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forward

A note from the President & CEO

For many people, summer means creating lasting memories with those we love. That's true in my family, and every summer, we plan multigenerational activities so everyone can participate. Being together, sharing experiences, keeps us close. Sometimes it's challenging as we try to accommodate each individual's needs. It takes a bit of time and effort, but the results of bringing everyone together are worth it.

For many people with MS, the heat of summer can be an obstacle to spending time together. In this issue, you'll read stories about how to cope with heat intolerance, a common and often vexing symptom of MS. When you have the right information, strategies and tools in place, you can do more of what you want to do—and live a more powerful life.

This summer, I'll also be spending a lot of time thinking about how the National MS Society can be most effective so that people can live their best lives with MS. We will be putting the final touches on our strategic plan—the document that will guide us from 2016–2018 in identifying and accomplishing the Society's largest priorities for changing the world. It will be a road map, helping us to plan where we need to go, and how to mark our progress.

The most important part in developing this strategic plan has been the input we've received from people affected by MS. The National MS Society exists because there are people with MS, and we want to do something about that. Therefore, it's critically important that we understand what it means to live with MS—from the everyday occurrences to the most pivotal moments. We're doing that by learning about people's experiences and their emotional journeys, from prediagnosis to decades of living with the disease. With this understanding we can better connect people to the information, resources, people and experiences that can help them lead their best lives.

I'd love to hear your stories, your hopes and dreams, and your challenges. Reach out and let me know what you would like to see happen in the coming years.

The Society's strategic plan will be presented for a vote at our Annual Meeting of the Delegate Assembly this November, when volunteer leaders from across the organization come together to affirm our direction and commit to achieving our goals. I am striving to receive their enthusiastic approval. We will need everyone, working together, to achieve the most powerful results.

The work ahead of us will be difficult at times, but our focus on it will be steadfast—because I know that when we remain focused, we can do more to create lasting, meaningful change in the world. I'm looking forward to sharing our progress with you, as we move closer to creating a world free of MS. ■

Cyndi Zagieboylo

Cyndi Zagieboylo

> **"It's critically important that we understand what it means to live with MS—from the everyday occurrences to the most pivotal moments."**

@

Let me know your thoughts
about the Society's
future. Email me
at **cyndi@nmss.org**.

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SUMMER 2014

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PHOTO BY CHIP SIMONS

On the cover: Dave Bexfield, hiking in the foothills of Albuquerque, N.M., wears a cooling vest so he can continue to enjoy one of his favorite summer activities.

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thrive

Beating the heat

Sweltering temperatures can make MS symptoms worse. Give them the cold shoulder with these sizzling ideas. **32**

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You can still enjoy your favorite summer activities—with a little adaptation. **36**

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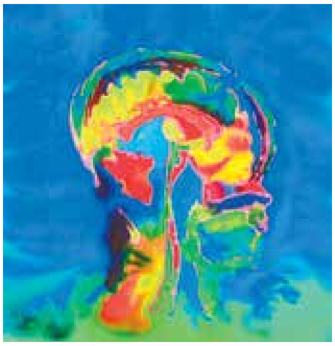

IMAGE BY ELIZABETH JAMESON

Artist Elizabeth Jameson reinterprets brain images.

Look for these icons throughout **Momentum**.

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The Content Advisory Team members provide input and feedback based on their unique and diverse experiences of life with MS. They are part of an international network of volunteers whose contributions and connections to the Society help bring us closer to a world free of MS.

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New guideline on emotional disorders in MS

The American Academy of Neurology (AAN) in January 2014 released a new clinical guideline, “Assessment and Management of Psychiatric Disorders in Individuals with Multiple Sclerosis.” To develop the guideline, a panel of experts reviewed and rated 115 research studies that met strict AAN criteria for methodological rigor—culled from thousands of research abstracts—to create recommendations for identifying, diagnosing and treating emotional disorders in individuals with MS.

This guideline is important because individuals with MS are at increased risk of emotional disorders, such as depressed mood, anxiety and pseudobulbar affect (PBA). If not detected and treated, these disorders can worsen functioning and quality of life and lead to other negative outcomes, including suicide.

Treatment findings

The panel found insufficient evidence in the research literature either for or against most types of cognitive-behavioral therapy (CBT) used for treating depressed mood or anxiety. One type—administered by telephone—was found to be possibly effective.

Similarly, there was not enough evidence in the literature either for or against the use of antidepressants for treating depressed mood. The panel found that a specific medication, dextromethorphan with quinidine (DM/Q), was possibly effective for treating PBA, an emotional disorder that occurs in up to 10 percent of people with MS. There was not enough evidence for or against other medications that are used for PBA.

The lack of conclusive evidence stems from several factors, says Dr. Sarah Minden, a psychiatrist and the lead author. First, while there is evidence supporting the effectiveness of pharmacologic and non-pharmacologic therapies for depressed mood and anxiety in the general population, many of these therapies have not yet been studied in people with MS. In addition, not all studies have broad relevance, such as those on telephone-administered CBT, because so few therapists use CBT in this way, she said.

“Our most important finding was that there are gaps in the literature and that so much more research is needed,” Dr. Minden added, noting that publishing the guideline might stimulate funding for new investigations.

Screening and diagnostic tools

The experts also found that some existing questionnaires are possibly effective for identifying individuals who may have emotional disorders common in MS. More research on new and existing screening tools is needed to improve identification of individuals with symptoms of emotional disorders who need further evaluation and treatment.

The panel concluded that, overall, more high-quality research is needed in each of these areas.

“The great news is that the American Academy of Neurology found that the topic of emotional disorders among people with MS was important enough to produce the guideline,” Dr. Minden said. “The other really good news is that we found evidence for things that do work, such as a particular type of CBT and one treatment for PBA. But the findings do beg for more research because they are just the tip of the iceberg.”

If you suspect that you are experiencing depression, anxiety or another emotional disorder, talk to your healthcare professional about treatments that can work for you, and call 1-800-344-4867 to talk to an MS Navigator for more support and resources in your area. ■

—Liza Berger

To learn more about the guideline, visit **nationalMSsociety.org/AANguidelines**.

For more information on mood disorders and treatments, such as CBT, see “Emotional Currents: The shifting tides of moods in MS” at **MomentumMagazineOnline.com**.

Emotional challenges and MS

Momentum's online survey last fall on mood and multiple sclerosis seems to have touched a nerve, with close to 2,000 readers participating. Respondents cited depression as the most common emotional challenge they have faced since being diagnosed with MS, followed closely by anxiety:

81 percent of readers said they have experienced depression since their MS diagnosis.

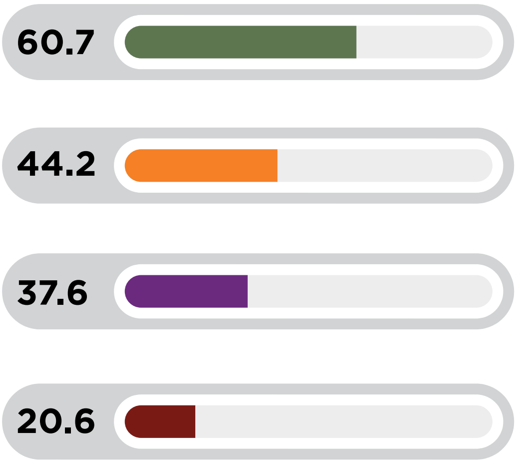
76.4 percent said they have experienced anxiety.

58.6 percent said they have experienced abrupt or inappropriate mood changes.

10.2 percent said they have experienced other challenges, such as frustration, anger, or uncontrollable crying or laughing.

For more information about mood changes in MS, call 1-800-344-4867 and ask for the Society's new book and DVD, **Cognition & Mood in MS: What You Can Do About It**, available later this summer.

Medication is the most widely used treatment option.



60.7 percent of respondents said they have used medication to manage these challenges.

44.2 percent said they have used exercise as treatment.

37.6 percent said they have used talk therapy.

20.6 percent said they have sought other options, such as talking with family members, reducing stress and considering self-medication.

More support for vitamin D

There is increasing evidence that vitamin D may help to reduce the effects of multiple sclerosis. Funded by the National MS Society and the National Institutes of Health, a team of Harvard researchers recently analyzed data on vitamin D intake and MS risk and progression that was collected in the BENEFIT study. This study evaluated the effectiveness of early interferon beta-1b (IFNB-1b) treatment in 465 people who had experienced a clinically isolating syndrome, or CIS, a single neurologic episode that indicates high risk for developing MS.

