

# momentum

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SPRING 2020



## Fulfilling the dream of family 26

For people with MS, adoption can be the answer.

PHOTO COURTESY OF ANDY RAFFERTY



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WITH MS** page 14

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# I'M READY

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### 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:
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    - 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”).
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  - For males with female partners who are able to become pregnant:
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### 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.

- o 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:

- o See **"What is the most important information I should know about MAVENCLAD?"**

- o **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.

- o **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

- decreased strength
- problems with balance
- changes in your vision
- changes in your thinking or memory
- confusion
- changes in your personality

- o **liver problems.** MAVENCLAD may cause liver problems. Your healthcare provider should do blood tests to check your liver before you start taking MAVENCLAD. 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

- o **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.

- o **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:

- o upper respiratory infection
- o headache
- o 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.

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# momentum

Momentum is published quarterly by the National Multiple Sclerosis Society

Vol. 13, No. 2

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ISSN 1940-3410

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## Stay connected

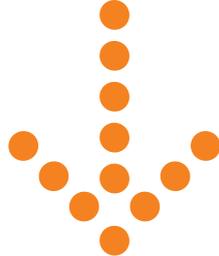
Turn to page 52 for your MS Connection newsletter. Find local events, stories and more!



Momentum's Winter 2018-2019 Website and App won an Award of Excellence in the category "Campaigns, Programs & Plans (Health & Medical)"



Momentum's Winter 2018-2019 issue received a 2019 Finalist Award in the category "Nonprofit Publication"



**W**e are determined to eliminate multiple sclerosis, and we are working on pathways to cures of all kinds — stopping MS from getting worse, restoring lost function and ending MS forever.

One thing we know is that quick diagnosis and getting on a treatment that works means people do better — they have less disability. We have to get in front of MS early. People need to get started on an effective treatment as soon as possible to stop MS from taking hold. But too often, there are delays in diagnosis and treatment.

Neurological care for people with MS is a specialty. With all the treatments available now, there are options that need to be considered. Monitoring is required. Unfortunately, not everyone has access to an MS specialist. Many people are being diagnosed and treated by community neurologists who might not have the expertise, experience or confidence to prescribe and monitor the newest, most effective disease-modifying therapies (DMTs).

The National MS Society is connecting community neurologists with MS specialists so people don't have to travel hundreds of miles to get the MS specialty care they need. Linking a community neurologist with an MS specialist can improve the speed and quality of care needed to get out in front of MS and minimize the damage caused by MS. One tried-and-true approach to do this is a hub-and-spoke model that sets up virtual clinics to connect MS specialists (the hub) with community neurologists (the spokes) to consult, provide expert opinions, discuss treatment options and provide support. Pilot programs called MS Project ECHO (Extension for Community Healthcare Outcomes) have shown promising success.

Kristen Clifford, vice president, healthcare access with the Society, says the program is more “telementoring than tele-medicine.” The Society organizes and works with hub sites — partners in MS care and comprehensive MS centers — and recruits community neurologists who are treating people with MS. To that end, we are launching three hub sites in 2020 that will each have up to 12 spokes. We hope to expand these hubs and spokes across the country.



PHOTO COURTESY OF THE NATIONAL MS SOCIETY



Let me know  
your thoughts.  
Email me at  
[cyndi@nmss.org](mailto:cyndi@nmss.org).

“We want to be sure we’re doing our part to connect community providers with MS specialists so they will have more knowledge and higher confidence in diagnosing MS, prescribing DMTs and knowing when to refer patients and when to treat patients themselves,” Clifford says. This in turn will help more people get diagnosed faster and started on DMTs earlier and will give them access to high-quality MS care in their own communities.

We need to get people plugged in early in their journey to all the resources available to minimize the effect of MS on their lives. They need to be diagnosed and to get on a treatment effective for them as quickly as possible. It is urgent that we reach them.

What are your thoughts about how we can connect earlier with people who have MS? ■

*Cyndi Zagieboylo*

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

# 26

## on the cover

Now a father of two, Andy Rafferty chose to disclose his MS when he adopted his oldest daughter.



PHOTO COURTESY OF ANDY RAFFERTY

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## Momentum exclusive



PHOTO BY SABINA PIERCE

Photographer Sabina Pierce shares her story on p. 22.

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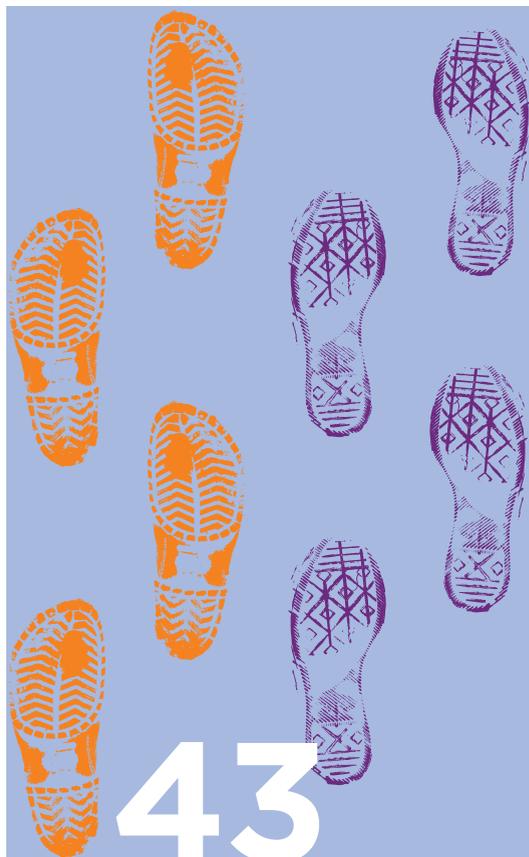
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## Help with Medicare medications

“Moving to Medicare” (Winter 2019–20) provides helpful ways to alleviate some of the financial burdens of expensive MS drugs. Additional things to consider are if the Medicare beneficiary qualifies financially for Medicare “Extra Help,” prescription drug assistance programs through their state, or Medicaid. The good news is that there are funding foundations like those mentioned in the article. Patients should contact their drug manufacturer’s patient assistance program or their neurologist for guidance. What is the point of having these life-changing medications if those who need them cannot afford them?

Helen Zazulak, Massachusetts

## My devices have names, too

Yes! Just like Ardra Shephard (“Awesome aliases,” Winter 2019–20), I have named my devices. My scooter is Mustang Sally. My power chair is named after my grandmother, Marie Schroder. My manual chair is named after my great-great grandmother, Martha Stafford. All three have the initials MS. When we go out, I can tell my husband whom we are taking with us, and he knows whom I am referring to. It is helpful to me to put a positive spin on things!

Tracy Moore, Maryland

## Ardra Shephard is a hoot

I just read “Awesome aliases” in your Winter 2019–20 **Momentum** and loved it. I have had MS since 2002, and although I’m still relatively free from devices, I do use a cane. When I’m having a good day, my cane’s name is “Citizen,” and when the day is not so good, its name is “Mutiny.” Ardra, you rock. Keep that positive attitude!

Frank Steck, Pennsylvania

## Welcome take on MS

When I saw the cover of the Winter 2019–20 issue of **Momentum**, my first thought was “Wow, my friend is on the cover!” I’ve never met Ardra Shephard in person, but I’ve come to think of her as a friend through her excellent blog, Tripping on Air. She gives a welcome, funny take on experiences we have shared and inspires me to keep as active as I can.

Anne Lucas, Ohio



PHOTO COURTESY OF RANDY J. HULING

## Images produce sense of déjà vu

Thank you so much for publishing the essay and artwork of Randy Huling (“Fragments from my brain,” Winter 2019–20). Mr. Huling possesses an enormous gift in his capacity to communicate the inner life of persons with MS. I was particularly struck by his themes of the fragmenting octopus or nautilus; their odd familiarity produces a powerful sense of déjà vu. His images seem to be directly channeled from the core of one of us who lives with this disease. Yes, his work can be tough to look at, but MS is every bit as much of a gut punch.

Julie Landau, Washington



## One step at a time

I just want to send out a thank you to all the people involved in ATO Walks Hard (“Walking tall,” Winter 2019–20). I really feel as though it’s a great DIY fundraiser. Also, I would like to give a big thanks to all of the scientists and researchers doing all they can to try to figure out MS. It is a gigantic mystery to everyone. Like so many discoveries, it takes one step at a time.

---

James Harmon, New York

## Difficult to accept

I agree with Nicole Bradley-Bernard (“Four things I wish someone had told me after my MS diagnosis,” Fall 2019) and it has been really difficult to mourn as I continue my MS journey. It took me almost two years to accept I was not going back to teaching, which I loved and found community in. Now, I am mourning my difficulties walking and the fear of losing my independence. However, after reading this article, I will not be mourning being weak but aiming to be stronger.

---

Lydia Andino-Demyan

## Real facts of life

Thank you for the article by Nicole Bradley-Bernard (“Four things I wish someone had told me after my MS diagnosis,” Fall 2019). We do need to be more prepared by doctors with how this can and does affect us daily. We fight a daily battle with an enemy that is silent in attacks and strikes at any time. Add in the rollercoaster of emotions and the picture becomes much clearer on dealing with MS. Hearing about how unkind MS can be is a hard thing to hear but knowing is much better than being in the dark. You can prepare yourself with a backup of friends and family to be there for support. Sometimes, the only question they need to ask you is, “How can I help you deal with this?”

---

L. Taylor Paris, Tennessee

## Still active and grateful

As someone that does still run, has heat intolerance, and lives in a hot and humid environment, I have learned to adapt and suck it up. Our mental state reflects our thoughts and vice versa. One of the many reasons I do not attend MS support groups is this “woe is me” attitude of so many with MS. I have had it for more than 17 years and am still very active. I could feel sorry for myself, but instead I am grateful for my body and mind. Keep up the good work at **Momentum**. ■

---

Sallie Stoner-Twyford, North Carolina

**Let’s hear it!** Share your thoughts and comments about this issue’s stories.



Email us at [editor@nmss.org](mailto:editor@nmss.org).



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Join discussions at [MSconnection.org](https://www.msconnection.org).

## Cleaning hacks

Reducing clutter in your home is a great way to make cleaning easier and faster (Less mess, less stress, page 10). But what about cleaning the rest of the house? MS symptoms like fatigue, pain and mobility issues can make certain tasks difficult. Here are a few tips to make cleaning your home a little easier.

- **Vacuuming:** Attend to certain rooms or sections of your home on different days, rather than trying to vacuum the whole house at once. If you have multiple floors, leave a vacuum on each floor so you don't have to carry it up and down stairs. If possible, invest in a lightweight, cordless vacuum to reduce the chance of tripping.
- **Cleaning supplies:** Put together a caddy or wheeled cart that contains all your cleaning supplies, such as dusters, microfiber cloths and cleaning solutions, so everything is in one easily transportable container.
- **Shower/bathtub:** Allow cleaning products to soak into the dirt, so you need less strength to scrub away the grime. If bending down to clean is difficult, consider purchasing a scrubber with an extendable handle.
- **Dishes:** Use the dishwasher as much as you can for dishes, pots and pans as well as other items. Many dishwashers can wash plastic items like shower seats, toys, and cleaning and gardening tools. Just remember to run a full clean cycle in the empty dishwasher before adding dishes again.

Practical ideas  
for living well  
with MS

# in the know

# Less mess, less stress

Cleaning and decluttering offer surprising benefits for people with multiple sclerosis.

by Shara Rutberg

**M**arie Kondo launched a legion of followers with her minimalist approach to home organization, showing people how to declutter by keeping only items that “spark joy.” Decluttering can deliver even more to people living with multiple sclerosis, clearing paths for emotional and physical benefits, says Stephanie Singleton, an occupational therapist diagnosed with MS in 2014.

“There’s substantial anecdotal evidence that clutter is common among people with MS,” says Jennifer Tamar Kalina, PhD. Kalina developed and led clutter management groups at an MS Center and wrote about them in the *International Journal of MS Care (IJMS)*. “Symptoms like fatigue, poor balance and mobility can lead to everyday activities becoming more and more difficult,” she says. “Clutter can start small, like not feeling like doing the dishes. Then, they pile up and pile up until what began as just rinsing off a coffee pot becomes a big ‘to-do.’”

“Diminished cognitive abilities including the capacity to categorize and to make distinctions between what is necessary and what is not” can also lead to clutter, says Josh Bacon, PhD, professor of psychology at Yeshiva University and a research associate professor at NYU Langone Multiple Sclerosis Comprehensive Care Center in New York City. Bacon was the senior author of research about hoarding and cluttering among the MS population presented to the Consortium of Multiple Sclerosis Centers 2019 Annual Meeting. “Hoarding is two to three times more prevalent in the MS community than in the general population,” says Bacon. Hoarding disorder is a Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) diagnosis. This is more serious than people with cluttered homes. Both, however, may share roots.

There may be psychodynamic factors contributing to clutter as well, Bacon says. “One of the main issues for people with MS is the slow loss of physical and



sometimes cognitive control,” he says. Difficulty getting rid of items “may be a metaphor for holding onto those things, whether they be capacities or possessions, over which one still has control.” In some ways, battling clutter is analogous to battling MS, says Kalina. “With MS, patients feel the disease is taking over their lives, just as clutter takes over their environment.” But clutter may exacerbate a sense of helplessness.

Clutter can have a pervasive and profound effect on daily functioning, including physical, financial, emotional, cognitive and social aspects, she says. For example, it can promote social isolation, as someone may be less likely to invite people to a cluttered home.

Sarah is a mother of two and was diagnosed with MS in 2012.

It can discourage a healthy diet—it's easier to grab a frozen pizza than chop a salad if the counter is covered in stuff.

Conversely, gaining control of the clutter can make a huge positive difference.

“Over the years at our center, dozens of individuals with MS have reported that reducing clutter has had a positive impact on their symptoms and quality of life,” Kalina wrote in *IJMS*.

### Start with a plan

Begin your clutter-busting crusade with a distinct plan, says Singleton, who practices in New Mexico. List the areas of your home you'd like to address.

Then prioritize them, says Dori Cohen, senior occupational therapist at NYU Langone Health.

But don't plan on doing it all at once. “Start small,” advises Ginny Rieger, an occupational therapist who practices in Wyoming. “Maybe focus on just one drawer first.”

People get really excited about managing clutter, but tackling too much at once can lead to increased levels of fatigue, Cohen says. To prevent that, “make a plan and don't spend more energy than you have,” she says. The therapists recommended setting aside 15–30 minutes for decluttering. “Remember,” Kalina says, “the clutter didn't accumulate in one day, and it will not be conquered in one day.”

Build rewards for short-term and long-term progress into your plans to help keep you on track. “If you're taking on your kitchen first, maybe reward yourself by baking brownies when you're done,” Cohen says. After completing an even larger project, reward yourself with something bigger, like having people over to enjoy your newly organized space, she says.

## Saying goodbye to sentimental stuff

Recycling towers of old medical bills is easy. Reducing roomfuls of belongings wrapped up in years of emotions is hard. Jennifer Tamar Kalina, PhD, and her clutter management group members found a couple strategies that help. “We encountered a lot of collections of things, like coffee mugs,” she says. “It helped to arrange the collection nicely, take a picture of it, then frame the photo.” Another method was choosing favorites. “One of the members couldn't bear to let go of her father's things after he died. But she lived in a New York City apartment. There was just no room. We worked on choosing just four or five favorite pieces and donating the rest.”

“**...Reducing clutter has had a positive impact on their symptoms and quality of life.**”

— JENNIFER TAMAR KALINA, PhD

### Ask for help

Once you've outlined and prioritized your tasks, find help. Not only can having a friend, relative or professional empower you to lift and move things you might not be able to on your own, having a third party can help clarify what things to keep and what to recycle or find new homes for without being encumbered by sentimental attachments. They can be a cheerleader to help keep you motivated.

“Most insurances cover occupational therapy services that can give you an ally who is specifically trained for these situations,” Rieger says. “We can come in and do everything from a home evaluation to create a list of recommendations for making your home safer by removing or rearranging furniture to lots of tools and tricks of the trade for arranging things to increase safety and conserve energy.”



PHOTO BY KEITH CARLSEN

Reducing clutter can help people with MS better manage their symptoms and improve their quality of life.

Less clutter can mean more energy, Singleton says. “For example, you’ll not waste time and energy looking for things, and it will make cleaning easier.”

### Take a seat and take your time

Do as much as you can from a seated position. “Sitting takes 25% less energy than standing,” Singleton says. Set a reasonable pace and take breaks. “Most of all, be kind to yourself. Stop. Take a breath. Then proceed with what you can do.” Make decluttering more fun by putting on some good music, she says.

