, which meant many individual data points were collected. Complex computer analyses then distilled these data into a simpler composite readout for researchers to use. Investigators compared the composite results with EDSS and other MS mobility/dexterity measures. The participants were also monitored at home for eight weeks while wearing three sensors (wrist, ankle and chest). During the home monitoring, researchers added measures related to activity, pulse rates and sleep.

Chitnis explains that the computer analyses calculated very useful measures from the reams of sensor data. More important, these measures were significantly correlated with the typical physical
assessments used by MS clinicians. Chitnis points out they could sense changes in mobility assessments measured in fractions of an inch, something that even trained observers would find difficult to detect using traditional assessments.

“This study opens up new avenues for using very sensitive biosensors to measure changes in disability, both in the clinic and at home,” Chitnis says. “In addition to identifying changes in mobility, this might include capturing falls, something people sometimes forget between routine six-month clinic visits.” She adds that previous MS studies often used a single type of biosensor measurement like balance or wrist motion. However, utilizing multiple sensors and sophisticated computer analyses allowed her team to detect many more changes and much smaller changes in disability. New technology could enable a neurologist to get a better sense of how someone with MS is doing, particularly if home monitoring is added.

**Work in progress**

While the results are promising, Chitnis tempers enthusiasm for any quick availability of these kinds of sensor devices with a reminder about the many lengthy steps involved in bringing a new medical device to market. For the findings to be validated, such a prototype must be used in more extensive studies and would have to be certified by the FDA for use in clinical settings, according to Chitnis. Only then can such a device be used to guide therapy, she says, something that could take a couple of years.

In the meantime, sensor technology keeps getting smaller and better, and it is being tested for many situations and medical disorders. One of the National Multiple Sclerosis Society’s research priorities in promoting recovery of function is to build consensus on the best metrics and patient-reported outcomes to use in studies of wearable sensors so that their results can be compared. This would speed efforts to get these tools into clinical use.

Mary E. King, PhD, is a medical writer in Boulder, Colorado.
IMPORTANT FACTS

• Painful and frequent urination

Your healthcare provider may delay starting or may stop your ZEPOSIA treatment if you have an infection.

2. Slow heart rate (also known as bradycardia) when you start taking ZEPOSIA: ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days that you take ZEPOSIA. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heart rate:

• dizziness
• lightheadedness
• feeling like your heart is beating slowly or skipping beats

Follow directions from your healthcare provider when starting ZEPOSIA and when you miss a dose. See “How should I take ZEPOSIA?” for more information about side effects.

What is ZEPOSIA?

ZEPOSIA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.

In a ONE-YEAR study:
People who took ZEPOSIA® (ozanimod) had 48% fewer relapses than a leading injectable medicine (Avonex).**

In a separate TWO-YEAR study:
People who took ZEPOSIA had 38% fewer relapses than a leading injectable.†

ZEPOSIA is scientifically proven to reduce MS relapses

48% FEWER RELAPSES

38% FEWER RELAPSES

See the full study results
Scan this code with your phone’s camera or visit ZEPOSIA.com/results

*Avonex (interferon beta-1a).
†One-year study: People taking ZEPOSIA had an Annualized Relapse Rate (ARR) of 0.181 vs 0.350 with a leading injectable. A total of 895 people were studied (ZEPOSIA 447, a leading injectable 448). Two-year study: People taking ZEPOSIA had an ARR of 0.172 vs 0.276 with a leading injectable. A total of 874 people were studied (ZEPOSIA 433, a leading injectable 441).

IMPORTANT FACTS

The information below does not take the place of talking with your healthcare professional. Only your healthcare professional knows the specifics of your condition and how ZEPOSIA® (ozanimod) may fit into your overall therapy. Talk to your healthcare professional if you have any questions about ZEPOSIA (pronounced zeh-poof -see-ah).

What is the most important information I should know about ZEPOSIA (ozanimod)?

ZEPOSIA may cause serious side effects, including:

1. Infections. ZEPOSIA can increase your risk of serious infections that can be life-threatening and cause death. ZEPOSIA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 months of stopping treatment. Your healthcare provider may do a blood test of your white blood cells before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms of an infection during treatment with ZEPOSIA and for 3 months after your last dose of ZEPOSIA:

• fever
• feeling very tired
• flu-like symptoms
• cough
• painful and frequent urination (signs of a urinary tract infection)

• rash
• headache with fever, neck stiffness, sensitivity to light, nausea or confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

Your healthcare provider may delay starting or may stop your ZEPOSIA treatment if you have a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.

• shortness of breath
• confusion
• chest pain
• tiredness

2. A condition called PRES (posterior reversible encephalopathy syndrome) can cause serious side effects. Especially tell your healthcare provider if you take or have taken:

• certain medicines called monoamine oxidase (MAO) inhibitors (e.g., MAO-A inhibitors and MAO-B inhibitors)

Follow directions from your healthcare provider when starting ZEPOSIA and when you miss a dose. See “How should I take ZEPOSIA?” for more information about side effects.

What is ZEPOSIA?

ZEPOSIA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.

© 2021 Bristol-Myers Squibb Company. All rights reserved. Printed in the USA. 2084-US-2100219 04/21
One-year study: People taking ZEPOSIA had an Annualized Relapse Rate (ARR) of 0.181 vs 0.350 with a leading injectable. A total of 895 people.* Avonex (interferon beta-1a).