In the BENEFIT study, one group of participants received IFNB-1b immediately, while the other group received it later. All of the participants in the study had at least one vitamin D measurement taken, and 334 of them had two. Participants were followed for five years, and the Harvard researchers found that those who had higher blood levels of vitamin D, regardless of whether they were taking interferon treatments, had been less likely to progress to a diagnosis of definite MS. They also had a significantly lower amount of new disease activity, brain tissue volume loss and MS progression.

While this study offers more promise for the effects of vitamin D on MS, research in this area is ongoing. The study's researchers noted, "Further investigations are needed to determine the optimal levels of vitamin D and whether results apply to different races or ethnicities, to people with the secondary- or primary-progressive course of MS, or in combination with drugs other than IFNB-1b [interferon]."

A Society-supported clinical trial is currently underway to test whether vitamin D supplements, added to standard therapy, will benefit people with MS. People who have questions or concerns about their vitamin D levels should consult their doctors before taking any action. A blood test can determine vitamin D levels, if necessary. Visit **nationalMSsociety.org/vitaminD** for more information and the latest research. ■

—Andrew Conner

To learn more about the Harvard study, visit **nationalMSsociety.org/vitaminD**.

WEB EXCLUSIVES

Don't miss the bonus content online:

PHOTO BY CHIP SIMONS

Learn more about specific clothing and equipment to help you stay cool.

PHOTO BY PATRICIA LAY-DORSEY

View the photography of Patricia Lay-Dorsey, who lives with MS.

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Letters, thoughts and responses

From one carepartner to another

I've been married for 44 years and a carepartner for 18 years. Judy Stegman's story ("The still spot," Spring 2014) is mine. She is doing what I have been doing for quite a while, and I can understand her anger and frustration—the kind that no one can really relate to unless you're walking in our shoes. Imagine that the person you married and love is not the same, yet here you are—it's sometimes a very lonely place. Hopefully, we can all find our own ways of coping and allow some sunshine into our days. Thank you, Judy, for a wonderful and moving article that made me feel as if I have a soul mate in Colorado.

Jeannette Sturman, Maryland

Straight from the horse's mouth

Thank you so much for the article on hippotherapy ("Horse power") in the Spring issue of **Momentum!** I have had MS for at least 35 years and have participated in hippotherapy in two states for a total of almost 10 years. The benefits are exactly as given in the article—better muscle tone, improved balance and better overall outlook. The personal contacts, as well as those with the horses, are a huge plus. Hopefully the insurance coverage will become a reality so that more people can participate in this wonderful activity. Thanks to all the volunteers who make it possible!

Betty Gibson, Florida

IN THE NEXT ISSUE

Medical marijuana has staunch advocates—and opponents. Learn what the MS community has to say about it, and what the research shows.

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

Email us at **editor@nmss.org**.

Like and comment on our page at **facebook.com/nationalMSsociety**.

Tag your thoughts **@mssociety** using **#Momentum**.

Join discussions at **MSconnection.org**.

Corrections:

- "Know your deductions" (Spring 2014) contained incorrect information about the threshold for deducting unreimbursed medical and dental expenses. In 2014, they must exceed 10 percent of adjusted gross income.
- Ashlyn Snell was mistakenly identified as her mother, Carin Snell, in two photos in "A Step forward" (Spring 2014).
- Nicole James was the makeup artist for the photo shoot in the Spring 2014 issue featuring Shemar Moore and his mother, Marilyn Wilson-Moore.

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in the know

Day-to-day solutions for life with MS

Inside this section

Color your plate

Summer is a time of farmers markets and bountiful fruits and vegetables. Take advantage of them in recipes that don't heat up your kitchen. Learn how on p. 22.

Blowing hot and cold

In some circumstances, utility assistance can help people with MS stay cool—without breaking the bank.

by Maureen Salamon

When the temperature rises above 72 degrees, life changes radically for Kirk Williams. Like approximately 70 percent of people with multiple sclerosis who are sensitive to environmental heat, Williams endures worsening symptoms whenever the mercury surges, indoors or out.

"Being overheated results in an inability to think clearly, to do anything but close my eyes and rest," says Williams, 60, who was diagnosed with MS in 1999, six years after his symptoms began. "Heat makes a huge difference in my ability to function. Air conditioning isn't just a nice thing—it's something I need."

His sensitivity to heat propelled the Denver-area man to spearhead an intense legislative battle, along with National MS Society staffers in the Colorado-Wyoming area, when he learned in 2010 that Xcel Energy—the largest provider of residential electricity in Colorado—had instituted a tiered-rate system. Designed to reward electricity conservation efforts, tiered rates apply from June through September, and work on a graduated scale that charges increasingly higher rates to customers using more electricity—essentially penalizing people with MS who need to crank up their air conditioning each summer to keep heat-exacerbated symptoms at bay.

> **"Air conditioning isn't just a nice thing—it's something I need."**

"To a certain extent, tiered rates really punish the MS community," says Kara Hinkley, the Society's manager of Southeast Advocacy. "It's honestly dangerous. If people with MS forgo their energy needs, it may mean they're out of work because of an exacerbation, or that they can't pay for their medications because they're paying for utilities."

MS activists win exemption

After a three-year effort, the hard-fought legislation—Senate Bill 13-282—mandated Colorado's Public Utilities Commission (PUC) to offer medical exemptions to tiered rates for those whose health conditions require higher power consumption. In addition to MS, several other conditions either trigger heat sensitivity or require medications that, as a side effect, induce it.

Scheduled to be implemented this summer, the new law will permit a medical exemption to tiered rates for anyone in Colorado with a documented medical need, and an income of no more than 250 percent of the federal poverty level. This year, that equates to $29,175 annually for one person or $59,625 annually for a family of four.

Seeking a standard

All 50 states have their own version of a PUC, which regulates the utilities that provide essential services such as energy, telecommunications, water and transportation. PUCs must also approve any rate increases, but no national standard exists among PUCs to provide reduced rates or special pricing for people with medical conditions or income limitations, and some state PUCs may provide little if any relief for these groups.

California's PUC, however, goes as far as specifically mentioning MS in its policy, providing an increase in the amount of energy that can be charged at the lowest possible rate, called the "medical baseline allowance." Other states, such as Pennsylvania, offer energy assistance programs to help people experiencing medical emergencies or economic hardship to lower their energy usage or pay their bills. In Arizona, a federally funded program assists low-income households in paying their heating and cooling bills, with higher priority granted to those who are disabled.

Thanks to a successful legislative effort led by Kirk Williams, below, Coloradans who consume more power because of health conditions might be able to receive exemptions from tiered rates.

PHOTO COURTESY OF KIRK WILLIAMS

"Each PUC varies quite a bit on their programs for people with medical needs," Hinkley explains.

Breezy ways to save energy

Even if your state's PUC doesn't offer a break on utility costs, several easy measures can help keep your house cooler and save energy during the hottest months:

- Close window drapes and blinds or lower shades during the hottest part of the day to keep the sun from heating the room.
- Adding awnings to south- and west-facing windows can reduce solar heat gain by up to 77 percent, according to the U.S. Department of Energy. They cost around $200 per window, but the upfront expense may pay off in the long run, depending on your specific home configuration.
- Apply film on windows that reflects the sun's heat back outside.
- Avoid using heat-generating appliances at midday, including the dishwasher, stove, oven, washer and dryer.
- If you do have air conditioning, close the doors to unused rooms (if you have window units) or close air vents in unused areas (if you have central A/C) so you're not paying to cool empty space.

If you're in the market for a new air conditioning unit, the U.S. Department of Energy offers helpful information and guidelines for selecting energy-efficient models. Visit **energystar.gov** and select "Energy Savings at Home." Then click on "Heat and Cool Efficiently." ■

Maureen Salamon is a New Jersey-based writer. She has written for **The New York Times**, **CNN** and other major outlets.

Want to help create medical exemptions in your state? Call the National MS Society at 1-800-344-4867 to see what your state is doing, or to get involved.

Too hot to cook?

Delicious, low-effort recipes can deliver mealtime satisfaction and healthy nutrition—without heating up your house or your body.

by Elizabeth Yarnell, ND, CLT

What's the secret to preparing healthy, tasty meals in the heat of summer without making your kitchen—or your body—feel scorched? Don't be afraid to let some common appliances and prepackaged foods do the work for you.

Blending in

Consider the common blender. Sure, you've probably used it to whip up frothy drinks or smoothies in the summer, but you can also put your blender to good use making cold soups out of fresh produce. Try making a cold melon soup by blending cantaloupe with almond milk on low speed, along with a dash of cinnamon and nutmeg.