Labeling can be a great tool in long-term clutter management, says Cohen, especially for people experiencing cognitive symptoms. “It helps people remember where things are and where they belong,” she says, suggesting labels for everything from file folders to bins in the linen closet.

### Stay motivated

To prevent the piles from becoming mountain peaks in your mind, “Keep in

mind that decluttering helps you remain as functional as possible for as long as possible,” Rieger says. “Remember, you’re taking action to keep your independence high.”

Kalina recommends creating a “model space” in an obvious place, “like a coffee table in the middle of the living room, or a two-by-four-foot section of countertop.” Clear it, and do not put anything on it that doesn’t belong. “This can work as a visual incentive to how the whole room — and ideally the whole apartment — should look.”

Don’t be afraid to dive in and get started, Kalina advises. Spring is the ideal time to bust clutter for a fresh start, sparks of joy and a safer, more functional home. “And once you get going,” she says, “it really does get easier.” ■

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Shara Rutberg is a writer in Evergreen, Colorado.

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**Care to comment?** Email us at [editor@nmss.org](mailto:editor@nmss.org).

 in the know

# At home with **MS**

Affordable, accessible apartments designed just for people with MS make life easier for them.

by Matt Alderton



Harmon Apartments in Boston is a supportive, independent community of 36 accessible, affordable apartments.

PHOTOS COURTESY OF HARMON APARTMENTS



Accessible apartments often have community rooms where support groups are offered.

**T**he year was 2006 and Susan Stellmacher was loving life. Although she'd had a rough go of things a few years before — she'd divorced, lost her job and was having multiple sclerosis flare-ups again after years of remission — things were finally looking up. In good health once more, the 51-year-old Minnesotan had moved back to her home state from Maryland, had a job she loved recruiting donors for a local blood bank, drove a zippy Chrysler PT Cruiser and lived independently in a beautiful apartment with a wood-burning fireplace that she adored.

Then came an MS relapse so bad that it literally knocked her down.

“I awakened one morning, and it felt like somebody had stabbed my left eye with a knife,” recalls Stellmacher, now 65. “When I went to stand up and get out of bed, I fell on the floor. After that, I eventually ended up in a wheelchair.”

After her physical fall came an existential one: Because she could no longer drive or work, Stellmacher had to give up her car, her job and, ultimately, her apartment, which because of her new permanent



For many people with MS, supportive housing is appealing for the sense of community it fosters.

disability was no longer affordable or practical.

“When I got sick, I couldn't afford the rent anymore,” Stellmacher says. “Plus, it wasn't a safe environment for me at all. My bathroom, for example, had a combination shower/bathtub, so you had to step over the tub to get into the shower. There were no grab bars. So if you lost your balance, guess what?”

Although she still recalls with sadness everything she lost back then, Stellmacher also beams with joy at what she gained soon thereafter: a new two-bedroom apartment at Kingsley Commons, one of the nation's first apartment buildings designed to provide independent living exclusively for people with MS. Located in Minneapolis, it offers 25 accessible, affordable apartments with wheelchair-friendly features like roll-under countertops, roll-in showers with folding seats and safety bars, wide doors and low cabinets, just to name a few.

“It has served me well and will always continue to do so — whether I'm walking or not,” says Stellmacher, who moved into Kingsley Commons when it opened in 2007 and has recently begun walking again after years

of using a wheelchair.

For people such as Stellmacher, communities like Kingsley Commons are unicorns: as magical as they are rare. As their numbers slowly grow, however, they're proving that people with MS can live as independently as they can happily. All they need is a safe place to do it.

### Building independence

Kingsley Commons was developed jointly by nonprofit housing developer CommonBond Communities and local partner the Powderhorn Community Council, who teamed up to build the \$2.9 million project using a combination of public and private funds.

Although not everyone celebrated it — critics decried Kingsley Commons for segregating people with disabilities and said developers should build blended residences instead—many people who got wind of the concept loved it. Among them: Ken Regan, vice president of Regan Development Corp., an Ardsley, New York-based developer of affordable housing. After being diagnosed with MS himself in 2003, he began researching the MS community and discovered what he believed was a major housing gap.

“There are a lot of people out there who have physical and cognitive disabilities that arise out of their MS, but they're not so disabled that they need to be in a nursing home,” Regan says. “I had the idea to create specialized housing for those people to enable them to thrive in a more independent setting.”

Regan visited Kingsley Commons for inspiration and research, and subsequently has built six communities in New Jersey and Connecticut that are reserved either

wholly or in part for people with MS.

Regan's first MS-focused development was Kershaw Commons in Freehold, New Jersey, which opened in 2011 and has 30 fully accessible one- and two-bedroom apartments designed and built for people with MS.

“We took the state's existing affordable housing development funds and secured private investment on top of that to create what in effect is a community of



Kershaw Commons in New Jersey has 30 fully accessible one- and two-bedroom apartments that were designed for people with MS.

PHOTO COURTESY OF KERSHAW COMMONS

people where almost everyone is living with disabilities that at varying degrees are a result of MS,” Regan explains. “In some cases we have older people who were previously in a nursing home because there really were no alternatives to that for them, and in other cases we have young people in their 20s and 30s who thought they were going to have to live in an institutional setting for the rest of their lives but now have a place where they can live independently.”

## 5 ways to make your home more accessible

People living with MS can make their homes safer, more comfortable and easier to navigate with a few simple changes.

**Remove area rugs** - Rugs can be a tripping hazard for everyone, so avoid them in high traffic areas or use carpet tape to secure them to hard floors.

**Install a raised toilet** - Toilet safety frames are available at most home improvement stores and offer a low-cost way to increase bathroom safety.

**Pick the right appliances** - Consider a front control range, side-by-side refrigerator and front-loading washers and dryers to make household chores easier.

**Take a seat** - Adding a chair to the area where you get ready can help you combat fatigue and balance challenges.

**Rethink your doorknobs** - Lever style doorknobs and keypad locks are a good solution for people with dexterity challenges.

Keeping people with MS out of institutions benefits the social safety net as much as it does individuals, according to Fran Murphy, chief financial officer at The Boston Home, a skilled nursing facility in Boston that specializes in residential care for people with MS. In May 2019, The Boston Home opened Harmon Apartments, a supportive, independent community of 36 accessible, affordable apartments for people with disabilities — including people with MS, who occupy about 15 of the apartments.

“Nursing-home care is not adequately funded by the government. It’s a very difficult cost structure, so we began looking for ways to facilitate a lower-cost housing model that’s supportive of people with progressive diseases and mobility impairments,” Murphy says. “We looked at the work that was being done by others, including Kingsley Commons and Regan Development, and decided that their model made a lot of sense. If you can build homes that are flexible enough to continue supporting people with progressive diseases as they decline, they can stay in those homes longer.”

But accessible housing developments don’t just keep people with MS out of institutions. They also keep them out of homes in which they’re uncomfortable, unsafe and isolated.

“In many cases you’re taking people from a negative housing situation — they might live in a second-floor walk-up, for instance, where they can’t get in and out easily — and you’re giving them an opportunity to thrive,” Regan says. “That’s life-changing.”

### Home sweet home

To comprehend just how life-changing supportive housing can be for people with MS, one need only look at the apartments themselves, which often exceed Americans with Disabilities Act (ADA) standards.

At Kershaw Commons and other Regan properties, for example, residents have: automatic door openers for the building and each apartment entry door; 42-inch doors that are wide enough for wheelchairs; hardwood and ceramic tile floors instead of carpeting for easy mobility; custom horizontal sliding windows that are easy to open from a seated position; linen closets



J.R. Hardenburgh lives at the Harmon Apartments with his companion dog, Gilly.

“

**The best part about living at Ojakian Commons is we all ‘get’ each other.”**

—DIANE E. KEENEY

with slide-out cantilever shelving trays; accessible light and thermostat controls; bathrooms with roll-in showers, accessible mirrors and grab bars; kitchens with accessible cabinets that have roll-under access and slide-out cantilever shelving trays, front-control cooking ranges, side-by-side accessible refrigerators and countertop microwaves; and common areas with wide hallways, railings and automatic entry doors. There even are trash chutes with automatic openers so residents won't have difficulty pulling open doors to empty their garbage.

At Harmon Apartments, technology is set to play a major role. Apartments already feature secure keyless entry, for example — residents open their doors by swiping an RFID card and pushing a button — and eventually will be equipped with a smart home system that allows residents to control lighting, temperature and window shades from their mobile device.

What sound like amenities are so much more than that. At Kingsley Commons, for example, Stellmacher raves about her accessible bathroom. “There’s a nice pull-down seated bench in the shower with extra-long shower attachments,” she says. “I did not have that at my previous apartment at a time when I really needed it, which caused me to fall and so severely sprain my right ankle that I had to be in a boot cast for eight weeks.”

Falls also are a concern for J.R. Hardenburgh, a 64-year-old resident at Harmon Apartments. “My MS has progressed to the point where balance, gait and fatigue affect me every minute of every day,” says Hardenburgh, who five years ago began using a scooter to avoid falls. At that time, the father of three grown children decided to sell his longtime home — which



PHOTO COURTESY OF DIANE E. KEENEY

Diane E. Keeney, a resident of Ojakian Commons, enjoys gardening and socializing within her community.

had stairs in it — and move into a handicap-accessible apartment with his wife. When they subsequently divorced, he spent a year living with a friend, then couch surfed for two months before finally moving into a brand-new, fully accessible apartment at Harmon with his companion dog, Gilly.

“It’s got everything you could possibly want in an apartment as a handicapped person,” Hardenburgh says of his one-bedroom home, which he calls “nirvana.” “I’m never leaving.”

### **Creating community**

For many residents, supportive housing is appealing not only because of the activities they can enjoy inside

their apartment, but also because of those they can enjoy outside of it.

Take Kershaw Commons. For residents there, it provides educational programming, a self-help group and yoga classes, including chair yoga for people who use wheelchairs or scooters.

Similar programs exist at Kingsley Commons and Harmon Apartments. The former offers adaptive yoga classes, adaptive boxing, a monthly MS support group and a large community room while the latter enjoys proximity to The Boston Home, where there's a Wheelchair Enhancement Center that provides customized enhancements to wheelchairs to make them more comfortable and functional. Both communities also have onsite social workers to help residents coordinate social services.

"Everyone here has a neurological disease. Some are far worse off than I am, some are a little bit better off, but we're all in the same boat," Hardenburgh says. "It's nice being surrounded by people who understand the challenges you face on a daily basis."

The community health benefits are what attracted resident Andrea Novak to Kershaw Commons when

she moved there in 2011.

"I saw an ad for Kershaw Commons, and I wanted the programs, support group, exercise classes, not to mention having an MS Center in my backyard," Novak says. "In short, I wanted to learn how to live well with MS."

And she is. "I didn't know much about MS [when I was diagnosed]," Novak continues. "Meeting people here and sharing our experiences with MS has been helpful."

Diane E. Keeney can relate. A resident of Ojakian Commons — a Regan development in Simsbury, Connecticut, that has 48 apartments, 40 of which are reserved for people with disabilities — she finds solace in her neighbors. "The best part about living at Ojakian Commons is we all 'get' each other," Keeney says. "Everyone has their own symptoms, as well as good days and bad days, but for the most part, we can relate and empathize with one another on what we are going through."

### A new 'lease' on life

The people who live in communities like Ojakian Commons say social support is crucial to their well-being. But so-called "supportive housing" is only truly supportive if it's also affordable, Regan argues. "The key with this kind of housing is to make sure that we provide not only the accessibility features that people need, but also the financial structure that makes them economically secure," he says. "Especially with MS, situations change. If you move into a community and you're working, then your disability status changes and you can't work anymore, you shouldn't have to worry that you won't have enough money to pay your rent."

Although each has its own financial structure, most supportive housing communities for people with MS accept housing choice vouchers from low-income tenants. In some cases, tenants obtain from local public housing agencies their own vouchers that allow them to choose their own housing. In other cases, public housing agencies grant project-based vouchers that are attached to individual communities. In both cases, tenants typically pay 30% of their monthly income toward rent; the government-funded vouchers



PHOTO BY ROBERT BENSON PHOTOGRAPHY

Residents of Harmon Apartments have access to a Wheelchair Enhancement Center that provides customized improvements to wheelchairs to make them more comfortable and functional. (Pictured, from left: Tara Mizrahi, vice president of Affirmative Investments; David Ennis, president of Affirmative Investments; and residents Theresa Norwood Hart and Loretta Martin.

cover the balance of their rent.

At both Kershaw Commons and Ojakian Commons, Regan Development Corp. obtained project-based vouchers for each of its apartments. The same is true at Kingsley Commons, where residents have an average annual income of \$18,800. For Harmon Apartments, on the other hand, The Boston Home only received project-based vouchers for roughly a quarter of its apartments and rents the remaining affordable apartments out at a discount but accepts housing choice vouchers from tenants who have them.

For residents like Stellmacher, the assistance she receives is a lifeline. “Without it, there wouldn’t be a place for me to live,” she says. “I would be homeless.”

### No place like home

If you ask the people who build, manage and live in them, supportive housing communities have only one major flaw: There aren’t enough of them.

“[The National MS Society] gets a lot of calls from community members, and one of the biggest reasons they call is that they’re looking for affordable, accessible housing,” says Erin Poznanski, vice president of the Society’s MS Navigator Services. “Those two words together — affordable and accessible — are really, really hard to come by.”

According to the Society, there are currently about 15 listings in Connecticut, Kansas, Massachusetts, Minnesota, New Jersey, Ohio and Pennsylvania. Of course, low supply means high demand. As a result, communities often have long wait lists. Residents who get an apartment typically rely on a mix of luck and need. When she applied for residency at Kingsley Commons, for example, Stellmacher says apartments were awarded on a first-come, first-served basis. Novak says the same was true for her at Kershaw Commons. For Harmon Apartments, on the other hand, The Boston Home held a lottery; applicants with disabilities were given priority and moved to the top of the list

along with Boston residents, and those who were chosen had to complete an interview and supply a doctor’s note attesting to their physical needs.

Newer communities like Harmon Apartments are a sign that Regan’s vision is alive and well. “It’s been a thrilling experience talking to residents who live at

Harmon Apartments and seeing how their lives have changed because of it,” says Marva Serotkin, former CEO of The Boston Home. “When people need accessible space and don’t have it, their lives are defined by inaccessibility. But now the windows are open and the doors are open, and they can come and go as they please. It just gives people a lot more options in their lives.” ■

“  
It’s got  
everything you  
could possibly  
want in an  
apartment as  
a handicapped  
person.”

—J.R. HARDENBURGH

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Matt Alderton is a Chicago-based writer and editor.

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For information on accessible housing, contact an MS Navigator by calling 1-800-344-4867, emailing [ContactUsNMSS@nmss.org](mailto:ContactUsNMSS@nmss.org), or online at [nationalMSSociety.org/navigator](http://nationalMSSociety.org/navigator).

Check out the National Multiple Sclerosis Society’s Guide to Accessible Housing at [ntlms.org/AccessibleHousing](http://ntlms.org/AccessibleHousing) or contact an MS Navigator at 1-800-344-4867 or email [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org) to receive a copy.

For additional information about locating accessible housing and legal issues related to accessible housing, visit [nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Documents/Housing-Challenges.pdf](http://nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Documents/Housing-Challenges.pdf).

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).



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**National  
Multiple Sclerosis  
Society**

# Wobbling

I look at my multiple sclerosis as a gift.

PHOTOS COURTESY OF SABINA PIERCE



Sabina Pierce was diagnosed with MS when she was 23.

by Sabina Pierce

“**W**eebles wobble, but they don’t fall down.”

When I was a kid, I had a set of Weebles, which are these egg-shaped toys with faces on them. No matter how hard I tried to knock one over to prove the jingle wrong, it’d snap right back up with a smile on its face.

I’ve walked through life with that jingle as one of my mantras. It has served me well.

Fresh out of university, excited to be starting as a photojournalist, I woke up at 23 with double vision. A few tests later I was diagnosed with multiple sclerosis, a disease that caused my mother to be bedridden in my teens and would force my aunt into disability retirement.

Sabina Pierce has photographed for top newspapers. Her subjects include the Dalai Lama, Pope Francis and Barbaro, a famous racehorse.

# through life

After a good cry, I decided to look at my MS as a gift, a wake-up call. As the poet Mary Oliver wrote, “Tell me, what is it you plan to do with your one wild and precious life?”

I wanted to be a photographer.

I dug in.

Single and self-employed, I knew that if I didn't work, I wouldn't eat. I had just started to freelance for the Associated Press, which is a big deal so early in a photographer's career. I put an eye patch on, said I had an eye infection and kept on shooting.