IMPORTANT FACTS

after your last dose of ZEPOSIA:

Call your healthcare provider right away if you have any of the following symptoms of slow heartbeat. Talk to your healthcare professional if you have any questions about the following symptoms. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heartbeat:

- lightheadedness
- dizziness

ZEPOSIA therapy. Talk to your healthcare professional if you have any questions about the following:

- rash
- infection of the lining around your spine
- stiff neck
- sensitivity to light

ZEPOSIA is made by a Bristol-Myers Squibb Company. Avonex® is a registered trademark of Biogen.

Once daily, you can take ZEPOSIA 1 time each day. This may reduce the risk of slowing the heart rate.

Do not take ZEPOSIA if you:

- have had a cardiac arrest, heart failure, or a heart attack
- have any of the following conditions.
- do not know if you have any of these conditions.

Before taking ZEPOSIA, tell your healthcare provider about all of your medical conditions, including if you:

- have had heart, lung, or kidney disease
- have a history of high blood pressure
- have diabetes
- are pregnant or plan to become pregnant. ZEPOSIA may harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if ZEPOSIA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ZEPOSIA.

Tell your healthcare provider about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Using ZEPOSIA with other medicines can cause serious side effects. Especially tell your healthcare provider if you take or have taken:

- medicines that affect your immune system, such as alemtuzumab
- medicines to control your heart rhythm (antiarrhythmics), or heart beat
- strong CYP2C8 inhibitors such as gemfibrozil or clopidogrel
- medicines that inhibit breast cancer resistance protein transporters, such as cyclosporine and etromobag
- CYP2C8 inducers such as rifampin
- opioids (pain medicine)
- medicines to treat depression
- medicines to treat Parkinson’s disease

You should not receive live vaccines during treatment with ZEPOSIA, for at least 1 month before taking ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Vaccines may not work as well when given during treatment with ZEPOSIA.

Tell your healthcare provider if you are not sure if you take any of these medicines. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I take ZEPOSIA?

You will receive a 7-day starter pack. You must start ZEPOSIA by slowly increasing doses over the first week. Follow the dose schedule of:

Days 1-4: 0.23 mg 1 time a day.
Days 5-7: 0.46 mg 1 time a day.
Days 8 and thereafter: 0.92 mg 1 time a day.
This may reduce the risk of slowing the heart rate.

- Take ZEPOSIA exactly as your healthcare provider tells you to take it.
- Take ZEPOSIA 1 time each day.

Swallow ZEPOSIA whole. Do not chew, crush, or open ZEPOSIA. Do not give ZEPOSIA to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for information about ZEPOSIA that is written for health professionals. For more information, call 1-833-ZEPOSIA (1-833-937-6742) or go to ZEPOSIA.com.

This is a brief summary of the most important information about ZEPOSIA.
We’re inspired by a single vision:

Transforming patients’ lives through science™

We’re proud to support the multiple sclerosis community

Visit bms.com to see how we’re bringing a human touch to everything we do.
Music therapy helps people with MS who have difficulty walking.

by Brandie Jefferson

Whether it’s a tap of the foot, a bop of the head or even some air guitar, people tend to move to music. Often, we move to the beat without even knowing it.

The drive to move and, specifically, move to the beat has proved useful when it comes to treating a variety of medical conditions. This particular type of music therapy, known as rhythmic auditory stimulation (RAS), has been used to help treat people who have difficulty walking from neurologic conditions like Parkinson’s disease.
New developments
As interest in the clinical applications of music grows, multiple sclerosis specialists, too, are investigating how RAS might help people who have difficulty walking.

“Music therapy has been used in Parkinson’s [treatment] and with people who have had a stroke, but for MS, the interest has been more recent,” says Francois Bethoux, MD, director of rehabilitation services in the Mellen Center for Multiple Sclerosis in Cleveland Clinic’s Neurological Institute. He is also the chair of the Department of Physical Medicine and Rehabilitation.

“The idea is to use a rhythmic stimulus to try to improve the way people walk,” Bethoux says. The principle is fairly straightforward, but, he says, “the devil is in the details of how to make it happen.”

He has been working to figure out those details through research and in his role as the medical director of the Cleveland Clinic’s Arts and Medicine Institute, where he is also the chair of the Department of Physical Medicine and Rehabilitation.

The principle underpinning RAS is called rhythmic entrainment — synchronizing the body’s internal rhythm to an external one. We have brain circuitry dedicated to controlling rhythmic activities, such as walking, Bethoux says.

External cues such as music can trigger that circuitry and maybe even reset it.

Bethoux has reason to be optimistic. He has already carried out a small study with results that were encouraging, he says. After four weeks, practicing five days per week for about 20 minutes, people who walked with RAS showed a slight improvement over those who walked without music and those who only listened to music but didn’t do walking exercises.

He’s now conducting another study using technology to personalize the RAS experience, both for enjoyment and to maximize the potential benefits to participants.

It may sound obvious: no one particularly likes walking to a metronome (a device that produces a click at a regular interval of time). Bethoux says people he’s worked with say walking to just a steady rhythm is also boring. In the past, out of respect for musicians’ copyrights, he has only used music composed specifically for his research. For the current study, Bethoux has partnered with MedRhythms, a company that uses sensors to monitor users’ gait and change the tempo of the music they are hearing in real time.

This system can offer users a wider variety of music. Bethoux serves on MedRhythms’ scientific advisory board. “If we can use music that people enjoy,” Bethoux says, that’s even better. “We’re just starting to understand how emotions can change the way our bodies function, from cardiovascular health to the functioning of the immune system.”

Improvements in gait
Eric Klawiter, MD, says he’s always been intrigued by the positive effects music. With a pilot grant from the National MS Society, the neurologist at Massachusetts General Hospital is also researching how RAS can affect gait in people with MS.