For a refreshingly creamy, cold cucumber soup with a bite, blend 1 English or other seedless cucumber with 1 pitted ripe avocado, ½ cup ice, 1 tablespoon white vinegar, ½ teaspoon of Asian wasabi powder (or substitute horseradish), and ½ teaspoon sea salt. Adjust the amount of wasabi and salt to taste, pour into four shallow bowls and top with chopped chives.

Gazpacho, another summertime favorite, comes together as easily as tossing veggies into a blender. While traditional gazpacho usually includes a base of tomatoes, garlic, salt and pepper, almost any other vegetable is fair game. Kale, cucumbers, carrots, celery, bell peppers, onions—whatever you have on hand can go into the pitcher. Switch the blender on until you like the texture—gazpacho can run the gamut from chunky to smooth, depending on personal taste—and serve in bowls or mugs. For a slightly spicy version, try the recipe at right.

Don't overlook other kitchen appliances that could be pressed into service to prepare easy and deliciously healthy meals without heating up the house. Broil fish in a toaster oven; grill chicken on an electric indoor grill; stew vegetables and meats at low heat in a crockpot; or steam grains, vegetables and meats in an electric rice steamer. Little appliances can do big jobs without generating a lot of heat in your home.

Package deals

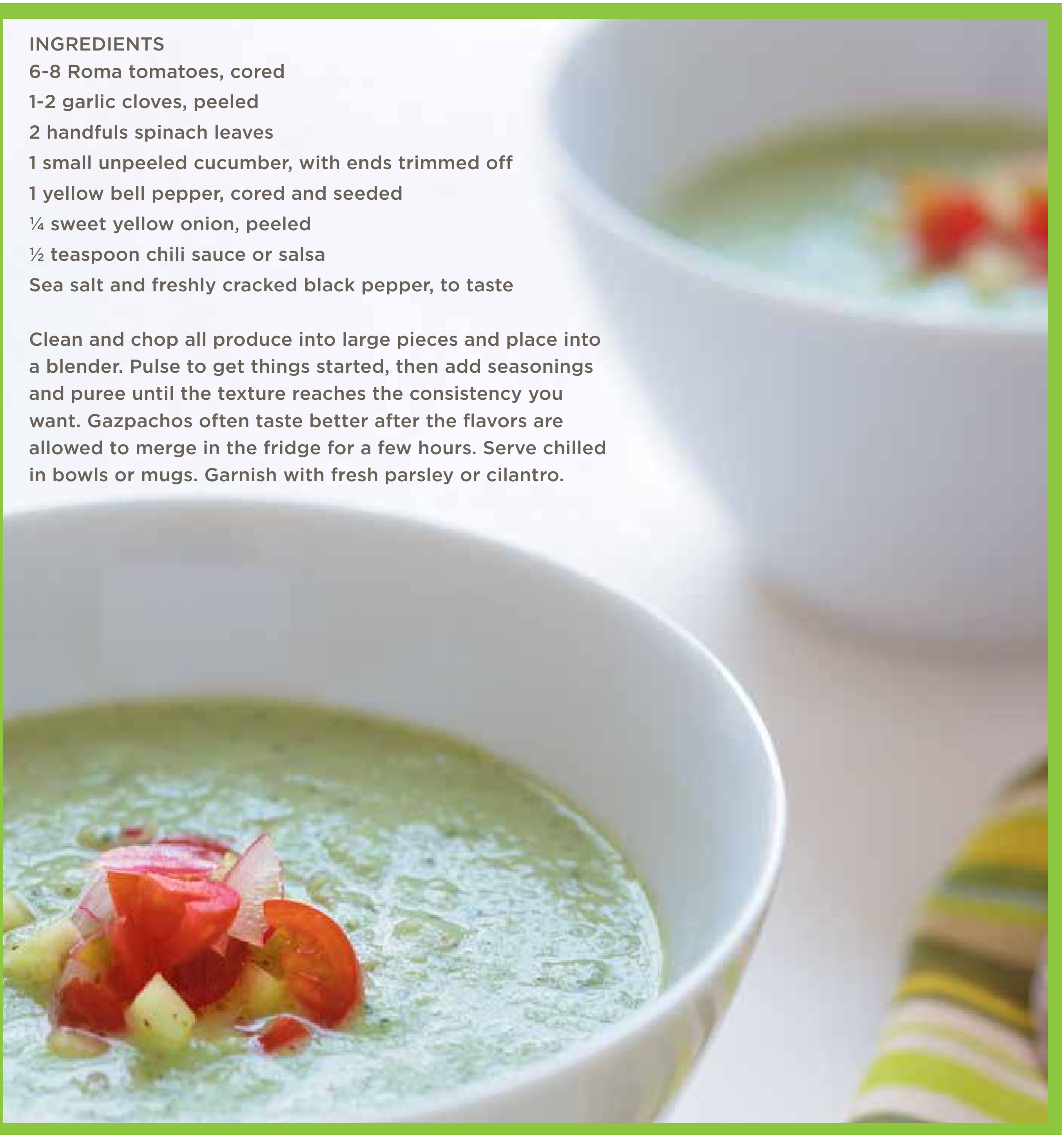
Prepackaged foods may cost a bit more but can save time and reduce heat generated by preparation. For example, a piece of salmon pulled from the fridge, whether smoked, cured or poached, can be a cool addition to a chopped salad or cabbage slaw. Purchase prepared salmon in vacuum-sealed packs from your grocer's cooler or from the fish counter; then, all that's left to do is open it and flake it onto your salad, or serve it with crispy rice crackers,

Cold gazpacho soup

INGREDIENTS

6-8 Roma tomatoes, cored
1-2 garlic cloves, peeled
2 handfuls spinach leaves
1 small unpeeled cucumber, with ends trimmed off
1 yellow bell pepper, cored and seeded
¼ sweet yellow onion, peeled
½ teaspoon chili sauce or salsa
Sea salt and freshly cracked black pepper, to taste

Clean and chop all produce into large pieces and place into a blender. Pulse to get things started, then add seasonings and puree until the texture reaches the consistency you want. Gazpachos often taste better after the flavors are allowed to merge in the fridge for a few hours. Serve chilled in bowls or mugs. Garnish with fresh parsley or cilantro.



diced red onion and a couple teaspoons of capers.

Craving pasta salad, but don't want to heat up the house boiling water? Use this energy-saving method of cooking noodles and the stove will only be on for a few minutes rather than the half-hour or more usually needed for cooking pasta:

Fill a pot with about half as much water as you would normally use, add a tablespoon of salt, cover with a lid and bring to a rapid boil. Add the pasta (penne, fusilli or rigatoni are good for salads), return the water to a boil, stir, and then cover and turn off the heat on the stove. Stir again a few minutes later and re-cover. The pasta should cook completely in 20 minutes or less. (Test it intermittently so it doesn't overcook.) Drain and rinse the noodles, and then place them in the fridge to chill until you are ready to toss the salad together.

Once the pasta is chilled, try adding cans of drained and rinsed beans, jarred artichoke hearts, grape tomatoes, thawed frozen organic green peas, or jarred roasted red peppers to add color, nutrition and interest without extra prep work. Toss it all together with your favorite Italian marinade or pesto from the supermarket.

If you're keen to make your own pesto, remember that it doesn't have to be made exclusively from basil. You can create a delicious pesto with a bunch of washed spinach or kale leaves, a handful of fresh basil leaves, a cup or so of shelled pistachios or walnuts, a couple cloves of peeled garlic, and olive oil, pulsed together in a food processor until it reaches the consistency of paste.

And pestos aren't only for dressing pasta. Slather some on a tortilla along with creamy goat cheese, roll it up and cut it into rings for a fun finger-food meal or snack. Or layer pesto onto deli-sliced roast beef on bread with sliced tomatoes for a summery sandwich that helps you stay full—and stay cool. ■

Do you have favorite no-cook recipes? Share them on **MSconnection.org**.

Elizabeth Yarnell, ND, CLT, is the author of the best-selling cookbook, **Glorious One-Pot Meals**. Connect with her at **ElizabethYarnell.com**.

Cool confections

Try this sweet, healthy treat to cool off in the heat of summer.

WATERMELON-MINT GRANITA

8 cups of watermelon chunks, rind and seeds removed

4 sprigs of fresh mint

1 lime, juiced

Sugar or honey to taste

Combine half the watermelon with half the mint and half the lime juice in a blender. Blend at low speed until pureed. Taste and add sugar or honey, if desired. Pour mixture into a 9″x13″ baking dish. Blend the other half of the ingredients and pour into the same baking dish.