Meanwhile, I found a great MS neurologist at the University of Pennsylvania — Dr. Markowitz. He loved photography, so we hit it off. Then I researched MS to come up with a game plan based on common sense, his guidance and research. I changed my diet to an anti-inflammatory diet long before it was mainstream. I exercised regularly back when it was seen as putting stress on your body. I took allergy pills to keep my immune system quiet. I started rowing to work on my balance. Most importantly, I kept my heart happy by doing what I love and surrounding myself with dogs.

Twenty years later I'm following where my eye has led me. I've photographed for top newspapers, including the New York Times, and took photos behind the scenes with presidents, Pope Francis, the Dalai Lama and Barbaro, a famous racehorse. One photo of him was chosen by Time magazine for its “25 Best Photos of the Year in 2006.” I was one of the American Society of Media Photographers' “Top Photographers of 2007.” I spent two years in a Philadelphia cop car working on a documentary project. I traveled across the country shooting pictures of chefs and dogs for a book that was featured on Good Morning America.

All while hiding my MS.

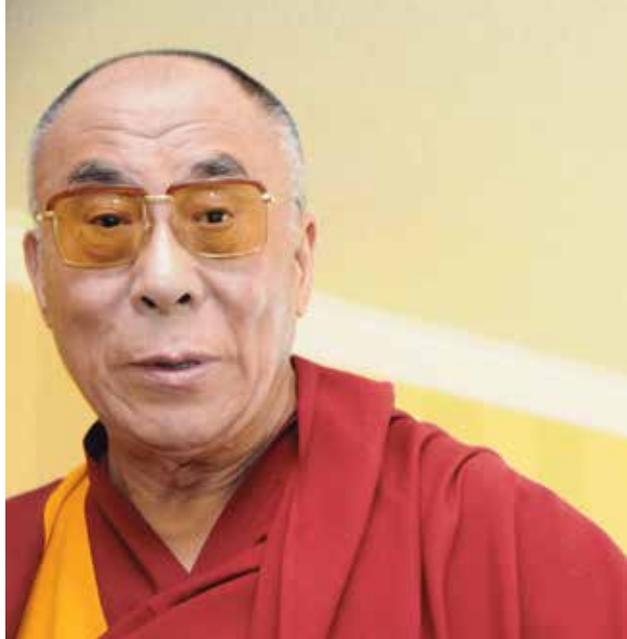
Currently I shoot for Fortune 100 companies along with a bit of photojournalism and personal photo projects. As time passes and my career speaks for itself, I've let clients know that I have MS. I want them to see that people with MS can still get the job done.

I'm no hero. MS has been challenging. It's knocked me to my knees on occasion, but I feel that by changing my perspective and making the disease my friend and not my foe, I've been able to take control of my story as best as I can.

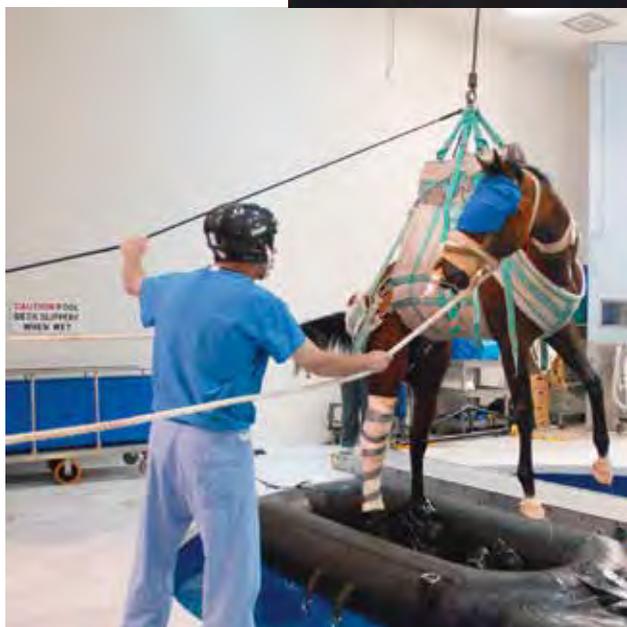
I am a Weeble, so whenever my MS is acting up, I remind myself that Weebles wobble, but they don't fall down. ■

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Sabina Pierce lives in Philadelphia.



See more of Sabina Pierce's photography at [sabinashoots.com](http://sabinashoots.com).



MS makes  
everything  
harder.

I am  
a great  
mom.



**Sarah**

Mom to Lola and Julian.  
Walk MS® Team Captain.  
Diagnosed in 2012.

Hear Sarah's story at  
[nationalMSSociety.org/  
sarah](http://nationalMSSociety.org/sarah)



National  
Multiple Sclerosis  
Society

Michelle, diagnosed with MS in 2001.

## What is online therapy and how does it work?

Many people living with MS experience depression, anxiety and other mental difficulties. Finding mental health care is important (page 34). While factors such as cost and location can get in the way of finding help, online therapy is changing the mental health landscape.

Online therapy resources like Talkspace, BetterHelp and Rethink My Therapy make finding a licensed therapist as easy as

logging into an app on your phone. With video and phone calls or private chat rooms, you can talk to someone however you feel most comfortable. Some sites charge a fee to join along with fees the therapists charge.

So, whether you have depression, are feeling anxious about starting a new chapter in your life (page 26), or just need some extra support, online therapy could be an option.

# thrive

Forging a path to your best life

Inside this section: Fulfilling the dream of family 26 // Head space 34

Andy Rafferty, who lives with MS, adopted his oldest daughter, Lily (right), and had his youngest daughter, Autumn (left), biologically.



PHOTOS COURTESY OF ANDREW RAFFERTY

# Fulfilling the dream of family

For people with MS, adoption can be the answer.

by Aviva Patz

**W**hen Andy Rafferty was diagnosed with relapsing-remitting multiple sclerosis at age 22, he made a conscious decision not to have children even though he'd always wanted them. He recalls thinking at the time: "It would be selfish to condemn a loved one to a future of caring for me. And how could I raise a child that I could never even play catch with?"

Twelve years later, thanks to a few twists of fate, he is a father to two school-age softball players whose teams he coaches, and he couldn't be happier. "I could not overexaggerate the blessing my daughters are," says Rafferty, an executive sous-chef in Redmond, Washington. "Lily [12] and Autumn [10] are now what keeps me up, keeps me moving. They are like a daily medication that is 10 times stronger than the drugs that come in a syringe."

The road to adoption may look different for every family, but for people with MS, it can mean the

Rafferty disclosed his MS during the adoption process as well as to his daughters. He says they are a huge help to him at home.



fulfillment of a lifelong dream. Here's what you need to know about becoming an adoptive family when one or both parents has MS.

### **Why adopt?**

People have varied motivations for adoption. "Those who adopt due to reasons of infertility or disability generally do so because they want to love and parent a child, and it is either impossible or not advisable that they become pregnant," explains Chuck Johnson, president and CEO of the National Council for Adoption.

It's important to note that for women with MS, several large studies have demonstrated that pregnancy, labor, delivery and the incidence of fetal complications are no different in women who have MS than in control groups without the disease, according to the National Multiple Sclerosis Society.

After getting married at age 24, Kat Snyder and her husband, Justin, spent the next five years trying to get pregnant, even changing her disease modifying therapy (DMT) to one that is thought to be safe during pregnancy.

"I always wanted to be a mother — that was my dream," says Snyder, who was diagnosed with relapsing-remitting MS in 2005 at age 20. After two rounds of in vitro fertilization (IVF) and an ectopic pregnancy that led to emergency surgery and then a bad MS relapse, the couple gave up on having a biological child. They started looking into adopting without knowing whether it was even a possibility with Snyder's MS. Ten years later, Snyder and her husband have a 5-year-old daughter, Claire, and a

21-month-old son, Carson, and are so grateful for the chance to have adopted them at birth.

Others might choose adoption for reasons that have nothing to do with their MS but simply out of concern for the welfare of children.

“There are so many children in foster care around our country, we felt called to help in some capacity,” says Melissa Evensen of North Dakota, who wasn’t yet diagnosed when she and her husband, Todd, adopted their daughter. She learned she had relapsing-remitting MS in 2019, after she and Todd finalized the adoption of Jocelyn, now 10, a special-needs child the Evensens had been fostering for six months. The Evensens also have two biological children, Abigail, 17, and Natalie, 15. And even now, with the fatigue, difficulty balancing and short-term memory lapses that come with her disease, Melissa is still considering renewing the family’s foster care license so she and her husband can continue to care for children with special needs.

### The challenges

The adoption process for people with MS or any illness or disability is no different than for people without them. According to **Childwelfare.gov**, most people are eligible to adopt regardless of their age, income, or sexual orientation, or whether they

“ There are so many children in foster care around our country, we felt called to help in some capacity.”

—MELISSA EVENSEN

are married or single, and having a disability is not grounds for disqualification. “Most adoption agencies will consider a prospective adoptive parent with disabilities as long as they can demonstrate that the disability will not prevent

them from parenting the child,” Johnson says. That’s one reason all prospective adoptive parents are required to provide a medical evaluation, whether they have a disability or not. Many adoptions also require references from family and friends.

Melissa Evensen’s family consists of both biological and adopted children.



PHOTO COURTESY OF MELISSA EVENSEN



Kat and Justin Snyder decided that adoption was the best option for them to start a family.

PHOTO COURTESY OF KAT AND JUSTIN SNYDER

People with MS do face one unique hurdle when it comes to open adoptions. “Most infant domestic adoptions involve openness with the birth parents, and the birth parents may not be open to selecting a family in which someone has a disability,” Johnson says. “However,” he adds, “I have personally worked cases where the birth parent selected families with known disabilities or past illnesses that were required to be disclosed, including polio, amputations, cancer and more, so it’s not

impossible.” International adoptions may be trickier, he adds, as many countries have additional health requirements that people with MS might not meet.

### **The process of adopting**

When it comes to adoption, there are many different types and options. According to **Childwelfare.gov**, you can adopt children from the foster care system, from other states or jurisdictions

or from other countries. You can adopt infants domestically through a licensed private agency or via an attorney (independent adoption); and you can even adopt an adult — to formalize an existing relationship, for example, secure inheritance rights, or provide continued care for someone with disabilities or cognitive delays. Adoption training and requirements can vary from state to state and even from one county to the next.



**Kat and Justin Snyder's adopted son, Carson, plays with the family's pet goat, Pearl.**

PHOTOS COURTESY OF KAT AND JUSTIN SNYDER

Evensen adopted from the North Dakota foster care system through a program called Adults Adopting Special Kids (AASK), which finds homes for children who have a mental or physical disability, are older than typical adoptive age, or are part of a sibling group. “Our daughter was our 18th foster match in almost a year and a half,” Evensen says. “When she came to us, her biological parents’ rights had already been terminated; once other biological family adoptive options were ruled out, we were given the first opportunity to be an adoptive match since we had already established attachment and permanency.” Evensen and her husband were thrilled to have the opportunity to adopt the child they had been fostering.

For Rafferty, a private adoption through an attorney made the most sense since he was adopting his then-girlfriend’s daughter. “It was expensive, time-consuming and also quite the mound of paperwork,” he recalls. “I hired a lawyer to make sure it was done correctly but I was doing most of the work and she was checking it,” he remembers. One step he found a bit funny was the inspection of his household, including going through a checklist of childproofing, fire extinguishers, background checks and more.

“All of this happened even though she had already lived with me almost her entire life!” he says. He ended up having his second daughter, Autumn, biologically with his girlfriend, and after that relationship ended, he assumed primary custody of both girls.

Snyder used a local agency, Adoptions From the Heart, to adopt her two children. At the initial information session she and her husband attended, she remembers asking: If you have a medical problem can you still adopt? The social worker right away said “Yes, as long as your doctor says you’re physically and mentally able to take care of a child. We have cancer survivors and others going through different health battles — even people with biological children have health conditions.” From that point, Snyder says, “I knew we would use this agency and that it was going to be possible!”

Adoptions From the Heart provided a timeline with steps for prospective adoptive families to follow. “You go to classes about adoption, you meet the birth parents, you learn the laws,” Snyder explains. “You have a home interview to be sure you have a safe environment to raise a child, then you put together a book about your life to be shown to the birth parents.”



Kat and Justin Snyder enjoy a family vacation with their son and daughter.

### How to decide what to disclose

Snyder felt close enough to her social worker to open up about her MS. “She was very reassuring, saying it was OK if I wanted it to be a part of our book, but if not — that was OK, too,” she says. Ultimately, Snyder and her husband decided not to mention it. “Only because we didn’t want someone assuming the worst-case scenario when reading about us,” she says. Today, Snyder’s family sees the children’s birth parents once a year and exchanges emails and pictures, but the birth parents don’t know their address or phone number, or that Snyder has MS. “We are building a friendship and one day our children will know everything about their birth story, and then they can choose who they tell about being adopted and who they tell about their mom having MS,” she says.

Rafferty, by contrast, chose to disclose his MS. “It’s something I felt I had to be up front about in every way to protect Lily and myself,” he recalls. His lawyer asked a few questions and took notes, but it didn’t come up again at all in the legal process. “My own judgments on myself were way more harsh than that of the court,” he says. “It turns out they knew far better than I that you don’t need to be able to walk to love and support

a child.” As far as disclosing his MS to his daughters, he told them on day one and continues to explain his condition at levels they can understand as they age.

Though Evensen hadn’t yet been diagnosed during Jocelyn’s adoption process, she believes she’d need to disclose it if the family were to adopt again. “I wouldn’t want there to be any secrets, especially if I were adopting an older child,” she says. Jocelyn thought Evensen was going to die when she was diagnosed, and it took several weeks to convince her that she wasn’t going anywhere anytime soon. “Kids need to know the truth so they aren’t caught unaware, especially those adopted out of the foster care system who may already have suffered some level of trauma, even if it was only the separation they experienced from their biological parents,” Evensen says.

### Factors to consider

The adoption process is no small hurdle, but a critical factor for people with MS to consider is whether they’re able to balance the needs of an infant or child with the needs and demands of their illness.

“Having a newborn is exhausting with not getting a lot of sleep,” Snyder says. She was lucky to have a support system in her husband, mother and mother-in-law. “They made sure I didn’t overdo it, including moving the baby clothes and changing table downstairs so I wouldn’t have to do the steps so much.” Washing bottles became her husband’s job since hot water is painful on the nerves in her hand. The family has learned to go to the park in the early morning before it’s hot to accommodate her discomfort with heat. “We went to Disney and I rented a scooter because it was way too much walking,” Snyder says. “The kids loved riding with me. We saw everything we wanted to see and did everything we wanted to do.”

Rafferty admits to getting a lot of help from his mother and an “extremely fantastic village of help — it really does take a village,” he says. Though he’s able to work and enjoys full mobility, he often gets vertigo and can be suddenly overcome with fatigue. “These symptoms cause me to struggle with day-to-day tasks such as making dinner and doing dishes,” he says. “In both cases, the girls jump in and help out so I can lay low.”

Beyond coping with her own symptoms, Evensen has the additional challenge of parenting a child with special needs. “My daughter needs two parents helping to give her the highest level of success every day, and when I’m not at my best, I really struggle with the guilt of knowing I’m not carrying my share of the weight,” Evensen says. Her husband doesn’t complain, but she knows it’s hard on him to pick up where she leaves off. “I really worry that I’m neglecting my family. Adjusting to our new normal has been harder than I anticipated when I was



PHOTO COURTESY OF MELISSA EVENSEN

Melissa Evensen and her husband, Todd, were thrilled to have the opportunity to adopt a child.

first diagnosed.” But then she adds, “My daughter is a blessing to our family — we would be incomplete without her.”

Evensen’s advice to prospective adoptive parents: “Be really honest with yourself and your licensing agency about your limitations. It’s easy to tell yourself that something won’t be too hard, but there’s no going back once you fall in love with an amazing child.”

Snyder adds, “Set up a great support system of family and friends to help and live in the moment. Do not let fears or unknowns scare you. You may not be able to run around the playground or play on the beach in the hot sun, but you can sit under an umbrella with a cooling vest at the beach, you can have a picnic lunch at the park, you can rent or buy a scooter to go to amusement parks. Your child will love it regardless because of your love and support, and they will see how strong you are.” ■

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Aviva Patz is a writer in Montclair, New Jersey.