Of the limited data available, Klawiter says, “They do show there can be improvement in velocity, stride length or cadence. Through multiple therapy sessions, a therapist can gradually increase, for instance, the cadence of the music to improve gait speed.”

For his part, Klawiter is looking at the efficacy of RAS on gait problems and how to understand the underpinnings of music’s effect on the brain, using advanced neuroimaging, such as functional MRI. A functional MRI allows a real-time glimpse of the brain at work to see activity in specific brain circuits and areas during the performance of a task.

“One aim is to look at the effect of RAS on brain networks to determine, if there is an effect on gait, why?” Klawiter
says. “Are there biomarkers we can use to determine why there might be a different effect between one person and another person?”

Klawiter’s research uses a slightly different setup than Bethoux’s. The research group decided on a crossover design — one group begins the study doing RAS therapy while the other does a non-musical walking exercise program. Then both groups stop, and they are evaluated by researchers. Next, they switch: the general walking exercisers move to RAS therapy, and those previously walking with music move to a generalized walking program.

The study was put on hold due to COVID-19, and researchers were devising a way to deliver RAS remotely. “This isn’t something I’ve prescribed in the past,” Klawiter says. “It’s a new area to me, both from the research and the clinical perspective.”

On the other hand, the Cleveland Clinic has had a therapeutic arts program for more than a decade, and Bethoux has referred patients to music therapy in the past. Recently, it’s even made its way into the infusion room at the Mellen Center to help with stress.
Bethoux would like to expand its use beyond the clinic and even beyond a medical setting. “Sometime in the near future, I’d like to make it available for people to try,” he says. He hasn’t seen any safety issues but says he wants people to be evaluated before they dive in to make sure their gait is safe — even if they plan to use RAS at home.

“It’s low-cost, easy to do and noninvasive,” Bethoux says. “When people are stuck at home, maybe we can try to give them another option, something to help them get motivated.”

“I always want to be humble,” Bethoux says. “I don’t pretend we understand this completely or can work magic with the arts, but music therapy shows great potential — not to replace, but to be used in addition to more traditional treatment options.”

Brandie Jefferson is a writer in St. Louis, Missouri. She was diagnosed with MS in 2005.
Inspiring people

The MS movement remains resilient. The winners of our 2020 Inspiration Awards went above and beyond to keep us moving forward during challenging times.

Dawnia Baynes sees obstacles as opportunities.

by James Townsend

Dawnia Baynes has left her mark on too many National Multiple Sclerosis Society programs to list.

Born in Pittsburgh and now living in Compton, California, Baynes was diagnosed in 2006 when her body became numb from the chest down. She’s one of those people who refuses to succumb to despair and who sees every obstacle as an opportunity. The source of her enthusiasm and positivity? “I have to say that it’s my
Josh Jacobson of Minneapolis doesn’t have multiple sclerosis, nor does anyone in his family. Yet the 58-year-old lawyer has participated in Bike MS: Ride Across Minnesota for 14 years, raising over $104,000 for the MS movement. "I love the cause, but it’s the people who keep me coming back as much as the cause," says Jacobson, a winner of the National Multiple Sclerosis Society’s Inspiration Award. "Even the first year, I was amazed at how friendly everyone was. I resolved then that even if I didn’t ever ride again, I would come back and volunteer."

Less than a success

Jacobson first heard about Ride Across Minnesota, the Society’s five-day, 300-mile bike ride, in an article in the Minneapolis Star Tribune in 2007. At the time, he had just gone through a divorce and was experiencing a midlife crisis. "I hadn’t ridden a bike in almost 25 years," he says. "I didn’t even own a bike at the time." But something about the event intrigued him. His first ride was less than a

I know that I wasn’t diagnosed just for the heck of it but have been given a real chance to ask, ‘How can I help?’ and treat people like I want to be treated. I thought, ‘Well, apparently I must be able to handle this,’ so I just started finding things I could do.”

— DAWNIA BAYNES

relationship with God. If it wasn’t for Jesus, I might have fallen into an attitude of ‘woe is me.’

“I know that I wasn’t diagnosed just for the heck of it but have been given a real chance to ask, ‘How can I help?’ and treat people like I want to be treated. I thought, ‘Well, apparently I must be able to handle this,’ so I just started finding things I could do.”

Diagnosed in her 20s while living in Georgia, Baynes couldn’t find anyone her age to talk to about her disease. When she moved to California, she joined a group of people her age with MS called YPG, or Youthful Peers Group. She now leads the group.

“‘It made a real difference for me,” she says.

In 2017, Baynes organized a self-help group for high school and college students called MS Youngsters, which currently meets monthly through Zoom because of the pandemic.

In March 2020, knowing the MS Youngsters were feeling down about missing in-person events, Baynes invited the award-winning actor Yvette Nicole Brown, who starred in the television comedy “Community,” on one of the group’s Zoom calls as a surprise. “I knew the kids would remember her from her many roles in TV and movies,” Baynes says. “That was a great experience for them. She spent an hour and a half with them and answered all their questions.”

Baynes turned the group’s annual barbecue into a virtual graduation party for the high school seniors in August 2020, which Brown joined as well.

Baynes doesn’t have children of her own, but the MS Youngsters call her “MS Mama.”

Never one to sit still for long, Baynes has begun working on a book about her life and experiences. “I’ve written about 130 pages so far and hope to publish it in 2021 using a large type that people can more easily read. I even have ideas for the cover!”

James Townsend is a writer in Boulder, Colorado.
smashing success. He spent a lot of time with heat exhaustion in the “SAG wagon,” the support and gear van that gives the road-weary a break. But no one looked down on him for taking rests, and the nurse who treated him at the time became his friend. “I met some incredible people,” he says. “The camaraderie was amazing, not just on my team but on my ride as a whole.” Jacobson kept coming back and was eventually recruited to join the Krebs Cyclers team, which he now co-captains.