Cover dish with plastic wrap and set into a freezer for two hours. Remove from freezer and uncover, then gently scrape all the ice crystals with a fork to break them apart. Cover and return to the freezer. Repeat every 2-3 hours until granita is thoroughly crystallized.

Serve in dessert glasses garnished with mint leaves or lime wedges.

Summer slumber

by Matt Alderton

People with MS often have trouble sleeping. In the summer, when the days are hotter and longer, it only gets worse. Here's help.

Sleep is sacred.

According to the National Institutes of Health, shut-eye is mission-critical for the human body, influencing everything from metabolism and immunity to cognition and mood. Without a good night's sleep, people have difficulty focusing, reasoning and problem-solving; they also can become irrational and irritable. In the event of long-term sleep deprivation, people are prone to depression, weight gain and accidents, as well as chronic conditions such as diabetes and heart disease. Clearly, sleep disturbances can be serious. But on a hot summer night—particularly for people with MS who are already sensitive to heat—the prospect of nodding off can feel like a pipe dream.

Restless sleep

People with MS have a higher risk of sleep disorders than the general population, according to Dr. Rock Heyman, associate professor of neurology, director of the MS Center and chief of the Division of Neuroimmunology/Multiple Sclerosis at the University of Pittsburgh Medical Center. "Nobody has done the perfect study comparing 1,000 people with MS to 1,000 people without the disease, but the impression from those of us who treat MS and pay attention to sleep is that there are an awful lot of sleep problems out there in the MS community," he says.

Many people with MS seem to struggle year-round with true sleep disorders, such as sleep apnea (periodic interruptions in breathing) and periodic limb movement disorder (a cousin of restless leg syndrome).

"Sleep apnea may occur more frequently in people with MS because they tend to be less physically active; they're fatigued and have trouble walking, which causes them to gain weight [a common risk factor for sleep apnea]," says Dr. David Brandes, a neurologist at Hope Neurology Center in Knoxville, Tenn., and assistant clinical professor at the University of California Los Angeles School of Medicine. And, Dr. Brandes adds, some studies have shown that periodic leg movements occur in people with MS at nearly twice the rate of the general population.

> **"When MS patients get hot, it makes their MS symptoms worse. If your MS symptoms are worse, certainly that can disturb your sleep."**

MS on the mattress

In addition to these disorders, MS itself can ruffle bed feathers. Some MS-related symptoms, like anxiety and pain, can make falling asleep more difficult, Dr. Heyman says, while others can make it harder to stay asleep, preventing the body from entering the most restful stage of sleep, known as delta or slow-wave sleep.

"Depression and incontinence, for instance, can certainly cause people to wake up well before their alarm, even though they're not refreshed," he explains.

Dr. Heyman says some medications used by people with MS, such as interferons, steroids and stimulants, can create a vicious cycle. "If you take interferon injections [which can cause flu-like symptoms as side effects], your doctor may say, 'Take them at night so they don't bother you during the day.' But then you don't sleep well because you have aches and pains at night from the interferon." The resulting sleeplessness can exacerbate MS-related fatigue the following day.

Managing seasonal insomnia

Sleep disruptions can occur all year round, but summer is an especially difficult season for some sleep-challenged individuals.

"When MS patients get hot, it makes their MS symptoms worse," explains Dr. Brandes. And, he says, "If your MS symptoms are worse, certainly that can disturb your sleep."

Discuss sleep concerns with your doctor, who may recommend a sleep study or sleep diary to determine the source of your problems, or possibly recommend medication. Your physician also can help you address lifestyle issues such as diet, exercise and stress—all of which can impact sleep quality—and rule out other sleep-disruptive conditions, such as diabetes. ■

Matt Alderton is a Chicago-based freelance writer.

Trouble sleeping? Check out these Society videos: "Getting a Good Night's Sleep with MS" at **ntl.ms/MSsleep1**, and "Managing Pain and Sleep Issues in MS" at **ntl.ms/MSsleep2**.

Sleep soundly

Tips for staying cool at night

1

Chill out: Try a cooling vest, neck wrap or cap, or even a cold shower or bath an hour or so before bed to bring down your core temperature, Dr. David Brandes suggests.

2

Keep your bedroom cool: "If you don't have whole-house air conditioning, try to at least have an air conditioner or ceiling fan [where you sleep]," Dr. Rock Heyman says. Keeping blinds and shades closed during the day can help keep rooms cool.

3

Dress right: "Wear lightweight, loose-fitting pajamas," advises Kathleen Costello, MS, ANP-BC, MSCN, associate vice president of Clinical Care for the National MS Society's Advocacy, Services and Research Department. For bedding, she suggests that people with MS avoid synthetic fabrics, which tend to trap perspiration, and opt instead for natural fibers like cotton, which wick away moisture and permit greater air circulation.

4

Start early: The best way to keep cool at night might be to monitor your temperature during the day. "Because heat exposure during the day makes most MS symptoms worse, often by the end of the day you feel really crummy," Costello says. "Really, your best bet is to be proactive about addressing heat intolerability early and throughout the day."

thrive

Strategies for living well with MS

Inside this section

Happy trails

For people with MS, hot summer days can be anything but carefree. Learn why—and what you can do about it—on the next page.

Dave Bexfield's wife, Laura, carries a portable stool on their hikes so Dave can rest on the trail. Read more about ways to keep having fun in the sun, beginning on p. 36.

PHOTO BY CHIP SIMONS

Beating the heat

Sweltering temperatures can make MS symptoms worse. Give them the cold shoulder with these sizzling ideas.

by Vicky Uhland

> "My No. 1 weapon to deal with the heat is decaffeinated, ice-blended coffee beverages. Nothing makes a bigger difference in cooling me down."

Bambi Lint's family and friends often urge her to go outside and enjoy the fresh air on hot summer days. "They'll say it's just for a little while, but they don't understand that even a little while can be too long," says Lint, an Appleton, Wis., jewelry designer and gardener who was diagnosed with multiple sclerosis in 2001.

Lint started noticing problems with heat the first summer after she was diagnosed. "I was building a rock garden for one of my neighbors and the fatigue hit me like a brick. The heat caused so much spasticity and weakness in my legs that I just couldn't go on anymore," she says. "And it seems to have gotten worse every year. Now, if I'm outside and the sun is pounding on me and it's warmer than 75 degrees, I can't last more than 15 minutes."

Heat intolerance is such a pervasive symptom in people with MS that the "hot bath" test used to be one of the main ways of diagnosing the disease. In the 19th and early 20th centuries, doctors immersed people whom they suspected had MS in water that was around 105 to 110 degrees. If neurologic symptoms appeared or worsened, the doctor concluded that the patient did indeed have the disease.

With the advent of magnetic resonance imaging, spinal taps and other modern-day diagnostic tools, the hot-bath test has become an antiquated anecdote. But that doesn't mean that heat sensitivity is any less of an issue. Researchers estimate that 60 to 80 percent of people with MS have a temporary worsening of their symptoms when they become overheated. In a 2004 international survey of more than 2,500 people with MS, 70 percent reported that heat worsened their MS symptoms. And a 2011 Swedish study of 265 people with MS found that 58 percent had heat sensitivity that significantly increased their fatigue, pain, concentration or urination urgency.

Raising the thermostat

Known as Uhthoff's phenomenon, after the physician who first discovered it in 1889, heat sensitivity affects people

ILLUSTRATIONS BY STUART BRIERS

with MS and other demyelinating diseases. Basically, says Teresa Frohman, PA-C, who co-authored a 2013 paper published in **Nature Reviews Neurology** on Uhthoff's phenomenon, as little as a half-degree increase in body temperature makes it harder for nerve impulses to operate normally. "Heat changes the amount of energy the body needs to keep the nerve impulses going," she says.

This in turn creates pseudoexacerbation—a temporary worsening of physical and cognitive symptoms. So people who experience weakness, fatigue, balance issues, spasticity, blurred vision, concentration problems, memory difficulties or other MS symptoms are likely to feel them more acutely if their body temperature is raised, whether due to heat, exercise, fever, infection, or even psychological stress or, for women, menstruation.

The good news is that a pseudoexacerbation is not the same as a relapse and disappears once the body's temperature reverts to normal. "It's usually very short in duration—less than 24 hours—and totally reversible," says Frohman, who is a clinical specialist at the Multiple Sclerosis Clinic at the University of Texas Southwestern and co-author of the National MS Society's book, **Multiple Sclerosis for the Physician Assistant**.