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An advertisement for Redman Power Chair. It features a man in a dark jacket and cap sitting in a black power chair, leaning back. The chair has large rear wheels and smaller front wheels. The background is a brick wall. Text on the image includes: "THE ORIGINAL POSITIONING POWER CHAIR PIONEERS" in large, bold, black letters at the top left; the Redman logo (a stylized sun with a face) and "REDMAN POWER CHAIR" in blue and red text in the center; and "FREE DEMO RedmanPowerChair.com 800.727.6684" in white text at the bottom.

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# Head space

Cognitive behavioral therapy can help you manage your pain and fatigue as well as your emotions.

by Vicky Uhland

Imagine if someone constantly told you that your multiple sclerosis made you an unproductive member of society. That your balance issues meant you would be using a wheelchair soon, or your occasional memory lapses would morph into a future with severe cognition issues. Or even that because of your MS, you wouldn't be able to take care of your family.

You'd probably cut that horribly negative person out of your life, right? But imagine if that person was you. Imagine having those kinds of thoughts and not being able to stop.

"I think of those voices in my head as like a neurotic roommate," says Elysa Lanz, a Covington, Washington, resident who was diagnosed with MS in 1989 at age 28. "I think about what I would do if I had a roommate who said those things to me. I would make them leave the house, I'd change the locks and block their number on my phone."

Lanz used to be one of the many people with MS who felt victimized by anxious and depressive thoughts about her disease. And after she had a severe exacerbation in 2007 that left her in constant pain and unable to walk without canes, those thoughts escalated.

"I knew that I had to get control over my emotions and pain to be able to continue to live a happy and productive life," Lanz says. So she signed up for a University of Washington study on cognitive behavioral therapy (CBT) for MS pain management.

Within a few months, Lanz could see changes in her depression, anxiety and pain levels. "I learned to stop catastrophizing and obsessing about my decline and how I was going to take care of my family," she says. "I learned that beating myself up with thoughts like, 'Will I not be able to walk tomorrow?' wasn't doing any good — and was actually making me feel worse."



PHOTO COURTESY OF ELYSA LANZ

Elysa Lanz, diagnosed with MS in 1989, gained control over her emotions thanks to cognitive behavioral therapy.

## Types of therapy

**CBT:** Cognitive behavioral therapy

**ACT:** Acceptance and commitment therapy

**MBCT:** Mindfulness-based cognitive therapy

### How CBT works for MS

CBT is a widely accepted type of talk therapy that's been around since the 1950s. It's based on the idea that how you think, what you feel and how you act are all linked.

"It's not a Freudian thing where you tell your deepest, darkest secrets," says Meghan Beier, PhD, a rehabilitation neuropsychologist in Johns Hopkins University's MS Rehabilitation Research Program. "It's more of a problem-solving strategy."

Over the years, CBT has evolved into a menu of different types of intervention strategies and techniques that can be tailored to fit the individual. But the basic tenet remains the same: If you learn how to manage your negative thoughts or behaviors, that helps you feel better.

One of the key concepts behind CBT is to put your thoughts "on trial." For instance, Beier says, you may be having pain and thinking "I can't stand this pain." But is that really true? What's the evidence for and against that thought?

Once you realize you are indeed withstanding that pain, then you can change your thought to something like: "Yes, it stinks to have pain, but here are the things I can do to help alleviate that," such as physical therapy and relaxation techniques. The goal is to learn how to identify unproductive thoughts and then change them to help rather than harm you.

A related form of psychotherapy that focuses on thoughts and feelings is acceptance and commitment therapy (ACT). In general, people either tend to ruminate on their thoughts or avoid them, says Ivan Molton, PhD, associate professor in the University of Washington's Department of Rehabilitation Medicine. But by learning how to accept your negative thoughts and allowing them to pass by without judgment, you can prevent

them from causing you harm.

"Notice the thought, write it down, notice how much it occurs," Molton says. "But don't engage it. Think of it like a tape — if you wait, the tape will end. The more you engage negative thoughts, the more power they have over you."

Mindfulness-based cognitive therapy (MBCT) operates along the same lines as ACT. One goal is to recognize that although a thought may be realistic and valid, it's not useful to you, says Dawn Ehde, PhD, a clinical psychologist in the University of Washington Medicine Division of Clinical and Neuropsychology.

"For instance, when people are depressed, they can have thoughts like: 'My MS doesn't allow me to do what I once could,'" she says. "That may be a realistic thought, but it's often unhelpful. It doesn't make you feel better." But if you use CBT techniques, you can turn that thought into a helpful one, like, "Yes, my MS is making me do less, but I can still be a parent; I can still work," Ehde says.

CBT has been used for people with MS for more than two decades, and research shows it can be effective for the depression and anxiety associated with the disease. There are also studies on CBT's impact on pain management and fatigue. And there's research underway on how CBT can help people cope with the uncertainty of MS.

CBT can be done with a therapist or on your own with books or apps (see the sidebar for suggestions) — although therapists say the DIY version requires self-motivation and may not be effective if you have a high level of distress. Because it's considered a gold standard of psychotherapy, CBT is covered under most types of health insurance with mental health benefits, Molton says.

Studies show that the most effective course of CBT therapy is eight to 16 sessions. Generally, sessions last an hour



In my mind, I was convinced that my MS was doing all of this to me.”

—ALEJANDRO GUADARRAMA



PHOTO COURTESY OF ALEJANDRO GUADARRAMA

and are done weekly in person or by phone, with “homework” in between. Molton says a good CBT practitioner will give you a plan for your therapy, including thoughts or behaviors you want to address. Because there are so many forms of CBT, it can be highly individualized. So if you don’t see progress after a few sessions, Molton says your therapist should make adjustments that work for you.

Here’s how CBT can help you manage common MS symptoms.

### Overcoming anxiety and depression

After Alejandro Guadarrama was diagnosed with MS in 2017 at age 42, he barely

talked about his disease and only with his wife, mother and brother. “I didn’t want to give anyone else the weight of knowing and worrying about my MS,” he says. “I started withdrawing from social events and rarely left the house over the weekends.” In his mind, he felt like he had a good handle on things and preferred to fly under the radar.

But about a year later, he underwent a series of stressors. Shortly after having a second daughter, Amalia, he and his family moved from the city to the suburbs of Washington, D.C. The move happened over the December holidays, draining his energy and bringing crippling fatigue with it. The political climate created extra pressure in his job, especially as a pro bono lawyer

CBT helped Alejandro Guadarrama develop ways to manage his negative thoughts, and learn to enjoy life again.

## Additional CBT resources

If you'd like to try CBT on your own, psychologists Meghan Beier and Ivan Molton recommend the following books and apps.

### BOOKS:

- **Get Out of Your Mind and Into Your Life: The New Acceptance and Commitment Therapy** by Steven C. Hayes (New Harbinger Publications, 2005)
- **Solve for Happy: Engineer Your Path to Joy** by Mo Gawdat (Gallery Books, 2017)
- **The Stress and Mood Management Program for Individuals with Multiple Sclerosis** (Oxford Press, 2010)
- **Cognitive Therapy for Chronic Pain: A Step-by-Step Guide, Second Edition** by Beverly E. Thorn (Guilford Press, 2017)

### APPS:

- **Woebot (woebot.io)**  
This free CBT app developed by Stanford University psychologists offers daily lessons and check-ins for people with depression or anxiety.
- **Curable (curablehealth.com)**  
This online CBT pain psychology program features Clara, a virtual pain coach with lessons and exercises to manage pain. You can try it for free, but then you'll need to pay anywhere from \$5.99 to \$14.99 a month.

representing low-income immigrants. And then his 5-year-old daughter, Carlota, was hospitalized for a few weeks in January because of congenital heart complications.

"I realized I had lost my joy in things. It felt like I was just a bystander in my own life," Guadarrama says. "I could not sleep and my neurologist said I was severely depressed."

He started taking medication for depression, but it wasn't effective. So he called four of his friends and told them about his MS and what he was going through. "They rushed to my house and told me they loved me and my family." That's when his mind also started telling him that not talking to them about his MS was one of the biggest reasons why he ended up the way he did.

One friend told him about an intensive program for depression at Johns Hopkins. Guadarrama enrolled, and in the spring of 2019, began a two-month course of CBT.

"In my mind, I was convinced that my MS was doing all of this to me," he says. His breakthrough moment came when he understood that his inability to hold ideas and impaired concentration were signs characteristic of clinical depression. Armed with knowledge, he was able to also self-identify signs of severe anxiety.

CBT showed Guadarrama that his persistent, depressive thoughts were not necessarily true. "I would tell myself that if I forgot something it was due to my MS, and it would just get worse. But there are all kinds of reasons for forgetting something."

Still, some thoughts wouldn't go away despite Guadarrama's best attempts at reasoning. That's when he relied on coping skills such as the 5-4-3-2-1 CBT technique. Focus on five things you see, four things you hear, three you feel, two you smell and one you taste. The idea is to change your focus

“I’ve always been able to depend on my cognition ... so losing it was crippling.”

—KRISTIN CAULFIELD

and turn off unwanted thoughts for a few minutes. “With practice, this gives you better control over your thoughts,” Beier says.

CBT also helped Guadarrama to put things in perspective and recognize his strengths. “Even when you’re at the lowest of lows, you don’t lose those strengths,” he says. “Believing in that gives me hope that I could get through things.”

The program taught Guadarrama to step back and evaluate how his thoughts or feelings influence his decisions. He also learned CBT-related coping strategies for dealing with memory issues.

“With CBT, I learned it doesn’t matter what the cause is when I forget something — it’s what I do about it,” he says. “So now I write down someone’s name or my supermarket shopping list rather than trying to remember it. I set an alarm, so I don’t miss catching the bus home. That way, I don’t forget and then get demoralized or depressed.”

The goal of his CBT course, Guadarrama says, was to learn skills that could help him “create good habits and routines that take you out of the situations that make you feel bad, sad or mad. CBT is a part of how I see things today. I like it. It gives me a chance to order my feelings and thoughts.”

### Coping with anger

In 2013, Kristin Caulfield was 41 years old, had a PhD in nursing, was a Harvard-Macy fellow and was on the faculty tenure track at George Washington University. And then she was diagnosed with MS.

Her main symptoms were cognitive, including reduced processing speed. As her symptoms worsened, they began affecting her job. “I had to retire,” Caulfield says. “And I was so angry and resentful, and then I was diagnosed with depression. I didn’t realize how much of my identity was wrapped up in my job.”

For two years, Caulfield focused on what she couldn’t do. “The thing I’ve always been able to depend on is my cognition. I’ve always been the smart one. So losing it was crippling.”

Finally, Caulfield realized her life vision was in the past. “I’d always say things like, ‘I used to be able to ...’ or, ‘Before MS ...’ I call it going through the tunnel.” So she decided to see a neuropsychologist, met Beier and began three years’ worth of CBT.

One of the first things Beier taught Caulfield was how to stop focusing on what she couldn’t do. “We came up with a visualization of a dark cloud over me, and how it always blows away and sunshine comes through,” Caulfield says. Then they designed workarounds so the cloud didn’t appear as often.

“The goal is to not suppress your anger, but limit it,” Beier says. “Give yourself worry time or anger time — for instance, say, ‘I’ll let myself think about this for five minutes.’ Or tell yourself: ‘Now’s not the time to think about this. I’ll think about it at 5 p.m.’ That allows you to have thoughts but not ruin your day.”

They also worked on practical tips to deal with cognitive challenges, like setting alarms to pick up the kids from school. Caulfield also uses hourly alarms to help prioritize things that are good for her, like rest and exercise. And they instituted a “50% rule.”

“I was always so disappointed I couldn’t get things done,” Caulfield says. “So each day, I make a list of three to five things I want to accomplish. If I get 50% of that done, it’s a good day.”

Now, Caulfield feels at peace with her new job: taking care of herself and her family in their new home in Hawaii. “It’s taken me a long time to accept that,” she says. “It’s a slow process — there’s no magic fix. It requires patient engagement through CBT.”



PHOTO COURTESY OF KRISTIN CAULFIELD

Kristin Caulfield, diagnosed with MS in 2013, says that CBT helped her manage her anger.

## Handling pain, fatigue and sleep issues

After her 2007 exacerbation that left her with neurological pain, neuropathy in her hands and feet, and severe spasms, Lanz found that CBT helped with her depression and anxiety. And that in turn helped with her pain. “My perception of my pain levels dropped because I wasn’t focusing on it so much,” she says.

Ehde, who teaches eight-session CBT pain-management courses like the one Lanz took, says the key is educating people about how their thoughts, behaviors and emotions affect their pain, and vice versa.

“Pain is not a sensory phenomenon,” Ehde says. “For instance, say your arm hurts, and you think, ‘Oh no, here I go again. This pain is just going to get worse.’” That can trigger the “fight or flight” response to stress, in which your muscles tense up, your blood pressure rises and you become anxious. And that in turn can create more pain and suffering. But if you can alleviate that stressful thinking, you can change how your brain processes pain in ways that can reduce pain and suffering, Ehde says.

Ehde is currently enrolling people for a National Multiple Sclerosis Society-funded study on MBCT training for pain (for more information, visit [ntlms.org/paintrial](https://ntlms.org/paintrial)). The theory is that MBCT training can help you notice the pain, and then notice the reactions you have to that pain that are helpful or nonhelpful. Then you can disengage from the unhelpful reactions and respond with self-compassion. And that helps you relax, which lessens the pain.

Lanz learned to focus on what she could do — cook dinner, walk around the cul-de-sac — rather than what she couldn’t. She also learned to visually flush down the toilet worries like, “What if I can never walk again?”

## Participate in a CBT study

**Dawn Ehde, PhD, a clinical psychologist in the University of Washington Medicine Division of Clinical and Neuropsychology, is enrolling people for a National Multiple Sclerosis Society-funded study on mindfulness-based CBT training for pain (for more information about enrolling, visit [ntlms.org/paintrial](https://ntlms.org/paintrial)).**

“When I was out walking, I would look at the trees and say internally: ‘Stop and find something beautiful to think about. Be in the moment and don’t worry about the future,’” Lanz says.

Within a few months of practicing these types of CBT techniques, Lanz says she had alleviated most of her depression and anxiety about her pain. And within a year, she could automatically take control of any negative thoughts.

The same CBT exercises that deal with pain can also help with fatigue or sleeplessness. “By removing unhelpful thoughts, you can trigger the parasympathetic nervous system that brings the body to relaxation,” Ehde says. “And relaxation can improve fatigue.”

Lanz says this is particularly helpful when she wakes up in the middle of the night worrying about something and can’t get back to sleep.

“You can’t just take away the thought — you have to add something back in to fill the void, something that makes you feel calm,” Lanz says. “I say an affirmation over and over again. Or, something like a prayer, which I say one time: ‘Peace to my mind; let all my thoughts be still.’ It really works. It’s like putting your fingers in your ears and saying, ‘La la la la.’”

## Dealing with the uncertainty of MS

It wasn't until the third time a doctor told her she had MS that Robyn Roberts finally accepted her diagnosis. By then, she was having cognitive symptoms like not being able to find the right words or forgetting where she parked her car. She envisioned a future where she couldn't work at her job as an insurance counselor in Lexington Park, Maryland, and would become a burden on society and her family.

And then her worst fears came true.

In 2015, two years after Roberts finally accepted her diagnosis, her doctor suggested that because of her cognitive issues and chronic fatigue, she should quit her job. "My work was my life," says Roberts, who was only 34 at the time. "Without it, I felt like I was worthless."

Traditional CBT is based on examining negative or obsessive thoughts and figuring out whether they're valid. Often, they're not. But for people with MS, those thoughts may very well turn out to be true in the future.

For instance, the uncertainty of MS means someday you might not be able to walk without assistance or remember a friend's name. That's where more recent approaches to CBT, like ACT, can be useful.

"ACT works especially well with thoughts you can't prove or disprove," Molton says. "Your brain is trying to warn you of something bad in your future, but you need to examine whether that's useful information; whether you can act on it. If not, you may be better off just gently accepting the presence of that thought without trying to change it."

Molton is conducting a National MS Society-funded study on whether a form of CBT can help people who are newly diagnosed with MS cope with the

“ CBT gave me a different perspective. I think it's a beneficial but under-recommended tool for people with MS.”

—ROBYN ROBERTS



Robyn Roberts, diagnosed with MS in 2013, benefited from acceptance and commitment therapy (ACT).

PHOTO COURTESY OF ROBYN ROBERTS

uncertainty of the disease. He says the key when you have these types of thoughts is to compassionately accept them. “Thank your brain for warning you, acknowledge that you’re going to worry about the future and uncertainty of your disease, and then just let the thought pass.”

When fears about her disease get stuck in her mind, Roberts uses CBT-based coping skills that Beier taught her. “I’ve learned how to literally envision a stop sign and then take five deep breaths. It helps me stop when my brain won’t shut off.”