**Getting back more than he gives**

Jacobson has many favorite memories from past rides, including three and a half years ago when his son joined him. “You have to be 12 years to ride, and he was 12 and one day. He was the youngest rider and a bit of a celebrity as a result,” Jacobson says. “People sang ‘Happy Birthday’ to him at the rest stops.”

But Jacobson’s most powerful connection to Bike MS happened off the ride route when he lost his girlfriend, a fellow rider and volunteer, in an accident in July 2020. “The outpouring of love I got from the MS Society and other riders was amazing,” he says. “I got cards and emails. Donations to her Bike MS account poured in from volunteers, staffers and other riders. It meant so much.”

Jacobson plans to do the next Ride Across Minnesota and already registered for the next Bike MS: Twin Cities Ride. “I will do this ride until I’m in my 80s,” he says. “And then when I can’t ride, I’ll volunteer.”

Aviva Patz is a writer in Montclair, New Jersey.
Lisa McRipley learned an early lesson in empowerment.

by James Townsend

Early on in her life, Lisa McRipley learned the value of speaking up when she felt something was wrong.

When she was an eighth-grade Black student in a predominantly white school, a substitute teacher announced that the class would be watching the movie “Gone with the Wind” in segments over three days. After a scene in which the late Butterfly McQueen portrayed Scarlett O’Hara’s slave girl, Prissy, the teacher said, “It was so wonderful back then. I wish it were like that now.” McRipley had had enough: “I want you to take that back,” she told the teacher. “If it were still like that today, I would be a slave.”

The teacher scolded her, saying, “You are out of order!” But McRipley replied, “I refuse to watch this film,” and walked out of the classroom with her friend, the only other Black girl in the class.

“I called my mom and told her what happened. She drove to the school, met with the principal and stood up for me. She always told me never to let anyone tell us we were less than. Both my parents really helped me to feel empowered.”

McRipley, who went on to earn bachelor’s and master’s degrees, has worked in higher education in colleges and universities in Michigan and California. She’s a member of the Alpha Kappa Alpha Sorority, the first historically African American Greek-lettered sorority, whose members include Vice President Kamala Harris.

As an MS Activist, she has shared her story about dealing with unaffordable MS medications. She reached out to U.S. Rep. Rashida Tlaib of Michigan, who presented McRipley’s story during the House of Representatives Oversight and Reform Committee’s hearing on drug pricing. Tlaib is a member of the Congressional MS Caucus, which focuses on issues that affect people living with MS. “Rep. Tlaib is deeply committed to serving her constituents and passionate about serving her community,” McRipley says. “She helped me understand the importance of advocacy.”

“When I connected with the people in the MS Society,” McRipley says, “I knew I had found my tribe.”

My mom always told me never to let anyone tell us we were less than. Both my parents really helped me to feel empowered.”

— LISA McRIPLEY

James Townsend is a writer in Boulder, Colorado.
Lisa McRipley helped organize the Black MS Experience Summit.
For sheer commitment to the cause of raising awareness about multiple sclerosis, Delores Wolfe is an inspiration to many. Now 90 years old, Wolfe has participated in the National Multiple Sclerosis Society’s annual Walk MS in Lebanon, Pennsylvania, for more than 30 years, raising nearly $300,000.

She raises funds the old-fashioned way — with personal handwritten notes to the many friends, relatives and people she has met over her long lifetime. “When I get something in the mail hand-addressed and handwritten, I know I pay more attention to it, so I thought other people...
When I get something in the mail hand-addressed and hand-written, I know I pay more attention to it, so I thought other people would as well.”

— DELORES WOLFE

would as well,” she says. Her community is extensive. For her 90th birthday, Wolfe received 227 birthday cards.

When Wolfe’s late daughter was diagnosed with MS in the 1980s, they faced a dilemma. “Her doctor put her on medication that was quite expensive, and the insurance company wouldn’t pay for it,” Wolfe recalls. “So, I called the MS Society to see if they could help.” The Society helped her find insurance coverage for the medication. “I was so grateful, and I wanted to repay them by doing what I could to raise money toward a cure.”

Wolfe is also famous for her pies, particularly her Shoofly and Lemon Sponge varieties. She has sometimes made and sold as many as 100 pies. “I have a bit of a hard time rolling all that dough nowadays,” she says, “but my granddaughter does a lot of that work for me now.”

Wolfe’s family has been involved in her efforts for years. Four generations have participated in Walk MS. For the last several years, Wolfe’s granddaughter, Janella Camacho, who also has MS, has helped Wolfe continue to join in the Walk by pushing her in a wheelchair.

“Janella also is now hand-writing the letters for me because my writing has deteriorated, but I still address all the envelopes,” Wolfe says.

The first year Wolfe participated in the Walk, she raised nearly $1,000. Every year since, she has increased her goal and now shoots for $15,000.

Wolfe says the source of her long-standing dedication to the MS movement is simple: “It makes me feel good. And my hope is that I live long enough to see the cure for MS become a reality.”

James Townsend is a writer in Boulder, Colorado.
Sylvia Lawry founded the National Multiple Sclerosis Society in 1946.
If there was one philosophy that drove the late Sylvia Lawry, founder of the National Multiple Sclerosis Society, it would be the framed quote that hung in her office: “Never give up.”

Since its founding in 1946, the Society has raised over $1 billion for research, setting the standards in diagnosis, symptom management and clinical trial strategies. Today, the Society, which recognizes 75 years of progress in 2021, has more than 500,000 volunteers, is a resource for the nearly 1 million people living with multiple sclerosis in the United States and leads the global charge to create a world free of MS.