But knowing that it's not permanent doesn't make a pseudoexacerbation any less real or distressing when it's happening. "I may be feeling great, and then I go outside in the heat and do some planting in the garden, and bam! I can hardly move," Lint says. "The heat exacerbates the fatigue and other symptoms and nearly incapacitates me. One of the most frustrating parts is there are no warning signs. What I could tolerate yesterday, may or may not be the same as what I can tolerate today."

Understanding the thermostat

Evidence suggests that heat sensitivity becomes more common as the disease progresses, but researchers aren't sure why some people with MS are relatively unaffected by hot temperatures. And while many people with MS report that the old adage "it's not the heat; it's the humidity" is particularly true for them, Frohman says there's no scientific evidence that high humidity exacerbates MS symptoms more than high heat. It is true, however, that when humidity is high, sweat does not evaporate as efficiently, so it has less of an ability to cool the body. So people may perceive that their symptoms are worse.

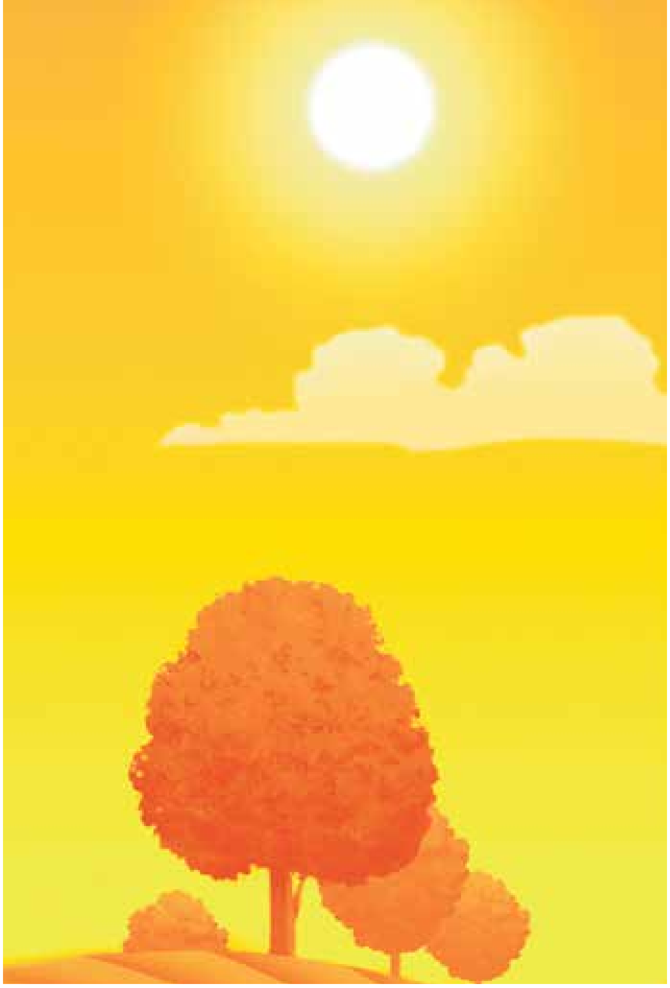
Frohman says people with MS may be particularly affected by heat because they tend to have resting body temperatures that are lower than the usual 98.6 degrees. "In our patient population of over 5,000, we've discovered that the average temperature is 96.9 to 97.5 degrees, so someone presenting at 99 degrees could actually have a fever," she says. A 2010 paper published in the **Journal of Applied Physiology** reported that this may be because MS affects areas of the brain and nervous system that regulate core body temperature.

This faulty internal thermostat may also affect the body's sweat glands, according to the study. The researchers found that people with MS don't tend to perspire as much as the rest of the population, which can lead to overheating because sweat helps the body cool itself. In addition, the researchers noted that people with MS-related bladder problems may restrict how much they drink, which also reduces sweating.

Certain treatments can increase or decrease heat sensitivity as well. People who take anticholinergic medications—a specific type of treatment sometimes used for bladder issues in MS—may have reduced sweating, Frohman says. Conversely, potassium-channel blockers such as 4-aminopyridine, or 4-AP, which are taken for relief of many MS symptoms, may improve heat-related fatigue or cognition problems. Frohman says she and her colleagues have found that Ampyra, a type of 4-AP approved by the Food and Drug Administration for gait-related issues, is also effective for Uhthoff's phenomenon, although it's not specifically approved for that use.

Lowering the thermostat

The faster you decrease your body temperature, the faster you reduce the accompanying symptoms. Frohman says the body has numerous points that act as heat conductors, so it doesn't matter which one you choose to cool—targeting your wrists and neck, for instance, is no less effective than focusing on your core. Here's a look at the most efficient ways to lower your body temperature, from the tried-and-true to the novel.



TIMING IS EVERYTHING

Lint loves to garden, but knows that even in the relatively cool Wisconsin summers, she can fight off fatigue longer if she does her planting and weeding closer to dawn and dusk. If she works in her garden from 6 to 7 a.m., she'll have enough energy left over to do another half-hour stint shortly before the sun goes down. And if she focuses on beds that are in the shade, she can last twice as long as she would tending a sunny plot. If she does get overly fatigued, she lies in shade on the cool soil until she can safely move again. "And I make sure my husband is home to help me inside if I need it," she says, because balance issues are her primary heat-related symptom.

Lint doesn't always follow her own rules perfectly, though, and sometimes finds herself exposed to the noontime sun. She's a big baseball fan and likes to attend games but makes sure to take her wheelchair in case the heat leaves her overly fatigued. For activities where restricting others' views isn't an issue, umbrellas can provide portable shade—and some even have UVB and UVA protection to block the sun's rays.

■ YOU ARE WHAT YOU EAT—AND DRINK

"My No. 1 weapon to deal with the heat is decaffeinated, ice-blended coffee beverages; nothing makes a bigger difference in cooling me down," says Michael Gerber of Los Angeles. Gerber, who has secondary-progressive MS and has used a wheelchair for almost four years, says high temperatures cause overall weakness and an inability to lift his arms, but Frappuccinos and similar drinks "reduce my symptoms almost instantaneously. All my friends know to call before they come over and ask, 'Does Michael need a drink?'"

Cold beverages are a great way to cool down, says Ashley Uyeshiro, OTD, OTR/L, assistant professor of clinical occupational therapy at the University of Southern California. Gerber is smart to choose decaf, she says, because caffeine and alcohol are diuretics that can reduce sweating. They also decrease the overall water content in your body, impeding your body's ability to regulate its temperature. Ideally, ice water is the best coolant, Uyeshiro says, because it's free of non-nutritional additives like sweeteners, and doesn't require energy expenditure to digest. Sports drinks aren't really necessary, because, although they replace electrolytes you may lose from sweating, everyone but hardcore athletes can get those lost nutrients from food, she adds.

Uyeshiro says chilled foods like yogurt, hummus, sherbet, juicy fruits, and frozen grapes or blueberries help you feel cooler but generally don't drop your body temperature as quickly as water. She recommends eating smaller, more frequent meals rather than a heavy meal that makes you feel sluggish.

■ CHILL OUT

Air conditioning is often the most powerful—and expensive—way to make summer heat bearable for people with MS. If you can't afford it, check with your utility company, Uyeshiro says; some offer rate discounts if you have a note from your doctor. (For more information, see "Blowing hot and cold" on p. 20.) In addition, air conditioning units or systems may be covered under your health insurance or could be deductible on your taxes, so check with your insurer and accountant.

In the workplace, you can ask for an office with an individual thermostat, or for a fan or air conditioner at your workstation, according to the Job Accommodation Network. You can also ask your employer for flexible scheduling or the ability to work from home on particularly hot days, especially if you have a long commute.

To avoid stifling cars, consider installing a remote starting system that will also activate your vehicle's air conditioning. Kits are available for as low as $50 at electronics or auto accessories stores or websites. Or go the low-tech way and have a friend or family member start and precool your car.

■ THE WATER'S FINE

Handheld spray misting bottles—some come with built-in fans—are a quick way to simulate sweat's cooling effect on your body. Keep them in the refrigerator for extra impact.

Simply putting hands or feet under a cold faucet also is an effective way to cool off quickly, Uyeshiro says. Frohman suggests packing a cooler with ice water and rags and applying the rags to your arms and legs if you anticipate being out in the sun for a long period of time.

For clothing, gear and devices that can help you stay cool in any environment, check out our Web-exclusive list at **MomentumMagazineOnline.com**.

Whichever method or device you use to keep your cool during sweltering summer days, one thing is key: Know your limits. "I'm a Type A person, so I tend to overdo things," Lint says. "But I've learned to slow down when the temperature goes up." ■

Vicky Uhland is a freelance writer and editor in Lafayette, Colo.