Roberts has also found that CBT helps her family. “No one’s walking on eggshells around me now that I can look at things from

different angles,” she says. “I thought maybe my husband and son would be happier if I just left. I assumed that my husband was thinking the same way that I was — that I was too needy because of my disease. But then I asked him, and he said that wasn’t true. That made me think about my disease’s effect on my family in a whole new way.”

Roberts knows she can’t control her disease. But she can control how she thinks and feels about it and how she behaves. “CBT gave me a different perspective,” she says. “I think it’s a beneficial but under-recommended tool for people with MS.” ■

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

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

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Research to stop disease progression, restore lost function and end MS forever

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## STEP BY STEP

10,000 steps a day is often touted as the goal for those looking to get more activity into their daily routines, but this number doesn't necessarily make sense for everyone. Your number can be whatever works best for your fitness ability.

To begin, track your steps on an average day to identify your baseline. Then, slowly increase that number each week. The Mayo Clinic recommends adding 1,000 daily steps each week, but if that's too many, choose a number that is challenging but still attainable for you. If walking is an issue, try spinning or swimming instead.

For more insights on how to stick to an exercise routine, turn to page 44 for the latest research on staying fit.

# Obstacle course

Researchers look for ways to help people with MS be more active.

by Lori De Milto

**P**eople living with multiple sclerosis who exercise regularly can feel better, move better and live better. But studies show that fewer than 20% of people with MS in the United States get enough physical activity to see these benefits. While exercise helps lessen depression, fatigue and difficulty walking, these symptoms also make it hard for people with MS to be more active. And a variety of other obstacles can prevent people from beginning an exercise program and sticking with it.

Exercise physiologist Robert Motl, PhD, explains that many people with MS “lack knowledge about how to appropriately and safely exercise. Some are afraid that exercise will worsen the disease.” Motl is associate director of research for the UAB/Lakeshore Research Collaborative and professor of physical therapy at the University of Alabama

at Birmingham. The cost of joining a gym or buying exercise equipment and having a safe and comfortable place to be active also can prevent people from being active.

Some groups face additional barriers as well, according to the studies. Some African Americans and other racial minorities with MS said they don’t have safe sidewalks in their neighborhoods for walking. Some minorities also said they don’t feel represented in exercise programs. “It shouldn’t be acceptable that you open an informational packet for an exercise program and you don’t identify with the people in it,”

says Dominique Kinnett-Hopkins, PhD, a research assistant professor in the Department of Physical Medicine and Rehabilitation at the Feinberg School of Medicine at Northwestern University.



Judy Boone, diagnosed with MS at age 40, says that exercising helps with her energy levels.

## Get moving

### For adults ages 18–64 with mild to moderate disability, at least:

- 30 minutes of moderate intensity aerobics twice a week
- Strength training for major muscle groups twice a week

A doctor, physical therapist or a trainer with experience working with people with MS can help you choose the right types and amount of exercise based on your MS symptoms.

#### Type

#### Frequency

##### AEROBIC EXERCISE

- Arm cycling
- Walking
- Leg cycling
- Elliptical trainer

Gradually  
work up to  
30 minutes

##### STRENGTH TRAINING

- Weight machines
- Free weights
- Cable pulleys
- Elastic resistance bands

10–15 repetitions  
of each exercise  
  
Gradually work up to  
doing this twice (2 sets)



SOURCE: CANADIAN PHYSICAL ACTIVITY GUIDELINES FOR ADULTS WITH MS

ISTOCK.COM: ORINOCO-ART

For children and teens with MS, lack of confidence in their ability to exercise and not setting goals are key barriers, according to research by Dr. E. Ann Yeh. Yeh is a professor of pediatric neurology at the University of Toronto. Yeh also is director of the Pediatric MS and Neuroinflammatory Disorders Program and senior associate scientist and a staff physician at the Hospital for Sick Children.

### Ways to make exercise easier

In their studies of exercise for people living with MS, these three researchers have found ways to overcome barriers and make exercise easier and more accessible. Motl suggests following the physical activity guidelines for adults with MS (see above), which call for aerobic exercise and strength training twice a week each. You can exercise at a gym or at home. But before starting to exercise, see your neurologist or primary care provider to make sure it's safe for you.

“Walking is the most popular form of aerobic exercise in people with MS. It has the most benefits for physical outcomes as well as cognitive outcomes and brain health,” says Motl. If you can't walk, try riding a stationary exercise bike. For strength training at home, Motl recommends resistance bands or even lifting a can of food in each hand.

“Small changes over time lead to great results,” Kinnett-Hopkins adds. “Start with going for a walk twice a week for five minutes or doing laps inside of your home. You may also order a resistance band and begin doing strengthening exercises at home.” Slowly increase how long and hard you exercise as you work toward meeting the guidelines.

For children and teens with MS, Yeh recommends decreasing screen time and increasing movement in everyday life. Ways to do this include taking the stairs instead of the elevator or walking to school instead of getting a ride. Social interaction also facilitates exercise.

“Find things to do with friends that will encourage you to be active,” like biking, skateboarding and dancing, Yeh says. Parents can help by providing a supportive and positive environment and leading by example.

### Improving knowledge about how to exercise

Helping people with MS learn how to exercise — and get encouragement from their doctors — is a key focus of Motl’s current work. He and his research team have found that people with MS want their neurologists to help them exercise. Neurologists are willing to do this, but they need training, tools and help from others. “We’re working on a framework for neurologists to help patients exercise safely,” says Motl. The framework will include training on how to guide patients in choosing the right types and amount of exercise based on their MS symptoms, and tools such as posters, pocket cards and patient handouts.

But many people living with MS don’t see a neurologist regularly. Primary care providers can also encourage exercise and provide resources.

Whether neurologists or primary care providers encourage exercise and provide the initial education, most doctors don’t have time for regular follow-up and support. Other healthcare providers and community support are needed to help people stay active over time. “Patients need resources to keep going,” Motl says. A nurse, for example, could provide more information about different ways to exercise or appropriate exercise programs. The Society’s services staff or community health providers can connect people with MS who want to exercise with resources to help them get started and continue to stay active. Find out more by calling 1-800-344-4867, or by emailing

**ContactUsNMSS@nmss.org.**

Motl’s research uses behavior change theory to help people living with MS learn skills and tricks to start and keep exercising. Through goal setting, action planning and self-monitoring, people can “see how much they’ve changed, and how easy it is to change,” he says. Motl also has worked on exercise guidelines, including the Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis.

### Exercise tailored to racial minorities

Kinnett-Hopkins began studying exercise in people living with MS when she worked in Motl’s research lab during college. “I fell in love with how exercise could be used to combat a disease we don’t have a cure for,” she says. Kinnett-Hopkins’ research focuses on how MS is different for African Americans and other racial minorities who may have a higher risk of poverty, social exclusion, discrimination and violence than other people. When she started focusing on this, little research was available on MS in such disadvantaged populations.

In one study of 40 African Americans, Kinnett-Hopkins found that participants wanted to see people like themselves in educational and motivational content for exercise programs. They also wanted to work with coaches who were African American and have faith-related content. Participants preferred weight/resistance training exercises and easy walking. Kinnett-Hopkins published these results in *Multiple Sclerosis Journal: Experimental, Translational and Clinical* in 2019.

Under a fellowship from the National Multiple Sclerosis Society (2019–2020), Kinnett-Hopkins is using data from the Chicago Area Patient-Centered Outcomes Research Network to identify the most disadvantaged people with MS in Chicago. Then she’ll compare their use of healthcare services and disease characteristics to that of people with MS who have more advantages and identify differences between the two groups. Kinnett-Hopkins will also assess the needs of disadvantaged people with MS, including for exercise. She hopes to identify neighborhoods where providing exercise and other MS programs can help the most people.

### More physical activity for children and teens

Yeh is developing and testing an app called ATOMIC (Active Teens with Multiple Sclerosis) linked to a Fitbit activity tracker that helps children and teens with MS be more active in their everyday lives. While group exercise programs for children and teens have shown benefits, it’s difficult for them to get to these programs.

Judy Boone's routine includes using an aerobic walking machine and twice-weekly strength training workouts.

**“ [Exercising has] given me a lot more energy to do the things I enjoy and take care of my family.”**

—JUDY BOONE

PHOTO BY RIKU FOTO

“We wanted to design something flexible that would enable kids to change their behaviors without requiring them to go any place,” she says. Yeh and her team used input from children and teens with MS when they designed ATOMIC.

A pilot study showed that kids were interested in using ATOMIC, and that the program was feasible. Fifteen children and teens with MS, with an average age of 16, participated in the 12-week study. They received coaching (a monthly call and weekly text messages) and education, and used the Fitbit to monitor their progress toward their goals. Participants could choose the type of physical activity that worked for them.

Suggested activities included skateboarding, scootering, dancing, throwing a frisbee, biking, hiking, taking the stairs and walking to school. Before each coaching call, participants increased their activity. Yeh calls thoughtful coaching “the secret sauce” to ATOMIC.

Based on the results of the 12-week study, the Society has funded a bigger three-year study of

ATOMIC at three centers: the Hospital for Sick Children, the University of Alabama at Birmingham and Children’s Hospital of Philadelphia. Fifty-six people with MS ages 11–21 will either receive the app and coaching on physical activity or a nutritional information program. Motl, who has helped Yeh develop clinical trials for children and teens with MS, will be part of the study at the University of Alabama at Birmingham. Much of Yeh’s other research focuses on wellness, physical activity and lifestyle in pediatric MS and other neuroinflammatory disorders. ■

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Lori De Milto is a Sicklerville, New Jersey-based freelance writer.

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

# ADVERTISEMENT



For adults.  
Not an actual patient.

## Slowing down active SPMS



### 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 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 (ECG) before you take your first dose of MAYZENT.

During the initial up dosing 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 up dosing. 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



means  
holding on to  
more moments  
like this



## The first and only pill studied and proven in active SPMS

In the overall study, nearly **3 out of 4 people taking MAYZENT®** showed no 3-month confirmed disability progression.\*

Talk to your doctor about holding on to more moments with MAYZENT. Visit [mayzent.com](http://mayzent.com) to learn more.

 **MAYZENT®**  
(siponimod) tablets  
0.25 mg • 2 mg

The effect of MAYZENT was significant in patients with active SPMS and not considered significant in patients with nonactive SPMS. SPMS=secondary progressive multiple sclerosis.  
\*74% of people taking MAYZENT, compared to 68% of people taking placebo.

- have diabetes
- have eye problems, especially an inflammation of the eye called uveitis
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your health care 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.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your health care provider about the best way to feed your baby if you take MAYZENT.

**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.

**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](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

**Please see Consumer Brief Summary on following pages.**

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## 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](http://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 (ECG) 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
- 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)
- body aches
- chills
- nausea

**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
- a blind spot in the center of your vision
- sensitivity to light
- unusually colored (tinted) vision

See **"What are 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
- 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 chicken pox or have received the vaccine for chicken pox. Your healthcare provider may do a blood test for chicken pox virus. You may need to get the full course of vaccine for chicken pox 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
- 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.
- 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.

Start your treatment with MAYZENT using the following titration schedule:

For the 1 mg daily maintenance dose:	Tablets a day
Day 1	1 x 0.25 mg tablet
Day 2	1 x 0.25 mg tablet
Day 3	2 x 0.25 mg tablet
Day 4	3 x 0.25 mg tablet
Day 5 and every day after	4 x 0.25 mg tablet

For the 2 mg daily maintenance dose, use the starter pack:	Tablets a day
Day 1	1 x 0.25 mg tablet
Day 2	1 x 0.25 mg tablet
Day 3	2 x 0.25 mg tablet
Day 4	3 x 0.25 mg tablet
Day 5	5 x 0.25 mg tablet
Day 6 and every day after	1 x 2 mg tablet

- 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
  - 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 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.

### 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?

Before opening:

- MAYZENT 0.25 mg and 2 mg tablets should be stored in a refrigerator between 36°F to 46°F (2°C to 8°C).

After opening:

- MAYZENT 0.25 mg tablets **in the Starter Pack** may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 week after opening.
- MAYZENT 0.25 mg and 2 mg tablets **in bottles** may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 month after opening.

**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.

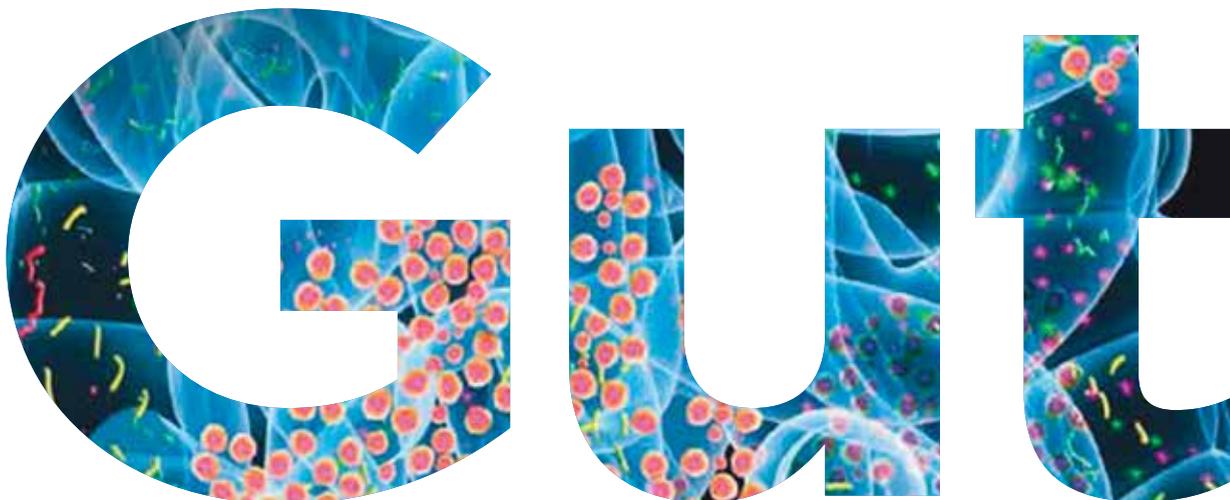
### What are the ingredients in MAYZENT?

**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.

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An update on microbiome research in multiple sclerosis and an in-depth look at the work the iMSMS is doing.

By Mary E. King, PhD

**H**ow do the bacteria that live in our gut affect the development and progression of multiple sclerosis? Sergio Baranzini, PhD, professor at the Weill Institute for Neuroscience at the University of California in San Francisco, is a founding member of the International Multiple Sclerosis Microbiome Study (iMSMS), a consortium of researchers that aims to answer this important question with a large study of the same name. Baranzini provides an update on the field of gut microbiome research in MS and an in-depth look at the work the iMSMS is doing.

### Why the interest in gut bacteria?

“We harbor as many bacteria cells in and on our body as our total number of human cells; that is, we are only about 50% human!” Baranzini stresses. So

far, he explains, researchers looking for MS risk factors have focused on the human genome, which includes about 25,000 genes. However, the gut microbiome, which contains all the genomes of all bacteria that reside there, includes about 1 million genes, far outnumbering our human gene pool. “What brought me into MS microbiome research from my background in human genetics is that we now know these bacterial genomes are tremendously diverse,” he says. “The fact that they code for so many times more genes than our human cells was surprising and exciting to me.”