All of this was made possible because one determined woman with no medical background committed her life to establish an organization. She aimed to find a cure for MS in an era when women were considered second-class citizens, more fit for the kitchen than the conference room.

“She left no stone unturned to get people focused on MS and didn’t care who got the credit,” says Cyndi Zagieboylo, who began her career with the Society in 1985 and is now president and CEO. “I think that’s why MS has had more discoveries than any other neurological disease. It started from seeds Miss Lawry planted.”

Born Sylvia Friedman on June 28, 1915, in Brooklyn, New York, Lawry was the eldest of her siblings: Bernard, Alice and Lillian. Great responsibility came to her at a young age. When her mother was diagnosed with clinical depression, teenaged Lawry took over running the household and raising the children. She and Bernard, who excelled at both academics and sports, were particularly close. In 1937, at age 21, Bernard started having double vision and other telltale symptoms that led to an MS diagnosis, a condition that Lawry had never heard of.

At the time, she was attending Hunter College and preparing for a career in law, but she abandoned those plans to help Bernard fight the disease. When Bernard’s neurologists could not offer much hope or a course of treatment, Lawry took matters into her own hands.

A movement is born

On May 1, 1945, she placed a small ad in the New York Times: “Multiple Sclerosis. Will anyone recovered from it, please communicate with patient.” Instead of success stories, she received over 50 replies from families and individuals equally desperate for guidance and reliable information. Since little was known about MS, Lawry determined that research was the key to finding a cure. In March 1946, she founded the Advancement of Research on Multiple Sclerosis (later changed to the National Multiple Sclerosis Society in July 1947).

“I really had no idea what I was getting into. Our intent was to spend 100% of the money we raised on research. But I thought the path would be a much easier one than it turned out to be. I really believed
impact

this would be a short-term undertaking. Of course, I was wrong,” Lawry said in “Courage,” Richard Trubo’s biography of her. Setting up shop in an 8-by-10-foot office donated by the Academy of Medicine, Lawry reached out to prominent individuals for support, financial and otherwise. She regularly put in 12-to-15-hour days, resulting in the Society’s first research grant of $54,000. The project made an important discovery that accelerated knowledge dramatically. Believing that providing services to people with MS and raising funds were crucial on the community level, she extended the Society’s reach to all 50 states. Under her leadership, the Society published manuals to educate the public on MS. She was building the Society during a time when there were few avenues open to women in the professional world.

Lawry learned firsthand that old prejudices die hard. In 1954, the new president of the Society asked her to relinquish her title of CEO because he believed “she didn’t fit the male stereotype of someone capable of running a fast-growing organization,” according to the Trubo biography. Considering how much she had accomplished already, she was rightfully floored but complied nonetheless, putting the Society’s goals first.

“None of us knew what the next day would bring. But there was always the hope the next day would provide the answer to multiple sclerosis,” Lawry said.

Breaking boundaries

After testifying before the Senate in May 1949 with a stellar team that included the widow of baseball giant Lou Gehrig, Lawry pushed the government to start the National Institute for Neurological Diseases and Blindness (now the National Institute for Neurological Disorders and Stroke) in August 1950, securing millions of dollars for research.

Whether she was talking to captains of industry, elite medical experts, celebrities or politicians, Lawry was relentless in asking for what she needed. She enlisted notables such as Shirley Temple Black, Frank Sinatra, Grace Kelly, President John
F. Kennedy and Dr. Jonas Salk, among others, to her crusade. Recognizing that MS didn’t stop at our nation’s borders, in 1967, Lawry pushed for the creation of the International Federation of Multiple Sclerosis Societies which today includes more than 40 member Societies worldwide.

After living with MS for 37 years, Lawry’s beloved brother Bernard died in 1973. Consumed by grief, Lawry renewed her efforts to bring hope to others. She stepped down as executive director in 1982 but remained secretary of the MS International Federation until 1997. Her two marriages ended in divorce and widowhood, but she raised two sons. Sylvia Lawry died on Feb. 24, 2001, at the age of 85.

**Changing the world**

Lawry may not have lived long enough to see a cure for MS, but her indomitable efforts paved the way for groundbreaking advances. The Society has recruited and trained more than 1,000 new MS researchers, doctors can diagnose MS much more quickly now, and more therapies are available today than at any other time in history.

As a direct, no-nonsense leader, Lawry also instilled confidence in the people who worked for her and brought out the best in them. “The thing that impressed me most about her was how ambitious she was,” says Weyman Johnson, former chairperson of the MS International Federation (MSIF). “At a conference, it was just the two of us sitting together. She pointed at me and just told me things I needed to do in Atlanta to make sure that we as an MS Society fully exploited all the resources there.”

Lawry was a private person, but sometimes colleagues saw behind what seemed to be a protective mask. Arney Rosenblat, who had an adjacent office in the communications department, remembers grabbing a bite with Lawry during long evening sessions.

“I always sensed a touch of sadness behind her eyes. Even while she talked glowingly of the many breakthroughs she helped shepherd, there was always this unspoken ‘but’ in the air that there is still no cure. When we sat down those nights to talk, it was there. It was very moving to me.”

Dolores Oria spent her entire career working at the Society, beginning in 1954 as a 17-year-old until her retirement in 2019. While it took her a long time to get up the nerve to talk with Lawry, Oria remembers getting some personal advice that stuck with her.

“As I was aging, she stopped me once in the ladies’ room and said, ‘You know, I don’t think you should ever let your hair go gray. You should always make sure you color it.’ She always wanted to look as young as she could. I guess I was starting to show some gray hair. All my years, I always dyed my hair,” Oria says.