What's your favorite strategy for keeping cool? Start or join a discussion at **MSconnection.org**.

Keep moving

You can still enjoy your favorite summer activities—with a little adaptation.

by Vicky Uhland

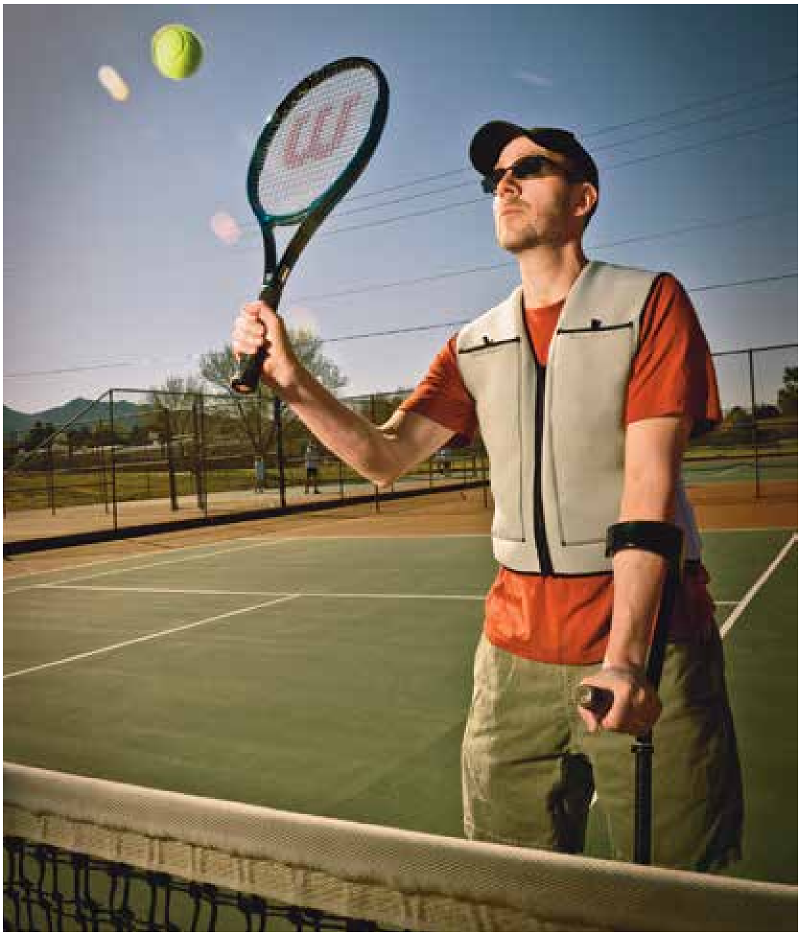


PHOTO BY CHIP SIMON

Dave Bexfield, diagnosed with MS in 2006, enjoys playing tennis, so he adapts the sport to his needs by wearing a cooling vest to manage heat and using a forearm crutch for balance.

Hundreds of studies show that exercise is physically beneficial for people with multiple sclerosis. Hundreds more report that sunshine provides a psychological boost for virtually everyone. So what could be better than biking, hiking, playing a game or just running around on a summer day?

If that last sentence made you cringe, you're likely one of the estimated 70 percent of people who have heat sensitivity related to MS.

Lisa Green, a psychotherapist in Colorado Springs, Colo., is well acquainted with this phenomenon. "I think I came out of the womb hating heat," she says, a trait that leads her to believe her nervous system may have been "going crazy" well before she was diagnosed with MS in 1997. As her MS has progressed, so has her sensitivity to heat. "It turns me into a wet blanket," she says. "Everything slows down, fatigue sets in, and my strength is zapped. It's what anyone would feel in 96-degree heat, but 10 times more."

Green could just spend her summer indoors, but she feels that would be even more torturous than the heat. Prior to being diagnosed, she ran an average of 5 miles a day and was a regular hiker. She says she was so fit that when she went to a gym, "people would ask me if I was a trainer."

PHOTO COURTESY OF LISA GREEN

Lisa Green, diagnosed with MS in 1997, has always been athletic. To accommodate her sensitivity to heat, she rides a modified bike that allows her to use less energy while riding.

When heat started interfering with her exercise regimen, Green devised a plan that allows her to still enjoy her favorite outdoor activities in the summer. “First, I had to grieve the fact that I can’t do what I used to do. I can’t exercise to the point of sweating anymore, and my 80-year-old mother outruns me,” she says. “Once I got through that, it was all about finding resourceful and creative ways to keep my body moving.”

Running, biking, hiking

Green replaced outdoor running with a treadmill workout. While she goes to her physical therapy clinic to use a specialized treadmill, called the Alter G, which holds her up and reduces the effects of fatigue and balance issues, standard treadmills are also widely available at local health clubs and city rec centers. These facilities may also have indoor tracks. You’ll get the benefit of air conditioning while being able to run or walk at your own pace.

Wherever you choose to run, Noriko Yamaguchi, PT, DPT, with University of Southern California Physical Therapy Associates, recommends starting with run-walk cycles, which are short bouts of running mixed with walking or a full pause when you need a rest. These types of drills help you gauge how much the heat is affecting you and allow you to quickly adjust your workout based on your energy levels.

If biking is your preferred sport, several alternative bicycle designs can help you expend less effort and energy on hot summer days. Tandem bikes allow you to ride while a partner does more of the work; recumbent adult trikes help with balance issues and also enable riders to lean back; and power-assisted bikes have an electric motor that kicks in if you get tired of pedaling.

Green is a fan of the BerkelBike, which is a hybrid between a recumbent bike and a handcycle. “I can use my legs and arms or just my legs or just my arms, and because I’m sitting I can really push myself,” she says. “I often wear a cooling vest, a visor or headband with cooling beads, and I plan extra time in case I need to stop and rest and spray myself with water.”

Physical therapists also recommend wearing bike helmets with extra or larger-than-usual vents to help keep your head cool, and carrying a cellphone with you in case you overexert yourself and need to call for help.

BerkelBikes are pricey—about $6,500—but Green hunted around for money to pay for hers, scoring grants from a pharmaceutical company and a local organization. The Challenged Athletes Foundation (**challengedathletes.org**) is also a good resource for equipment grants. Last year, it awarded over $2 million in grants to more than 1,100 people with disabilities. The program is closed until September 2014, when it will begin accepting grant applications for 2015.

Dave Bexfield, who was diagnosed with MS in 2006 and runs the nonprofit website **ActiveMSers.org**, still enjoys cycling and other summer activities despite balance, leg weakness and eyesight issues that are exacerbated by exercise and heat. For

How do you adapt your favorite summer activities? Share with others at **MSconnection.org**.

Rohrig says these are excellent strategies, but notes that being on the open water can lead to a significant amount of sun exposure. "Potential ways to manage this include paddling shorter courses or courses that allow for 'pulling over' in the shade," she says, "or using an umbrella or canopy-type system for some shade" on the watercraft. If water-sports enthusiasts find that wearing a life preserver creates additional heat, Rohrig recommends that they have cooling devices available and stay well hydrated.

Research shows that a preworkout shower or bath can also be a powerful coolant. Ideally, immerse your legs in about 70-degree water for 20 to 30 minutes before you're going to be exposed to heat. "Precooling allows the lower limbs to effectively serve as heat 'sinks' in order to blunt internal temperature increases and decrease reliance on … sweating," wrote researchers in a 2010 study published in the **Journal of Applied Physiology.** If you can't stay in water that cold for that long, a 5- to 10-minute pre- and post-workout shower that's as cold as you can comfortably tolerate can also prove to be somewhat effective, Rohrig says.

Green likes to cool off after exercise in a 10-foot-wide inflatable pool that she places on her shaded patio and fills with cold water. "I can sit in water up to my neck and read a book," she says.

Other outdoor options

Tennis, particularly with a partner, can be a good choice for a cooler summer activity if you have adequate hand-eye coordination, Yamaguchi says. The U.S. Tennis Association has adaptive programs specifically for people with challenges like MS, and can match you with local players with similar skills.

Softball and baseball offer frequent opportunities to rest in the shade, but require some arm power and ability to sprint short distances. If you have adequate balance to swing a club, Yamaguchi recommends golfing. Using a cart helps with fatigue and, because you play in pairs or foursomes, there's also a social aspect.

To evaluate whether a type of exercise is right for you, Yamaguchi recommends paying attention to your symptom patterns. "It can be helpful to keep a workout log listing what you did, how you felt immediately afterward, and how you felt later in the day or the next day," she says. And be sure to check with your physician before starting any new exercise regimen. Once clearance is granted, a physical therapist with experience treating individuals with MS could help structure your program.