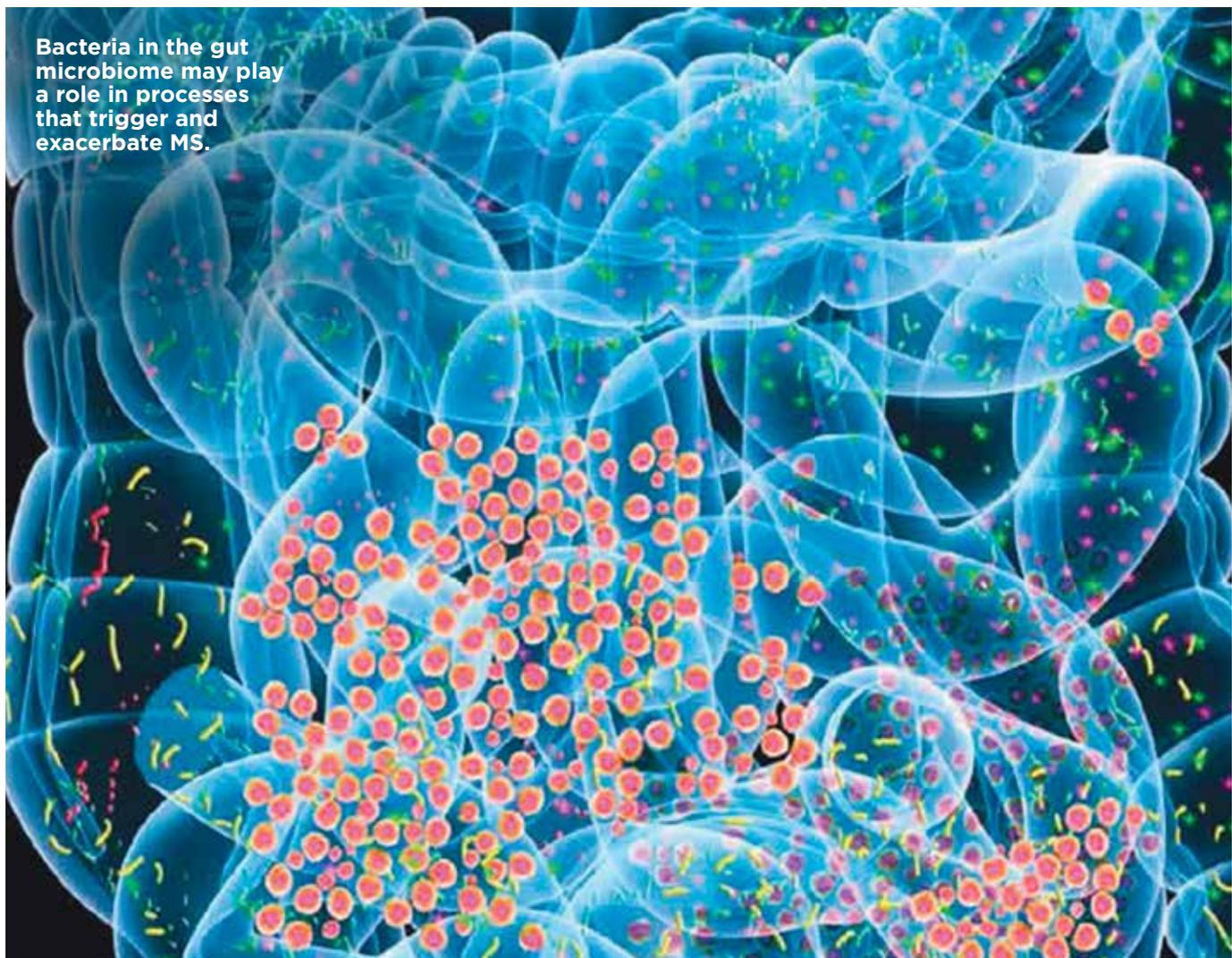
Previous research has shown that human gut bacteria definitely affect mouse models of MS (called EAE). For example, Baranzini demonstrated that transplanting gut bacteria

isolated from individuals with MS into mice raised in germ-free conditions produces worse EAE than using bacteria isolated from healthy individuals.

But how do bacteria from the gut affect the immune system and immune diseases like MS? “We know that the immune system comes into close contact with our intestinal flora in the gut where the immune system is affected — ‘educated’ — by the molecules that are released from these bacteria,” Baranzini explains. “We need to know what triggers MS, what exacerbates MS, and what perpetuates MS, and we think gut microorganisms play an important role in these processes.” We also have different bacteria in our guts in response to factors, such as our diet or whether we live in the countryside or an urban setting.

# check

Bacteria in the gut microbiome may play a role in processes that trigger and exacerbate MS.



ISTOCK.COM

Baranzini points out that this means our immune systems are being affected by these very same external factors through the changes they induce in our gut microbiomes.

### What is the iMSMS and what does it aim to do?

“Our research organization was created in 2013 as a small U.S.-based group, called the MS Microbiome Consortium, thanks in large part to funding from the National MS Society,” Baranzini says. “This Society program specifically awarded us money to start a new collaboration in MS research that otherwise wouldn’t happen. It stipulated that we include key researchers from outside the field of MS who could help spark new ideas and approaches among the group members.”

Society funding allowed the organizers to bring together experts in MS genomics, clinical care and research, neuroscience, microbiology and cutting-edge methods for identifying massive numbers of microbial species. “That was the beginning,” Baranzini says. “Without Society support, we couldn’t have obtained the preliminary data that enabled us to get further funding. We have now expanded to 12 research groups at 10 sites in North America, Europe and South America, and as our group expanded, we adopted the new name, International

MS Microbiome Consortium.”

The iMSMS objective is to recruit 2,000 patients worldwide and identify and sequence the DNA of their gut bacteria to create the largest microbiome study ever done in MS. “We are hoping this will be THE reference study for this subject and that our data and conclusions will stand for years to come,” Baranzini says.

### The iMSMS plan

The iMSMS has two main goals.

1. To establish a reference map of gut microbiome DNA in MS. “That’s why we are doing this large DNA sequencing project,” Baranzini explains.
2. To understand the role that the gut bacteria play in MS. He says iMSMS scientists are already making progress by taking certain specific bacteria that are present in stool samples from patients with MS and growing them with immune cells in the lab. This allows researchers to see how the immune cells are affected and may eventually help explain why and how some particular differences in gut bacteria influence MS.

Baranzini explains that it is difficult to control for environmental factors like diet or location when trying to compare the effects of the microbiome on a specific research question in MS. The iMSMS came up with a clever solution as part of the

study design. The research sites are recruiting household pairs, a person with MS and the person’s spouse or roommate, which provides a natural, matched control subject for each person with MS.

Researchers collect stool and blood from each participant. The different species of bacteria found in stool have distinguishing features in their DNA that can be identified by special types of laboratory techniques called DNA sequencing. Investigators purify DNA from bacteria isolated from stool samples and analyze it to determine which bacteria are present. (Some human cells are shed into the stool, and the gut also contains some fungi and other microorganisms, but 99% of the DNA will be from bacteria.)

The iMSMS is recruiting participants and collecting samples in a very rigorous and standardized way, “unlike many studies we and others have undertaken previously,” Baranzini states. “We are about halfway to our recruitment goal, which is exciting, but we need another two to three years to complete recruitment.”

### Hoping to translate research to treatment

“There is a lot to be discovered in how gut bacteria modify a person’s response to MS treatment as well as how they affect the availability of a treatment inside the body,

## Set of probiotic bacteria

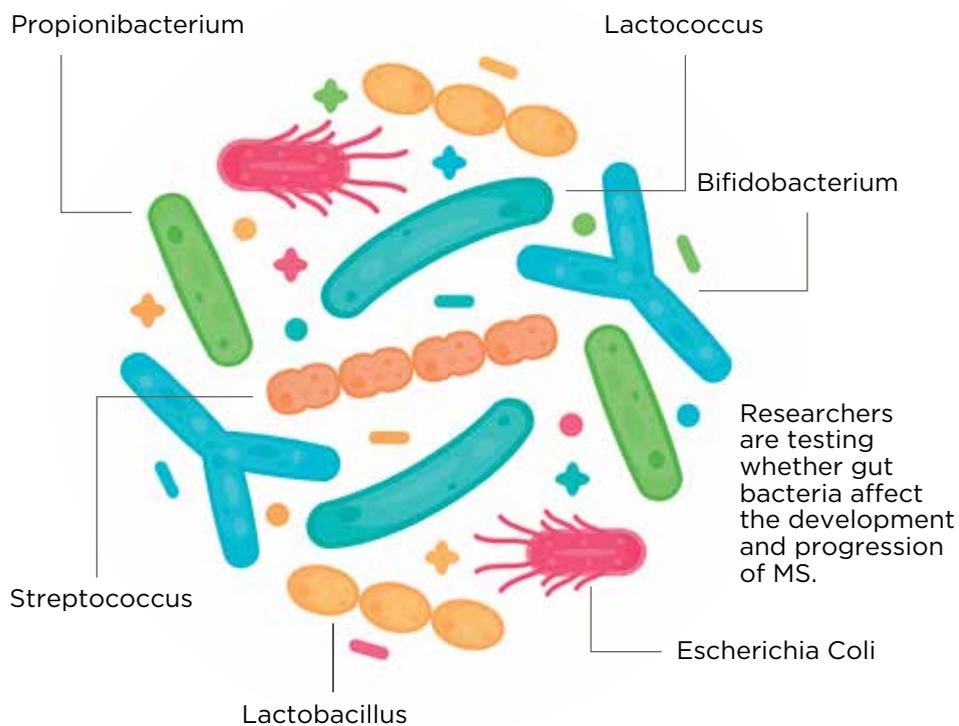
especially oral medications,” Baranzini says. He points out that cancer researchers have shown that the type of bacteria present in a patient’s gut can affect the response to a specific therapy. So it was natural to look at this question in people with MS, too.

Consortium researchers compared two groups of people with relapsing-remitting MS treated with different disease-modifying therapies (DMTs) and identified differences in the compositions of the gut microbiomes in the two DMT groups compared with the control group, known as the treatment-naïve group. These changes affected important pathways that alter vitamin, amino acid, energy and drug metabolism. This was just a first step in understanding the complex issues of interplay between the microbiome and treatment, Baranzini explains. The results underscore the need for more investigation in a large, well-controlled study.

Preliminary results from the first 256 participants (128 with MS and 128 controls) in the current large reference study were presented at the September 2019 meeting of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS).

### Can probiotics help?

Baranzini says that he is often asked about probiotics (such as yogurt or supplements)



and whether he can make any recommendations about them for people with MS. “Unfortunately, there is no strong evidence so far that any probiotics have any effect on MS. In the iMSMS we are recording probiotics as well as food intake, over-the-counter and prescription medications, supplements, etc. We hope to learn whether a certain probiotic has any effect on gut bacteria in individuals with MS and whether this has any positive or negative impact on the disease,” he explains.

Additional iMSMS results will be available in 2020. Full study results will take longer because recruiting participants

and doing the laboratory analyses are time-consuming. Baranzini is sympathetic to people with MS who need and want answers as soon as possible. “I understand the urgency of patients in understanding this question, and hopefully we will see new progress within the coming decade. Getting good, reliable answers takes large, responsible studies that then need to be verified. Unfortunately scientific progress proceeds at a slower pace than we would like,” he says. ■

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

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Care to comment? Email us at [editor@nms.org](mailto:editor@nms.org).

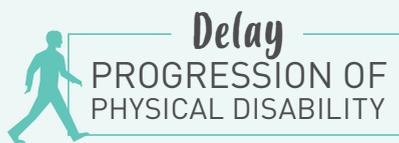
## ADVERTISEMENT



Laura S., living with relapsing MS

## Say **yes** to TECFIDERA—a pill that can **cut MS relapses**.

TECFIDERA is a pill shown to **work against relapsing multiple sclerosis (MS)** in **3 important ways**. TECFIDERA can:



### What is TECFIDERA® (dimethyl fumarate)?

- TECFIDERA 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
- It is not known if TECFIDERA is safe and effective in children under 18 years of age

### Important Safety Information

#### Who should not take TECFIDERA?

- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients

#### Before taking and while you take TECFIDERA, tell your healthcare provider if you have or have had:

- low white blood cell counts or an infection
- any other medical conditions

### Tell your healthcare provider if you are:

- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby
  - If you become pregnant while taking TECFIDERA, talk to your healthcare provider about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting [www.tecfiderapregnancyregistry.com](http://www.tecfiderapregnancyregistry.com). The purpose of this registry is to monitor the health of you and your baby
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your healthcare provider should decide if you will take TECFIDERA or breastfeed
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

### What are the possible side effects of TECFIDERA?

#### TECFIDERA may cause serious side effects, including:

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)

# opens up possibilities

- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your healthcare provider should do a blood test before you start treatment with TECFIDERA and while on therapy
- **liver problems.** Your healthcare provider should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your healthcare provider 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
  - have dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes
- **herpes zoster infections (shingles)**, including central nervous system infections
- **other serious infections**

#### The most common side effects of TECFIDERA 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 TECFIDERA with food 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 TECFIDERA may reduce flushing

These are not all the possible side effects of TECFIDERA. 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](http://dailymed.nlm.nih.gov).**

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This information does not take the place of talking with your healthcare provider about your medical condition or treatment.

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**Tecfidera**  
(dimethyl fumarate) delayed-release capsules 240mg



**Patient Information**  
**TECFIDERA®** (tek" fi de' rah)  
**(dimethyl fumarate) delayed-release capsules**

**What is TECFIDERA?**

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

**Who should not take TECFIDERA?**

- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients. See below for a complete list of ingredients.

**Before taking and while you take TECFIDERA, tell your doctor if you have or have had:**

- low white blood cell counts or an infection
- any other medical conditions

**Tell your doctor if you are:**

- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby.
  - If you become pregnant while taking TECFIDERA, talk to your doctor about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting [www.tecfiderapregnancyregistry.com](http://www.tecfiderapregnancyregistry.com). The purpose of this registry is to monitor the health of you and your baby.
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your doctor should decide if you will take TECFIDERA or breastfeed.
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

**How should I take TECFIDERA?**

- Take TECFIDERA exactly as your doctor tells you to take it
- The recommended starting dose is one 120 mg capsule taken by mouth 2 times a day for 7 days
- The recommended dose after 7 days is one 240 mg capsule taken by mouth 2 times a day
- TECFIDERA can be taken with or without food
- Swallow TECFIDERA whole. Do not crush, chew, or sprinkle capsule contents on food.
- Protect TECFIDERA from light. You can do this by storing the capsules in their original container.
- If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

**What are the possible side effects of TECFIDERA?**

**TECFIDERA may cause serious side effects including:**

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)
- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your doctor should do a blood test before you start treatment with TECFIDERA and while on therapy.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA 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
  - have dark or brown (tea color) urine
  - yellowing of your skin or the white part of your eyes
- **herpes zoster infections (shingles)**, including central nervous system infections
- **other serious infections**

**The most common side effects of TECFIDERA 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 TECFIDERA with food 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 TECFIDERA may reduce flushing. These are not all the possible side effects of TECFIDERA. 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](http://dailymed.nlm.nih.gov).**

**General Information about the safe and effective use of TECFIDERA**

- Medicines are sometimes prescribed for purposes other than those listed in this Patient Information. Do not use TECFIDERA for a condition for which it was not prescribed. Do not give TECFIDERA 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 doctor or pharmacist for information about TECFIDERA that is written for healthcare professionals.

**What are the ingredients in TECFIDERA?**

**Active ingredient:** dimethyl fumarate

**Inactive ingredients:** microcrystalline cellulose, silicified microcrystalline cellulose, croscarmellose sodium, talc, silica colloidal silicon dioxide, magnesium stearate, triethyl citrate, methacrylic acid copolymer - Type A, methacrylic acid copolymer dispersion, simethicone (30% emulsion), sodium lauryl sulphate, and polysorbate 80.

**Capsule Shell:** gelatin, titanium dioxide, FD&C blue 1; brilliant blue FCF, yellow iron oxide and black iron oxide.

Manufactured for: Biogen Inc., Cambridge, MA 02142, [www.TECFIDERA.com](http://www.TECFIDERA.com) or call 1-800-456-2255

# Tell it like it is

Practical tips for  
everyday living  
with MS

by Mike Knight



ILLUSTRATION BY MICHAEL MORGENSTERN

**Y**ou are about to begin your dream vacation — one you've put off for years due to anxiety about traveling with multiple sclerosis. Your plane has landed. A wheel from your wheelchair returns from baggage claim no longer round, but a sad oval instead.

Two hours into a five-hour long infusion, your need for the men's room is escalating into a "situation."

Barring a dramatic growth spurt, your balance issues and cane won't let you safely reach the deluxe mac and cheese mix on the top shelf of your kitchen cabinet. The package taunts you.

You've fallen. It won't be pretty, but you can get up. A small group of helpers who won't take no for an answer encircle you — Good Samaritan sharks coming in after the spill, unaware they're about to make matters worse.

MS and uncertainty go hand in hand. Mobility, balance, bowel and bladder issues, fatigue and cognitive problems all can present unexpected challenges that might be impossible to conquer on your own. Yet asking someone else for assistance isn't always easy either.

People living with MS and healthcare professionals alike weigh in on who to ask for help, when and how to tell others what you need so you can better manage the variety of situations you face every day.

### **Your favorite four-letter word: Plan**

"The good thing about MS is you have to plan," says Alexa Kane, PsyD, clinical health psychologist at the Mellen Center for MS Treatment at the Cleveland Clinic. "The bad thing about MS is you have to plan."

Though tedious (and no friend to spontaneity), a detailed plan, Kane says, will help you pinpoint where the going might get tough and anticipate the specific assistance you'll need to keep going if it does. "When it becomes challenging is when we aren't able to communicate our needs," Kane says, "or on the flip side, don't even know what our needs may be."