“She was a slight woman, but she had this presence. Heads turned when she walked down the hall. She created a worldwide movement, and that is bigger than an organization,” Zagieboylo says. “She engaged people and got them to carry the torch throughout the world. I think that’s her biggest accomplishment.”

---

Robert Lerose is a writer in New York.
Discover VUMERITY® (diroximel fumarate)—an oral treatment for relapsing MS. Together, let’s celebrate what makes you truly you.

VUMERITY MAY WORK AGAINST RELAPSING MS IN THREE WAYS:

What is VUMERITY® (diroximel fumarate)?
- VUMERITY is a prescription medicine used to treat people with relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease in adults.
- It is not known if VUMERITY is safe and effective in children.

Important Safety Information

Do not take VUMERITY if you:
- have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to diroximel fumarate, dimethyl fumarate, or any of the ingredients in VUMERITY.
- are taking dimethyl fumarate.

Before taking and while you take VUMERITY, tell your healthcare provider about all of your medical conditions, including if you:
- have liver problems.
- have kidney problems.
- have or have had low white blood cell counts or an infection.
- are pregnant or plan to become pregnant. It is not known if VUMERITY will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if VUMERITY passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while using VUMERITY.

Tell your healthcare provider about all the medicines you take including prescription and over-the-counter medicines, vitamins, and herbal supplements.

What should I avoid while taking VUMERITY?
- Do not drink alcohol at the time you take a VUMERITY dose.

What are the possible side effects of VUMERITY?

VUMERITY may cause serious side effects including:
- allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing). Stop taking VUMERITY and get emergency medical help right away if you get any of these symptoms.
- PML (progressive multifocal leukoencephalopathy) a rare brain infection that usually leads to death or severe disability over a period of weeks or months. Tell your healthcare provider right away if you get any of these symptoms of PML:
  - weakness on one side of the body that gets worse
  - clumsiness in your arms or legs
  - vision problems
  - changes in thinking and memory
  - confusion
  - personality changes

For help with financial, insurance, or treatment education, call 1-800-456-2255 Monday-Friday from 8:30 AM to 8 PM ET.

Hablamos español.
VUMERITY comes with support
For help with financial, insurance, or treatment education, call 1-800-456-2255 Monday-Friday from 8:30 am to 8 pm ET. Hablamos español.

ASK YOUR HEALTHCARE PROVIDER
or get more details at KnowVUMERITY.com

The most common side effects of VUMERITY include:
- flushing, redness, itching, or rash
- nausea, vomiting, diarrhea, stomach pain, or indigestion
- Flushing and stomach problems are the most common reactions, especially at the start of therapy, and may decrease over time. Taking VUMERITY with food (avoid high-fat, high-calorie meal or snack) may help reduce flushing. Call your healthcare provider if you have any of these symptoms and they bother you or do not go away. Ask your healthcare provider if taking aspirin before taking VUMERITY may reduce flushing

These are not all the possible side effects of VUMERITY. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. For more information go to dailymed.nlm.nih.gov

Please see Patient Information on the following page and full Prescribing Information at VUMERITY.com.

© 2020 Biogen. All rights reserved. 7/20 VUM-US-0402 • 225 Binney Street, Cambridge, MA 02142 • 1-800-456-2255 • VUMERITY.com
What is VUMERITY?
- VUMERITY is a prescription medicine used to treat people with relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease in adults.
- It is not known if VUMERITY is safe and effective in children.

Do not take VUMERITY if you:
- have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to diroximel fumarate, dimethyl fumarate, or any of the ingredients in VUMERITY. See “What are the ingredients in VUMERITY?” below for a complete list of ingredients.
- are taking dimethyl fumarate.

Before taking and while you take VUMERITY, tell your doctor about all of your medical conditions, including if you:
- have liver problems.
- have kidney problems.
- have or have had low white blood cell counts or an infection.
- are pregnant or plan to become pregnant. It is not known if VUMERITY will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if VUMERITY passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while using VUMERITY.
- are taking dimethyl fumarate.

Tell your doctor about all the medicines you take including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How should I take VUMERITY?
- Take VUMERITY exactly as your doctor tells you to take it.
- The recommended starting dose on days 1 to 7 is one capsule by mouth 2 times a day. After 7 days, the recommended dose is 2 capsules by mouth 2 times a day.
- If taken with food, avoid taking VUMERITY with a high-fat, high-calorie meal or snack.
- Swallow VUMERITY whole. Do not crush, chew, or sprinkle capsule contents on food.
- If you take too much VUMERITY, call your doctor or go to the nearest hospital emergency room right away.

How should I store VUMERITY?
- Store VUMERITY at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep VUMERITY and all medicines out of the reach of children.