One thing to keep in mind: A 2013 study published in the **Multiple Sclerosis Journal** reported that people with MS who do 30 minutes of endurance exercise have significantly greater increases in heat-related symptoms compared with people who do the same amount of resistance exercise. Endurance exercise includes aerobic activities like walking, running, biking and swimming, while resistance exercise focuses on weight lifting and strength training.

Of course, as the temperatures spike, none of these options can seem very attractive. Green realized that if she waited until she felt like exercising on hot days, she might never leave her couch. So she came up with a solution that she calls her 10-minute rule. "I do an activity for 10 minutes and then listen to my body. I check in and see if the feeling of wanting to continue follows," she says. "Often, after 10 minutes the feeling has kicked in. If it hasn't, I stop and try again the next day." ■

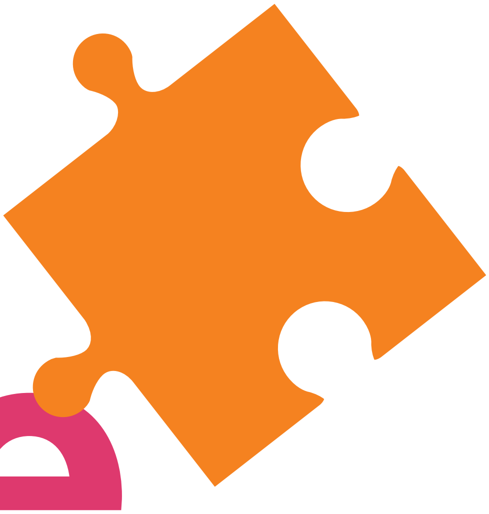
Vicky Uhland is a freelance writer and editor in Lafayette, Colo.

> **"I do an activity for 10 minutes and then listen to my body. I check in and see if the feeling of wanting to continue follows."**

For other summer sports opportunities and tips, visit **disabledsportsusa.org**.

connect

Building relationships to support your best life



The parenting puzzle

How can you manage your kids—and your MS?

by Maureen Heaney

Being a parent requires a person to assume many roles—cook, chauffeur, event planner, lion tamer—and sometimes the responsibilities can feel endless. At the best of times, parenting is still challenging. But when you are also dealing with the physical, cognitive and emotional issues that accompany multiple sclerosis, parenting can seem utterly overwhelming.

PHOTO COURTESY OF SARAH KEITT

Sarah Keitt has learned to set limits when it comes to organizing activities for her two children and their friends. She always has a low-key backup plan.

"Fatigue is my worst enemy right now," explains Sarah Keitt, a 44-year-old mother of two in Woodbridge, Va., who was diagnosed with relapsing-remitting MS in 2000. Her biggest concern, she says, is that her children, ages 8 and 9, will miss out on experiences because of her disability. "I think every mom struggles with 'mommy guilt,' but adding MS to the mix just makes it worse."

Michael Wentink Jr., a 37-year-old father of two in San Antonio, Texas, who blogs about his MS experience at **MSconnection.org/blog** and at **mjwentink.com**, had a fantasy of what fatherhood would be like prior to his 2008 diagnosis. But his physical limitations interfered with his plans. "I had envisioned leading an active lifestyle with my kids and looked forward to being involved with their sports teams," says Wentink. But instead, he continues, "extended periods of standing or walking can wipe me out."

Rosalind Kalb, PhD, vice president of Clinical Care at the National MS Society, suggests that parents allow themselves to think of new or different ways to interact with their kids. "Find activities and strategies that might work for you."

Wentink has done just that. "Since my diagnosis, I've started to enjoy many less-physical activities. I now bake and do puzzles with the kids, and I love that they are so engaged in these activities," he says. And they also find other ways to stay active. "We go on family walks, our kids play sports, and my wife certainly steps up, too, taking the children on longer walks, and even a little running, at a local park." That kind of flexibility can lead to greater happiness and success for parents and children alike.

PHOTO COURTESY OF MICHAEL WENTINK JR.

Michael Wentink Jr.

The father of two does fewer physical activities with his kids to conserve energy.

Keeping it real

Whether a parent is dealing with fatigue, weakness, visual impairment, cognitive difficulties or any other symptom of MS, it's best to identify and manage these issues upfront, says Deborah Miller, PhD, a social worker and associate professor of medicine at the Mellen Center for Multiple Sclerosis Research and Treatment at the Cleveland Clinic. For example, Dr. Miller says, "Many parents say they feel tired when the kids get home from school, just when snack and homework time starts." With this awareness, parents could try to arrange their schedules so they can rest a bit earlier in the day and conserve energy for later.

Keitt says she's learned not to make too many promises about outings, and always has a low-key backup plan in mind that's still fun for the kids, like having a movie-and-popcorn day at home. And when it comes to group activities, like being a scout leader or a classroom mom, Keitt says she manages her energy by setting limits. "I just don't have the cognitive stamina to organize anything beyond my family," she says. "Birthday parties have become less extravagant, and play dates are limited to one or two kids," she says.

"Parents often underestimate what kids are capable of dealing with," notes Peggy Crawford, PhD, a clinical psychologist and assistant professor at the University of Cincinnati. "Talk to them about MS in an age-appropriate way, and feed them more information as their ability to understand grows," she says. Explain to your children that fatigue or mobility or visual issues may disrupt plans, but also reassure them that you will try to find a backup person to get them to an outing, or that postponed plans will be rescheduled.

However, while learning that plans sometimes change is an important life lesson, kids may still feel disappointed. "Tell them this makes you sad, too," explains Dr. Kalb. "Kids understand sadness."

But kids also understand guilt, so it's important to avoid overcompensating for your MS by not enforcing rules. "From an early age, focus on consistency and strong discipline," just as a parent without MS would, advises Dr. Miller. "Parent in such a way that kids know your expectations."

Helping hands

An important item in the toolbox for parents with MS is the ability to seek out and accept help from others, whether it's asking someone to drive your child to an after-school activity on a day when your vision is bad, or to help you get dinner together when you're just too fatigued. Having a spouse pitch in is incredibly valuable, but if that's not possible, try to identify other people who can provide support, such as other parents, friends or family members.

"With a husband who is often deployed for long amounts of time with the Navy, having close friends who know what I have been going through and who are willing to help has been key," says Sharon Dodge, a Pearl Harbor, Hawaii-based mom to a 20-year-old son and 15-year-old twin daughters. "I always wanted to be able to say, 'I can do this!' but some days, I cannot. It took me a while to realize that's OK."

Dodge, who was diagnosed with MS in 1996, says she also enlists her children's support. "Everyone volunteers what they will be responsible for around the house, to help out Mom," she says.

Chores are a great way for children to learn life skills, too, Drs. Crawford and Miller agree. But kids also need opportunities just to be kids, and parents need to know where to draw the line when asking for assistance. "It's important to leave room for developmentally appropriate activities and interactions outside of the house," explains Dr. Miller. "Parents should never make their child their primary support person or caretaker," Dr. Crawford adds. (If you're concerned that your children may be doing too much, call an MS Navigator at 1-800-344-4867 to explore


PHOTO COURTESY OF SARAH KEITT

PHOTO COURTESY OF SHARON DODGE

Sarah Keitt

Diagnosed in 2000, this mom has learned to be gentler with herself when facing her limitations.

Sharon Dodge

Investing in some "me time" goes a long way, says the mother of three.

Discuss the challenges of parenting with MS at **MSconnection.org**.

ways to get additional support.)

Instead, kids should be responsible for simple tasks that add up, like putting things back where they belong. "A lot of time and energy is wasted searching for misplaced items," Dr. Kalb says. "An organized home can help minimize that." Also, keeping a family calendar can help everyone stay on track and reduces the cognitive demands on the parent with MS. "Families should review the calendar together at the beginning of each week, and kids can help to remind parents of upcoming events," says Dr. Crawford.

The kids are all right

Even when he follows the experts' advice, Wentink says he still feels guilty about what he can't do, like when his son's coach asks for volunteers to help during sports practice. "I don't tell everyone that I have MS. But I feel that, as a dad, I'm expected to do more physical things and I worry what people think about the fact that I'm not getting involved," he says.

Keitt says this affects her, too. "On good days, I can be the most fun and active mom. On bad days, I'm lucky if I can manage half of what needs to get done. I constantly feel that I should be doing more," she says.