Besides identifying your needs, Kane says the planning process can help you develop more precise requests for addressing them. That precision helps limit the need for interpretation, which leads to better results and reduces frustration, stress and anxiety for everyone.

Asking for help buttoning your cuffs, for instance, is more specific than asking for help getting dressed, which is more specific than just asking for help. "We assume people will know," Kane says, "or if they are medical staff, they will know what we need, and I don't think that is necessarily true."

Kane recommends asking those who know your MS



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challenges — trusted friends, family, neighbors — for help thinking through your plan and identifying your needs.

### **When things get personal: Keep calm, be direct, carry on**

Some doctor's appointments are more intimate and personal than others, MS or not. Mobility and capacity issues, fatigue and frustration caused by MS can all make them worse. Getting undressed, into a gown and then dressed again, up and down

“There is always someone who is there for help. Don't be embarrassed.”

—CATHY KILER



from the exam table, even stepping onto the scales (as if you want to) may be hard without the right kind of help.

Cathy Kiler is a peer mentor at Independence Care System, a care management organization based in the Bronx, New York City, that helps about 400 clients with MS direct their care. Kiler, who was diagnosed with MS in 2000, recommends letting the doctor's office know the type of assistance you'll need — in detail — when you make the

appointment. If someone you trust can accompany you to the appointment, all the better.

You may also be more comfortable receiving that help from somebody of the same sex, a request that may be easier to make in person instead of over the phone. And if you're worried about making that kind of request, Kiler says, don't be.

“You go right for the desk and say, ‘Oh yes, I'm here for my annual but I have a problem with my mobility. I would prefer assistance from a female nurse or practitioner,’” Kiler says. “Yes, you can definitely ask for that because some people aren't comfortable.”

Kiler emphasizes using an assertive but not aggressive, direct approach when asking for help for all needs, great or small. Just don't chicken out.

“Do not hesitate to ask for help,” Kiler says. “That is the first and foremost thing. There is always someone who is there for help. Don't be embarrassed. Say, ‘I need some assistance please.’ And when you get that help, and this is what I tell everybody, say ‘thank you.’ No matter what.”

### **The end of flier's remorse**

Gina Emrich is the senior manager of customer accessibility at American Airlines, a new department “whose only focus [is] customers traveling with any type of disability.” She says the airline

serves 2 million passengers annually, and she's quick to point out that her airline and others have “lots of opportunity to improve in the space” while also noting airlines share best practices in an effort to improve.

According to Emrich, following a few key steps can reduce some of the turbulence you might experience while flying with a disability.

The first is letting the airline know that you have a disability when planning your trip. Though they are happy to make arrangements upon your arrival at the airport, letting them know in advance allows them to update your passenger record, which gets shared throughout your flights.

“That information is helpful for our reservations agents, for our gate agents, for our flight attendants on board,” Emrich says. “So we would have that information in a person's record, so that we know how best to help them.”

Let them know if you are bringing mobility devices such as scooters and wheelchairs; that will generate a special wheelchair bag tag and ticket that helps track your device. Emrich says most needs can be handled by the general reservationist, but for those that can't, a special assistance desk exists that can.

Finally, know that there is additional help when all else fails. Emrich says “Complaint

Resolutions Officers” (CROs) are trained to step in and keep you on your way and are located at every airport. And though airlines try very hard to handle mobility devices gently, Emrich says accidents do happen. Most airlines have staff wherever they fly to make things right (American’s is called the Global Repair Group). “They immediately get you another chair, and they work to repair your chair,” she says. “Some of them can repair it right there on site.”

Whatever you do, Emrich says, don’t go away mad. “Don’t just leave the airport in anger,” she says. “Let us know as soon as you know there’s something wrong with your chair, and we’ll get it going as fast as we possibly can to get it fixed or repaired or replaced.”

To find out more about a specific airline, try an online search using the keywords “ADA information” along with the airline’s name.

### How to avoid friendly fire

Sometimes, it’s easier to not ask for help. John Haupt was diagnosed with MS when he was 16 years old. Now 63, Haupt has lived the better part of his life managing his disease. To say he is an overachiever is an understatement. Though he uses a wheelchair, Haupt works out regularly and competes in road races with his hand cycle. He also learned how to wakeboard in 2019. Wakeboard? That’s a water sport in which a rider standing on a short board — the wakeboard — with foot bindings is towed behind a motorboat across its wake.

Haupt says he rarely asks others for help. He doesn’t have to. “Usually, they see me struggling with whatever,” he says, “and they just offer.” For Haupt, sometimes the bigger problem is getting people not to help.

It was winter and Haupt, who lives near Milwaukee, Wisconsin, was dead tired, sitting on the ground in a shopping mall parking lot as he struggled to get his wheelchair into his car. “I had to call out to some guy and have him come over and tell him, ‘Listen, it’s kind of hard to explain, but I’m unable to stand up, can you help me out?’”

But Haupt’s would-be assistant didn’t know how to help Haupt manage his weight and center of gravity while he got his feet under himself. “He wrapped his arms around me, it was like giving me the Heimlich maneuver,” Haupt remembers.

Haupt says he’s been there before.

“If you pick up a normal person, you just assist them and then they get to their feet. As long as you do 50% of the job, they can do the rest themselves,” he says. “Not so with me.”

“I tell people that if you want to help me, you’re going to have to do the whole job, you’re going to have to take my entire weight. I’ve got to get my feet under me before I can stand up.”

Haupt frequently waves their help off because it’s faster and easier. “I’m always thankful for the offer to help and I make it a point to say so. However, I usually don’t want to go through the process of teaching people how to help when I don’t really need help. My way of doing simple tasks may look difficult or awkward to others but, frankly, it’s a source of pride to be able to do them.”

### Take a hero, make a hero

But there’s also the flip side. “People love to be a hero, even if it’s for a moment,” says Yvette Rojas. “They love wanting to help someone else. And we don’t give people that opportunity as much as we ought to.”

Rojas should know. She was diagnosed with MS in 1989, 10 years after her father’s diagnosis. In time, she became her father’s primary caregiver and witnessed his MS-related challenges firsthand. She was also the co-founder of a grassroots comprehensive care MS center and is now the director of the Norton Neuroscience Institute Resource Center in Louisville, Kentucky.

Whether it’s help getting your wheelchair out of your car, counting your change back to you twice because you’re fuzzy-headed or tired, or just helping you up some steps, Rojas advises to just ask. “There are so many people out there that are kind and want to help,” she says. “Give them that blessing. Just ask someone for help.” ■

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Mike Knight is a writer in Indianapolis, Indiana.  
He was diagnosed with MS in 2013.

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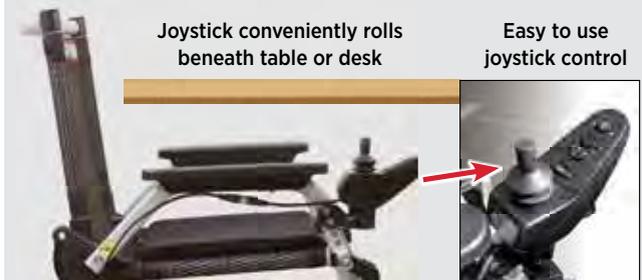
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# Steps in time

Walk MS has a long history and loyal participants.

by James Townsend

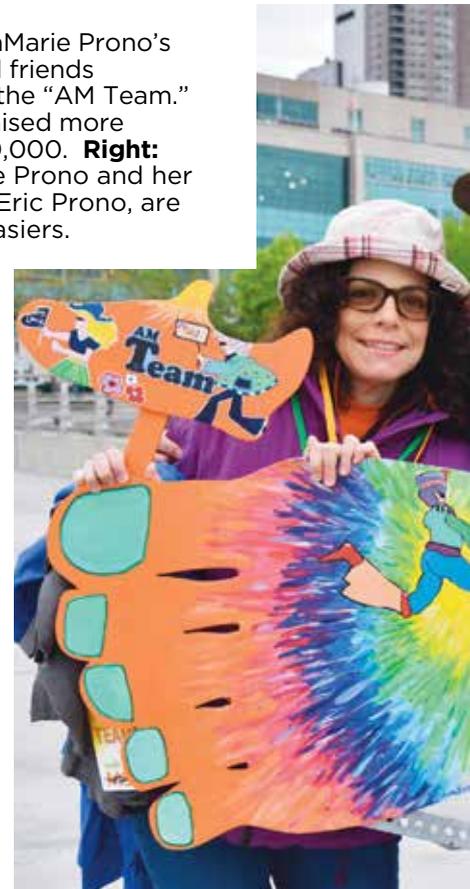
**W**hen she was diagnosed with multiple sclerosis 27 years ago, AnnaMarie Prono recalls, “My doctor told me, ‘We don’t have anything for MS. It’s an orphan disease because not enough people

have it for the pharmaceutical companies to invest in research. And it doesn’t have a good platform like Jerry’s Kids. (Comedian Jerry Lewis hosted the annual telethon for the Muscular Dystrophy Association for 45 years.)

“Well, that made me mad and I happened to see a poster on the subway about [the National Multiple Sclerosis Society’s] Walk MS, and signed up my mom, my sister and my cousin. We called ourselves the AM Team, and that’s what we’ve been ever since.”

For Prono, who lives in Forest Hills, Queens, in New York City, that first walk was a long one — about 13–15 miles, she says. “It was hard! We all had blisters, and we didn’t raise a lot of money that year.”

**Left:** AnnaMarie Prono’s family and friends comprise the “AM Team.” They’ve raised more than \$200,000. **Right:** AnnaMarie Prono and her husband, Eric Prono, are top fundraisers.



PHOTOS COURTESY OF ANNAMARIE PRONO

Since then, her team has grown to as many as 30 family members and friends and has raised more than \$200,000. “One year my husband made a giant wooden foot about four feet wide and a foot high and decorated it with Christmas lights. He’s carried it on the walk ever since.”

Since its beginning in 1988, Walk MS has become the 10th largest nonprofit series and the 13th largest nonprofit event in the U.S., according to Christine Wiley, marketing director for Walk MS and Challenge Walk MS. What began as 42,000 people at 42 sites, raising \$4 million, has grown to nearly 300,000 participants and volunteers at more than 350 locations. In 2017, the event surpassed \$1 billion in funds raised so that people affected by MS

can live their best lives as we seek a cure.

“Walk MS raises around \$38 million each year,” Wiley says. “It brings together communities from all walks of life. It funds MS research to find a cure as well as life-changing information and resources.”

Part of its success, she says, is that Walk MS is for everyone. The choice of a 1- to 3-mile route is so everyone can share a sense of accomplishment — and it’s fully accessible, not only to people who can walk unassisted, but also to those who use mobility aids of any kind. Prono is just one of several dedicated and passionate Walk MS participants who have been involved in the event for more than 20 years. Here are a few of their stories:

### Steve Oakes

Steve Oakes, 52, has participated in Walk MS every year since 1996, and these days he’s joined by his wife, two children, and his 2-year-old grandson in the Wilmington, North Carolina, Walk MS.

“My father had MS and died when I was 15,” Oakes says. “It was really painful watching him go downhill as the symptoms progressed year to year. Back then, there was very little in the way of medicine to help manage the disease. I believe the only thing that helped him was Valium. After that I felt that if there was anything I could do to help the cause, I needed to get involved.”

Then in 2003, Oakes himself was diagnosed with MS. But that hasn’t stopped him from participating in Walk MS.

“There have been a few years when the heat bothered me,” he says, “and in the beginning the walks were much longer. Now the one we do in Wilmington is about 3.5 miles, and we can manage that well.”

Another thing that continues to inspire him is the community support. It’s not really the money, but that they’re willing



Learn more about  
Walk MS at  
**WalkMS.org**



PHOTO COURTESY OF STEVE OAKES

Steve Oakes, diagnosed in 2003, has participated in Walk MS since 1996 to support his father, who also had MS.

PHOTO COURTESY OF CHERYL SCHACK



PHOTO COURTESY OF LYNNE KINDY



**Left:** Cheryl Schack’s family and friends first got involved with a Pooch Parade in 1998, which transitioned to the present day Walk MS. **Right:** Lynne Kindy (seated) has been volunteering for Walk MS for more than three decades.

to help. Some people even look for me every year to contribute.”

### Cheryl Schack

Cheryl Schack, now 73, was finally diagnosed with MS in 1987 after many doctors failed to recognize her condition. A longtime resident of Queens, New York, currently living in Westbury, Long Island, she got involved with the Society and its Pooch Parade in 1998, which eventually transitioned to the present day Walk MS.

“That was such a wonderful event with all the dogs,” Schack says. “I really miss it. And that first year we raised \$5,000 or \$6,000 with the help of our family and friends making contributions, no corporate sponsors.”

Since then she has taken part in both the Long Island and Manhattan walks, nowadays as a volunteer. “I always stay involved because I really believe people need to be educated about MS.”

The Long Island Walk takes place on Jones Beach, the largest beach on the island. Her team is named “The Cure,” and her son Neal serves as the team’s co-captain with his wife, Jennifer. “My grandchildren, Corey and Leah, have been participants since walking them in their carriages,” Schack says proudly.

“One of the things that inspires me most is meeting so many people who understand the disease, and all the spouses, partners, and relatives of the people with MS who walk to support them and the research,” she says. “I’ve made so many good friends over the years, a great group of folks.”

### Lynne Kindy

When Lynne Kindy was diagnosed with MS on her 31st birthday, she already had been looking around for

volunteer opportunities. “I just thought, ‘Well, it looks like this is what I’m supposed to be doing,’ so I found the MS Society and got involved with the walks.”

That was nearly three decades ago, and she has helped her local Walk MS event change and grow ever since, including currently serving as the event’s chair and part of the preplanning group. “There used to be walks in Flint and Saginaw [Michigan], but around 1994 we suggested that they be combined and moved to Frankenmuth. Our first year we nearly doubled the number of participants, and we actually did double the amount of money raised.” Today it’s Michigan’s second-largest Walk MS site. “Everyone knows that having MS is no fun, but as a result of being involved in this community I’ve met so many wonderful people over the years.”

Her team comprises many friends: coworkers at Team One Credit Union, and family including her 16-year-old daughter, Haley. “We’ve had as many as 100 people on the team, including volunteers,” Kindy says. “Even in lousy weather people come out in full force,” she says. “We’re getting ready for our 22nd year in Frankenmuth!” ■

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James Townsend is a writer in Boulder, Colorado.

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## INDICATION

AUBAGIO® (teriflunomide) 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.

## IMPORTANT SAFETY INFORMATION

### DO NOT TAKE AUBAGIO IF YOU:

- **Have severe liver problems. AUBAGIO may cause serious liver problems, which can be life-threatening.** Your risk may be higher if you take other medicines that affect your liver. Your healthcare provider should do blood tests to check your liver within 6 months before you start AUBAGIO and monthly for 6 months after starting AUBAGIO. Tell your healthcare provider right away if you develop any of these symptoms of liver problems: nausea, vomiting, stomach pain, loss of appetite, tiredness, yellowing of your skin or whites of your eyes, or dark urine.

**Do not take AUBAGIO if you have severe liver problems, are pregnant or of childbearing potential and not using effective birth control, have had an allergic reaction to AUBAGIO or leflunomide, or are taking a medicine called leflunomide for rheumatoid arthritis.**

Your healthcare provider will run certain tests before you start treatment. Once on AUBAGIO, your healthcare provider will monitor your liver enzyme levels monthly for the first 6 months.

- **Are pregnant. AUBAGIO may harm an unborn baby.** You should have a pregnancy test before starting AUBAGIO. After stopping AUBAGIO, continue to use effective birth control until you have made sure your blood levels of AUBAGIO are lowered. If you become pregnant while taking AUBAGIO or within 2 years after stopping, tell your healthcare provider right away and enroll in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2.

- **Are of childbearing potential and not using effective birth control.**

**It is not known if AUBAGIO passes into breast milk.** Your healthcare provider can help you decide if you should take AUBAGIO or breastfeed — you should not do both at the same time.

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**Before taking AUBAGIO, talk with your healthcare provider if you have:** liver or kidney problems; a fever or infection, or if you are unable to fight infections; numbness or tingling in your hands or feet that is different from your MS symptoms; diabetes; serious skin problems when taking other medicines; breathing problems; or high blood pressure. Your healthcare provider will check your blood cell count and TB test before you start AUBAGIO. Talk with your healthcare provider if you take or are planning to take other medicines (especially medicines for treating cancer or controlling your immune system), vitamins or herbal supplements.