What are the possible side effects of VUMERITY?
VUMERITY may cause serious side effects including:
- allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing). Stop taking VUMERITY and get emergency medical help right away if you get any of these symptoms.
- PML (progressive multifocal leukoencephalopathy) a rare brain infection that usually leads to death or severe disability over a period of weeks or months. Tell your doctor right away if you get any of these symptoms of PML:
  - weakness on one side of the body that gets worse
  - clumsiness in your arms or legs
  - vision problems
  - confusion
  - personality changes
- herpes zoster infections (shingles), including central nervous system infections.
- other serious infections.
- decreases in your white blood cell count. Your doctor should do a blood test to check your white blood cell count before you start treatment with VUMERITY and while you are on therapy. You should have blood tests after 6 months of treatment and every 6 to 12 months after that.
- liver problems. Your doctor should do blood tests to check your liver function before you start taking VUMERITY and during treatment if needed. Tell your doctor right away if you get any of these symptoms of a liver problem during treatment.
  - severe tiredness
  - loss of appetite
  - pain on the right side of your stomach
  - dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes
The most common side effects of VUMERITY include:
- flushing, redness, itching, or rash
- nausea, vomiting, diarrhea, stomach pain, or indigestion
- Flushing and stomach problems are the most common reactions, especially at the start of therapy, and may decrease over time. Taking VUMERITY with food (avoid high-fat, high-calorie meal or snack) may help reduce flushing. Call your doctor if you have any of these symptoms and they bother you or do not go away. Ask your doctor if taking aspirin before taking VUMERITY may reduce flushing. These are not all the possible side effects of VUMERITY. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

For more information go to dailymed.nlm.nih.gov

General Information about the safe and effective use of VUMERITY
Medicines are sometimes prescribed for purposes other than those listed in this Patient Information. Do not use VUMERITY for a condition for which it was not prescribed. Do not give VUMERITY to other people, even if they have the same symptoms that you have. It may harm them. If you would like more information, talk to your doctor or pharmacist. You can ask your pharmacist or doctor for information about VUMERITY that is written for healthcare professionals.

What are the ingredients in VUMERITY?
Active ingredient: diroximel fumarate
Inactive ingredients: crospovidone, colloidal silicon dioxide, magnesium stearate (non-bovine), methacrylic acid and ethyl acrylate copolymer, microcrystalline cellulose, talc, and triethyl citrate. Capsule Shell: carrageenan, hypromellose, potassium hydroxide, and titanium dioxide. Capsule Shell Ink: iron oxide, potassium hydroxide, propylene glycol, and shellac.

Manufactured for: Biogen Inc., Cambridge, MA 02142, www.VUMERITY.com or call 1-800-456-2255

This Patient Information has been approved by the U.S. Food and Drug Administration. Revised: 03/2020
Meditation and mindfulness helped save my life. I’ve had multiple sclerosis for approximately 60% of my 47 years on this planet. I started experiencing symptoms such as knee hyperextension, weakness in the legs and fatigue, in college. But it wasn’t until I was 27, when multiple sclerosis manifested as frightening focal-point seizures, running down the left side of my body, from face-to-foot, that I was diagnosed with relapsing-remitting multiple sclerosis.

I transitioned to secondary progressive multiple sclerosis a few years later. I’m now a quadriplegic with only limited use of my right arm and hand, and I continue to deteriorate.
My MS attacks the myelin in my spinal cord, not so much in my brain. So, even though I need assistance with all aspects of custodial care, and I remain mostly bedridden, I’m cognitively intact.

But I also suffer from depression, anxiety, toxic shame and other disorders categorized under Generalized Anxiety Disorder (GAD). These mental conditions are the result, directly and indirectly, of MS. Even though I took medication to help with all this, it didn’t control all of the depression. A few years ago, I endured a period of suicidal ideations, spending countless hours trying to figure out how to kill myself.

I was feeling hopeless and alone. And I was having a hard time finding a reason to keep on living.

I was back living with my parents. I had ruined my marriage, and, I felt, my life as well, with self-destructive behaviors caused by my inability to deal with my anger from having MS.

I had no place else to go except a nursing home. My parents gave me a bedroom on the second floor of their house, even though I could no longer walk or stand, let alone negotiate stairs.

I had no choice, and I was thankful my parents took me in. They had a stair lift installed for me, but it required so much effort to use that after a while, I only left my room when it was absolutely necessary.

Now, mostly bedridden, I’d spend broad expanses of time staring out the window (when I wasn’t researching suicide). My hospital bed faced the window, so I had no choice. It was a nice window — small — but appointed with an unpretentious handmade curtain of an almost diaphanous gauzy white cotton that fluttered blithely in the breeze like a lawn moth.

Underneath the window stood a clumsily restored American art nouveau desk fashioned from a patinated oak. A small potted heartleaf philodendron sat on top.

The window framed a row of nondescript suburban split-level homes circa 1955, with manicured plush green lawns juxtaposed against blacktop driveways and concrete sidewalks. Once in a while a moving car or a kid on a bicycle or peacefully drifting clouds and rustling trees animated the scene.

I thought concentrating on this view would give me some equanimity. But my mind was a maelstrom of incessant discordant mental images and chatter, fueled by all those harmful feelings of self-hate. And all this mental noise only stopped, at least consciously, when I finally fell asleep a few hours before dawn. I thought I was going crazy.

I don’t know if it was a subconscious scrambling for self-preservation, but I started to think more about my son. He was still a little boy, living across the country with his mother, and I missed him terribly. But instead of focusing on the wrenching pain and anger of missing him, as I had been doing, I found myself drifting into feelings of joy and happiness.

At first, I tried to ignore these thoughts and return to the familiar mental turmoil because there was a perverse, self-destructive sense of security there. But I couldn’t, no matter how hard I tried.

So I let these reflections on my son stay in my mind until they left of their own accord.

Before long, I began to evoke mental images of my son and our life together.

I’d focus on these memories and examine them. I’d recall every detail, every nuance:

- The fresh smell of his hair;
- The hardness of his head;
- The cherubic sound of his laughter;
- Those big limpid eyes;
- The wetness of his tears on my shoulder and chest;
- Spending time at the local café, ice cream shop or library;
- Watching him run around, usually with a soccer ball and the dog underfoot;
Small hand reaching for mine. These thoughts caused me deep anguish. But I stopped running from them. I began to accept the pain of missing my child, which was more powerful than anything I’d ever contended with. More than the ever-worsening multiple sclerosis. More than the divorce. More than the total loss of control over my life.