**AUBAGIO may cause serious side effects, including:** reduced white blood cell count — this may cause you to have more infections; numbness or tingling in your hands or feet that is different from your MS symptoms; allergic reactions, including serious skin problems;

breathing problems (new or worsening); and high blood pressure. Patients with low white blood cell count should not receive certain vaccinations during AUBAGIO treatment and 6 months after.

Tell your doctor if you have any side effect that bothers you or does not go away.

**The most common side effects when taking AUBAGIO include: headache; diarrhea; nausea; hair thinning or loss; and abnormal liver test results.** These are not all the side effects of AUBAGIO. Tell your healthcare provider about any side effect that bothers you.

Consult your healthcare provider if you have questions about your health or any medications you may be taking, including AUBAGIO.

**You may report side effects to the FDA at 1-800-FDA-1088.**

**Please see Medication Guide for AUBAGIO on adjacent pages and full Prescribing Information, including boxed WARNING, available on [www.aubagio.com](http://www.aubagio.com).**



PILL ACTUAL SIZE

Once-daily  
**AUBAGIO**<sup>®</sup>  
(teriflunomide) 14mg tablets

## Medication Guide

**AUBAGIO** (*oh-BAH-gee-oh*)  
(teriflunomide)  
tablets

## Rx Only

Read this Medication Guide before you start using AUBAGIO and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

### What is the most important information I should know about AUBAGIO?

#### AUBAGIO may cause serious side effects, including:

- **Liver problems:** AUBAGIO may cause serious liver problems that may lead to death. Your risk of liver problems may be higher if you take other medicines that also affect your liver. Your doctor should do blood tests to check your liver:
  - within 6 months before you start taking AUBAGIO
  - 1 time a month for 6 months after you start taking AUBAGIOCall your doctor right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - loss of appetite
  - tiredness
  - your skin or the whites of your eyes turn yellow
  - dark urine
- **Harm to your unborn baby:** AUBAGIO may cause harm to your unborn baby. Do not take AUBAGIO if you are pregnant. Do not take AUBAGIO unless you are using effective birth control.
  - If you are a female, you should have a pregnancy test before you start taking AUBAGIO. Use effective birth control during your treatment with AUBAGIO.
  - After stopping AUBAGIO, continue using effective birth control until you have blood tests to make sure your blood levels of AUBAGIO are low enough. If you become pregnant while taking AUBAGIO or within 2 years after you stop taking it, tell your doctor right away.
  - **AUBAGIO Pregnancy Registry.** If you become pregnant while taking AUBAGIO or during the 2 years after you stop taking AUBAGIO, talk to your doctor about enrolling in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2. The purpose of this registry is to collect information about your health and your baby's health.
  - **For men taking AUBAGIO:**
    - If your female partner plans to become pregnant, you should stop taking AUBAGIO and ask your doctor how to quickly lower the levels of AUBAGIO in your blood.
    - If your female partner does not plan to become pregnant, you and your female partner should use effective birth control during your treatment with AUBAGIO. AUBAGIO remains in your blood after you stop taking it, so continue using effective birth control until AUBAGIO blood levels have been checked and they are low enough.

**AUBAGIO may stay in your blood for up to 2 years after you stop taking it. Your doctor can prescribe a medicine to help lower your blood levels of AUBAGIO more quickly. Talk to your doctor if you want more information about this.**

#### What is AUBAGIO?

AUBAGIO 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.

It is not known if AUBAGIO is safe and effective in children.

#### Who should not take AUBAGIO?

##### Do not take AUBAGIO if you:

- have had an allergic reaction to AUBAGIO or a medicine called leflunomide
- have severe liver problems

- are pregnant or are of childbearing age and not using effective birth control
- take a medicine called leflunomide

#### What should I tell my doctor before taking AUBAGIO?

##### Before you take AUBAGIO, tell your doctor if you:

- have liver or kidney problems
- have a fever or infection, or you are unable to fight infections
- have numbness or tingling in your hands or feet that is different from your MS symptoms
- have diabetes
- have had serious skin problems when taking other medicines
- have breathing problems
- have high blood pressure
- are breastfeeding or plan to breastfeed. It is not known if AUBAGIO passes into your breast milk. You and your doctor should decide if you will take AUBAGIO or breastfeed. You should not do both.

**Tell your doctor about all the medicines you take**, including prescription and non-prescription medicines, vitamins, and herbal supplements. Using AUBAGIO and other medicines may affect each other causing serious side effects. AUBAGIO may affect the way other medicines work, and other medicines may affect how AUBAGIO works. Especially tell your doctor if you take medicines that could raise your chance of getting infections, including medicines used to treat cancer or to control your immune system.

Ask your doctor or pharmacist for a list of these medicines if you are not sure.

Know the medicines you take. Keep a list of them to show your doctor or pharmacist when you get a new medicine.

#### How should I take AUBAGIO?

- Take AUBAGIO exactly as your doctor tells you to take it.
- Take AUBAGIO 1 time each day.
- Take AUBAGIO with or without food.

#### What are possible side effects of AUBAGIO?

##### AUBAGIO may cause serious side effects, including:

- See "**What is the most important information I should know about AUBAGIO?**"
- **decreases in your white blood cell count.** Your white blood cell counts should be checked before you start taking AUBAGIO. When you have a low white blood cell count you:
  - **may have more frequent infections.** You should have a skin test for TB (tuberculosis) before you start taking AUBAGIO. Tell your doctor if you have any of these symptoms of an infection:
    - fever
    - tiredness
    - body aches
    - chills
    - nausea
    - vomiting
  - **should not receive certain vaccinations during your treatment** with AUBAGIO and for 6 months after your treatment with AUBAGIO ends.
- **numbness or tingling in your hands or feet that is different from your MS symptoms.** You have a greater chance of getting peripheral neuropathy if you:
  - are over 60 years of age
  - take certain medicines that affect your nervous system
  - have diabetesTell your doctor if you have numbness or tingling in your hands or feet that is different from your MS.
- **Allergic reactions, including serious skin problems.** Tell your doctor if you have difficulty breathing, itching, swelling on any part of your body including in your lips, eyes, throat or tongue, or any skin problems such as rash or redness and peeling.
- **new or worsening breathing problems.** Tell your doctor if you have shortness of breath or coughing with or without fever.
- **high blood pressure.** Your doctor should check your blood pressure before you start taking AUBAGIO and while you are taking AUBAGIO.

The most common side effects of AUBAGIO include:

- headache
- diarrhea

- nausea
  - hair thinning or loss (alopecia)
  - increases in the results of blood tests to check your liver function
- Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AUBAGIO. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-332-1088.

**How should I store AUBAGIO?**

- Store AUBAGIO at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep AUBAGIO and all medicines out of reach of children.

**General information about the safe and effective use of AUBAGIO.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AUBAGIO for a condition for which it was not prescribed. Do not give AUBAGIO to other people, even if they have the same symptoms you have. It may harm them.

This Medication Guide summarizes the most important information about AUBAGIO. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about AUBAGIO that is written for healthcare professionals.

For more information, go to [www.aubagio.com](http://www.aubagio.com) or call Genzyme Medical Information Services at 1-800-745-4447, option 2.

**What are the ingredients in AUBAGIO?**

Active ingredient: teriflunomide

Inactive ingredients in 7 mg and 14 mg tablets: lactose monohydrate, corn starch, hydroxypropyl cellulose, microcrystalline cellulose, sodium starch glycolate, magnesium stearate, hypromellose, titanium dioxide, talc, polyethylene glycol and indigo carmine aluminum lake.

In addition, the 7 mg tablets also contain iron oxide yellow.

This Medication Guide has been approved by the U.S. Food and Drug Administration.

Genzyme Corporation  
Cambridge, MA 02142  
A SANOFI COMPANY

Revised: September 2019

TER-MG-SL-SEP19

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# Slam



Professional basketball dunkers thrilled the crowd as part of Dunk MS, a DIY fundraising event in Los Angeles to benefit youth basketball and MS research.

PHOTOS COURTESY OF BLAKE ARNET

# dunk

A son honors his mother with a sports spectacle for MS.

by Robert Lerosé



On May 4, 2019, the Palisades High School gymnasium in Los Angeles echoed with the squeak of sneakers and the thump of basketballs. But instead of opposing teams battling each other, the participants were raising awareness and funds for multiple sclerosis.

For the second consecutive year, the world's top professional basketball dunkers thrilled the crowd as part of Dunk MS, a DIY fundraising event to benefit youth basketball and MS research at the National Multiple Sclerosis Society, UCLA Health and Cedars-Sinai. The fundraiser was created by former UCLA men's basketball player Blake Arnet.

DIY events let people unleash their imagination to dream up and run captivating activities of their own to raise money for MS. "There's a whole gamut of DIY events that people come up with, but this event was truly unique to witness from its beginning stages to its implementation," says Katie LoBianco, Senior Manager of Leadership Events for the Society. "Blake showed that anyone can execute a great DIY event, but his passion and commitment took it to another level."

Arnet was a preferred walk-on at UCLA, earning a scholarship in his junior year. Three years earlier, in 2007, his mother, Brigitte, was diagnosed with MS. She died in July 2009. After graduating with a degree in sociology, Arnet pursued marketing and entrepreneurial positions, but his mother's loss affected him deeply. His family had participated in Walk MS and Bike MS events, but he wanted to do more.

"In 2017, I thought: Why don't I create my own event where we can raise as much money as possible, where we can utilize my skills, my network and create a big annual event? That fueled me to have this new life passion, this new mission to find a cure for MS," Arnet says.

A dunk or slam dunk — where a player leaps in a gravity-defying move, positions the ball above the rim and hurls it through the net — seemed like a natural and exciting spectacle around which to build the event. Reaching out to the close-knit basketball community, Arnet enlisted celebrated athletes such as fellow UCLA alumnus Jon Clark, former Harlem Globetrotter Chris Staples, rising dunking star Elijah Bonds and Kentucky’s 5-foot-10 basketball guard Guy Oliver to display their jaw-dropping talents.

“At first, I looked at it as just another event, but man — the kids, the energy, it was amazing,” Staples said in an interview with television station KTLA in Los Angeles. “To see that and to see them enjoy themselves is something I never take for granted.”

### Rising to new heights

At the May 2019 event, more than 70 kids took part in the morning basketball clinic, followed by a silent auction and free tacos, before the pros performed in front of more than 300 spectators. “We added a new challenge where we had the pro dunkers test their vertical leaps, so the crowd could see how high they could jump,” Arnet says. Guy Oliver soared 49 inches and hit his head on the rim. “[This] is unheard of. It got picked up on SportsCenter’s Instagram account and he blew up on social media,” Arnet says. “We got over 5 million views on our dunks.” The 2018 and 2019 events raised a combined \$80,000 — and raised awareness as well, particularly after Arnet spoke to the crowd about his mom.

“Blake and the organization are an extension of family. It enlightened us and exposed us to what MS is,” says Brandi Morgan, whose 13-year-old son had been coached by Arnet. Before Dunk MS, Morgan knew no one who had MS.

Morgan noticed that her kids became more aware of how other people might walk differently and would ask her whether they had MS. “It was an eye-opener and gave them a passion and understanding of what people go through,” she says.

The thing that stood out for Morgan though was how the dunkers handled themselves when they missed

shots. “They didn’t give up. They got back up and did it again. I think the kids saw their tenacity and how they kept trying. I know it’s a serious thing, but from what I’ve learned, there is life after MS. It affects everybody differently and it’s real, but you can still live,” she says.

Luciana Brafman-Bienstock, who helped Arnet with corporate sponsorships, saw how community action made an impression on her 13-year-old son Max. “For him, he could see that if everyone can do a little bit, you end up with a lot and you can help make change. If you’re passionate about something like Blake is, you can get amazing support from people.”

Dunk MS continues to grow. It will feature six professional dunkers in 2020. Arnet plans to bring Dunk MS to other cities and countries as an annual event. “My mom was my best friend. I didn’t get to say good-bye to her. It was so sudden the night we lost her,” he says. “That drives me every single day, to have a legacy for her, to help people and provide hope for everyone who has the disease now.” ■

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Robert Lerosé is a Long Island, New York-based writer.

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Learn how to host your own DIY event at [diyMS.org](http://diyMS.org).

To participate in Dunk MS, visit [DunkMS.com](http://DunkMS.com).



Follow Blake Arnet on Instagram  
@DunkMS  
@MSHeartofHope



Blake Arnet (center) with two lucky winners at Dunk MS 2019.

Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).

# Still unshakable

My mom's MS is many things.

by Kimberlee Zabawa

**“D**o you need anything?” my mom asks. We are shopping. And by shopping, I mean strolling up and down the aisles and shifting hangers, occasionally holding up some article of clothing — not because it's nice-looking, but because we delight in showing off our tackiest finds.

“No,” I respond.

She comes around the rack, stumbles

into the knitted sweaters, and steadies herself with a small smile.

“I'm drunk today,” she tells me.

“I see that.”

I step closer and link my arm with hers so she has something to lean on.

My mom is not drunk.

My mom was diagnosed with multiple sclerosis in 2004, when I was 10.

Kimberlee Zabawa and her mom, Penny Zabawa, who was diagnosed with MS in 2004.



PHOTO COURTESY OF KIMBERLEE ZABAWA

## fired up

Multiple sclerosis is, firstly, a storyteller. From the outside, it can look like anything. It can even look normal.

I think that's one of the reasons my mom doesn't use her handicap parking placard when we pull up at the next store.

"I'm fine," she says. "I don't need it."

The doctor disagrees. But he's not here to tell her she should save her energy when she can, regardless of how it looks when a fit-looking woman parks up front and walks into the store with no assistance.

I don't argue. No one's ever glared at me when I got out of my car because they didn't think I deserved to park there.

We don't use words like "handicap" and "disability." Not because we're scared of them, but because we don't need them. We live with MS. We're not afraid of anything. Except change.

Because MS is, secondly, a progressive disease.

"I went to the hospital the other day," my mom says like she was telling me she planted new flowers in the backyard.

I pause and wait. MS teaches you to be patient.

"My arm went numb," she continues. "I didn't know if it was a symptom or if I was having a heart attack, so I called your Granny, and she met me at the hospital."

MS is a tricky companion. You never know if you're experiencing a new problem or a new symptom.

"I didn't tell you because I didn't want you to worry. I was there a few hours, but they ran some tests and didn't find anything wrong with me. Or anything else wrong with me." She smiles that sneaky smile. "I have a funny," she announces.

I have a funny. I don't know why we say that. Maybe if we have a disease then we can have a funny, too.

I say "we" because MS is, thirdly, a family disease.

"So, I wasn't home when your daddy got home, and he was worried so he looked up my location through my phone's GPS. It showed I was at a hospital." She's laughing now. "He was just about to come look for me when I called to tell him I was fine."

I can imagine this. I see my dad sitting in that creaky chair in front of the computer. I can't see his expression



Kimberlee Zabawa (left) writes that her mother, Penny (right), "is an unshakable woman whose identity runs deeper than what the body can do."

clearly because of the glare on his large reading glasses. I decide it's funny, too — for the sake of my mental health.

"Do you need anything?" she asks again, still chuckling as we head to the front of the store. When my mom goes to pay, the cashier asks if she found everything she was looking for.

I try not to hold my breath as I count the seconds. One. She's processing the question. Two. I look at her face to see if she understands. Three. She is just distracted looking for her wallet.

"Yes, thank you," she answers.

I relax. Sometimes she doesn't understand. People have to repeat themselves a couple of times before she knows what they're saying. I'm always on guard, ready to repeat the question or answer it before anyone gets flustered. Sometimes, I think this hurts her the most. More than the pain the disease causes.

My mom is not stupid.

When we leave the store, I pick her up at the front door. A cane sits next to the passenger seat. She pushes it aside to get in the car. She never uses it. Wants to put it off as long as possible, to cherish the feeling of autonomy.

MS is, fourthly, a thief — of independence, and of the life you used to live.

She apologizes for being tired as we head home.

"Sorry your mom can't keep up with you."

We can't do a lot of things together, but we can do everything that counts. In the end, the debilitating power of MS is no match for what it must leave untouched — an unshakable woman whose identity runs deeper than what the body can do.

"Do you need anything?" she asks as we leave.

Rain is falling now even though a sliver of blue sky is peeking through the clouds.

"No, I have everything I need." ■

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Kimberlee Zabawa is a writer and editor in Atlanta, Georgia.

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Care to comment? Email us at [editor@nmss.org](mailto:editor@nmss.org).



MS is a  
lifelong disease.

I am  
**ready**  
for it.

**Wesley**

Taekwondo (Purple Belt).  
High school student.  
Diagnosed in 2015.

Hear Wesley's story at  
[nationalMSSociety.org/  
wesley](http://nationalMSSociety.org/wesley)



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