And then, the strangest thing began to happen — the destructive feelings began to soften. Why did this transformation take place?

It’s not that I missed my son any less than I did before. Rather, feelings of love were replacing the negative emotions. Yes, these feelings of love were solely for my son. But that’s what beat back the suicidal ideations, what gave renewed purpose to my life. I’d been selfish. Whether I was with him in person or not, my son needed me. Full stop. If I couldn’t live for myself, then I’d live for my child.

Maybe using my son as my reason to live wasn’t the healthiest way to go about it, but, at that time, I didn’t care — this meditative vehicle kept me going.

By focusing my attention on my son, I became aware of the power of meditation. It’s not like I could flip a switch and stop the suicidal ideations. Moving back from that precipice took time. I backed away from death until I was far enough away that I could turn around and face my life.

I knew that it wasn’t my son that stopped me from doing something I could never undo. It was meditating on the image of my son that gave my unwell mind the needed ballast. I was, without knowing it, practicing visual meditation.

I began by focusing on a mental image of my son. I held it in my attention as long and as impartially as I could. When my mind started to wander, I tried to return my focus to his image. It became easier to remain centered without distraction. My mind began to relax and release into a place of emptiness, a state of being.

I began exploring other forms of meditation. I became interested in Vipassana Bhavana (clear insight meditation), an ancient Buddhist practice that uses mindfulness to focus on breathing. Mindfulness is the ability to focus awareness on the present moment, acknowledging, accepting, and then letting go of every thought and sensation.

I’d spent all these years hating my body and hating myself as I became weaker, paralyzed by MS, and having to rely on others. But focusing on the breath continuously entering and leaving my body compelled me to connect my thoughts and feelings to my physical being.

My rage at my atrophied muscles — my quadriplegic state — turned toward compassion. I felt sympathy for this body — my body — that used to be so strong and capable. And it was through this empathy for myself that I, after so many years and acts of self-destruction, began to accept myself and my MS.

Through meditation, I connect to the kinetic world around me. Everything is changing, even my body. Cells are born and die. Matter moves in and out. My body adjusts to the environment, which, in turn, adapts to it, to me.

Meditation feels grounding, stabilizing, yet vibrant and exhilarating. It’s humbling to be mindful of this connectivity I now feel to, well, everything. I’m realizing that I’m not that important, a part of a whole, and it’s from here, my happiness, my comfort in being me, may come.

Aaron M. Freedman is a writer on Long Island, New York. He was diagnosed with MS in 2001.
Summers have always been miserable for me with fatigue and tingling pain in my legs. I was always told that these symptoms were due to allergies ever since I was a teenager. When I woke up blind in one eye in the summer of 2005 when I was 35, I was alarmed and scared. I was diagnosed with optic neuritis through an MRI. My vision partially returned over time. After two years and many tests, I was diagnosed with multiple sclerosis in 2007.

A flare-up of optic neuritis five years later caused permanent damage to my other eye, leaving me with good peripheral vision but only fuzzy gray spots in the middle of my visual field in both eyes. I was now legally blind. With my new normal of “low vision,” my inability to drive has made the greatest impact on my independence.

At times I thought an MS diagnosis was the finish line for an obstacle course with limits and boundaries, but now I know that each day is a new starting point in a race to a horizon line that’s as far away as my determination can make it. I may not know what hurdles I’ll encounter but know that I will leap over them when I can and crawl under them when I can’t. I hope to inspire others to do the same.

I’m a visual artist. My vision loss is still frustrating and discouraging at times, as I cannot create the detailed and precise images that I used to make, but I have found ways to keep going with my artwork and have found art to be my greatest coping mechanism for the stresses of life. I have gone from visual to visionary, redefining what I think “art” should look like.

I combine bubble wrap, packaging foam, burlap, basket reed and plastic lids with paint and tinted silicone to create vividly colored compositions. I make do with what I have around the house and often take the pieces apart to reuse the materials to make new pieces. I take a photo of each piece of artwork to collect a memory. I often title the compositions using rhymes or puns to add humor.

The process of making is more important to me than the product, as it is the experience of living moment to moment that helps me manage everyday anxieties. I know that bad days will happen, but I can usually cheer myself up with some creativity.

MS has inspired me to redefine my art.

by Michelle Droll

At times I cannot create the detailed and precise images that I used to make, but I have found ways to keep going with my artwork.”
See more of Michelle Droll’s artwork at michelledroll.com.

**Presto!** — polystyrene packaging foam, netting, neoprene, fishing line

**Gold Digger** — polystyrene packaging foam, foam insulation, plastic, acrylic paint, tinted silicone

**Hot Spot** — burlap, paper, foam insulation board, paper, tinted silicone, acrylic paint

**Olé!** — spray foam insulation, tinted silicone, acrylic paint
Improved Mobility. MS Made Easier.

MEET DESTINEE, AVID HIKER, LOVES YOGA, DIAGNOSED WITH MS AND AN L300 GO USER.

L300 Go is a functional electrical stimulation (FES) leg cuff system that activates the nerves and muscles to lift your foot.

“With the L300 Go I can keep up with my friends again...I’m not 10 steps behind anymore, I’m right there with them!”

- Destinee

RECLAIM YOUR FREEDOM

L300Go.com | 844.667.9534

Individual results may vary. Consult with a qualified physician to determine if this product is right for you.

Important Safety Information and Risks: For Indications for Use, Contraindications, Warnings, Adverse Reactions, Precautions, and other safety information please refer to www.bioness.com/Safety_and_Risk_Information.php (also available in the L300 Go User’s Guide).