It's a reminder that the task of managing expectations—yours and your kids'—is ongoing. "Most people create a picture in their mind of the kind of parent they want to be, centered around specific activities they think they need to do with their kids," explains Dr. Kalb. "But parents need to realize that their job is much broader than these things. It's more important to create a safe and loving environment in which kids can grow and learn." Take a moment every day to acknowledge that you are often doing a better job than you realize.

Taking care of the caregiver

Good emotional health is also critical to functioning well as a parent, so find self-care measures that work for you. "There were times when my husband was deployed that I felt overwhelmed," says Dodge, who found that a little "me time" could go a long way. "I took time to do yoga, have coffee with a friend. It made all the difference to put a little focus on myself."

Connecting with others can ease the burden, too. Keitt finds it helpful to have positive friends to talk with about how hard parenting can be. If you are feeling isolated, visit **MSconnection.org** to interact with other parents with MS, or call an MS Navigator at 1-800-344-4867 for information about parenting resources and support groups in your area.

However, more severe emotional issues may require professional help. "With issues like mood changes, kids often think that they did something wrong," explains Dr. Crawford. Consult your healthcare provider about

PHOTO COURTESY OF SHARON DODGE

Sharon Dodge, center, whose husband, Bill, is a captain in the Navy, enlists their three children in doing household chores.

treatments or therapies that can help you manage mood changes or other symptoms affecting your family.

The silver lining

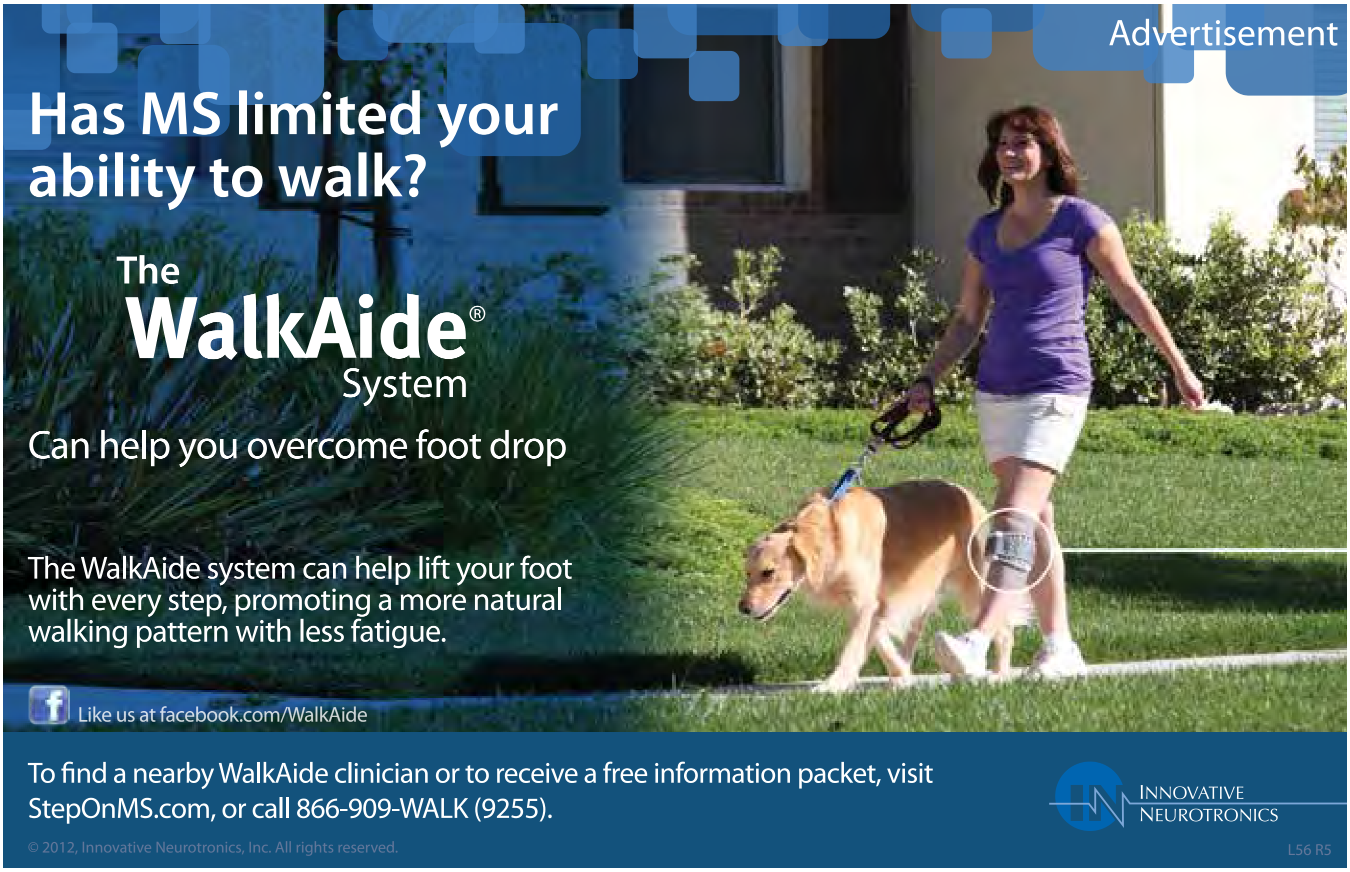
While being a parent with MS certainly can bring challenges and disappointments to families, there can be some positive aspects, too. “Families with MS can experience a level of closeness, trust and an ability to communicate that is very rewarding,” explains Dr. Kalb. “This is due to the unique ways in which they work together because mom or dad has MS.”

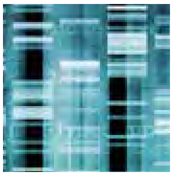
Children can benefit from seeing a parent overcome obstacles. “Part of growing up is adapting to unexpected situations that you don’t want,” explains Dr. Miller. “It is important for parents to communicate that life is full of bumps, and for parents to be a guide as to how to manage these bumps and turns.”

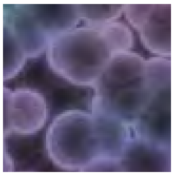
“The nature of MS is that it is unpredictable, so do what you can, when you can, and forgive yourself for everything else,” says Keitt. And when parents learn to be compassionate toward themselves, children learn to be compassionate with others—perhaps the most valuable life lesson of all. ■

Maureen Heaney is an East Northport, N.Y.-based freelance writer and mother of two. She was diagnosed with MS in 2011.

For help talking to your kids about MS, visit **nationalMSsociety.org/ks** to download **Keep S’myelin**, a newsletter for kids and parents, or call 1-800-344-4867 to ask for a subscription.



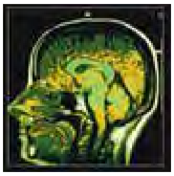


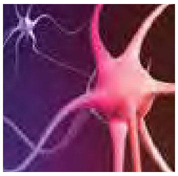


solve

Research to stop MS, restore function and end MS forever

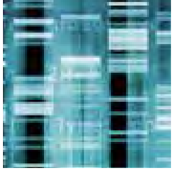
Inside this section

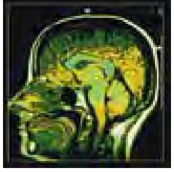


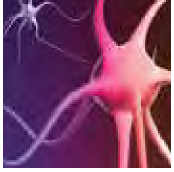


Jump in

Studies find that exercise can help improve cognitive function in people with MS. Find out more on p. 50.







Jump-starting myelin repair

Understanding why remyelination stalls could lead to new treatments.

by Mary E. King, PhD

Multiple sclerosis researchers are hot on the trail of why myelin repair sometimes works—and sometimes doesn't.

Myelin, the material that surrounds and protects nerve fibers in the brain and spinal cord, and increases the speed of signals transmitted through the nerves, is lost in the immune attacks that are characteristic of multiple sclerosis. This immune inflammation also damages oligodendrocytes, the type of cell that manufactures and repairs myelin.

"What we know is that the adult human brain has the ability to repair myelin," says Bruce Trapp, PhD, chair of the Department of Neurosciences at the Lerner Research Institute, part of the Cleveland Clinic. He adds that this repair, called remyelination, can occur in individuals with MS, but "the problem is that remyelination often fails. One of the goals of MS research is to determine why remyelination fails in some instances and why it succeeds in others."

Dr. Trapp studies slices of brain that he obtains through a special rapid autopsy program in the Cleveland area that enables people with MS to donate their brains and spinal cords to his research at their death.

Some of his recent work has focused on lesions that extend across both white matter (which contains a lot of myelin and whose lesions can be seen on a standard MRI scan) and gray matter (which has less myelin and whose lesions cannot be seen on an MRI scan). By directly comparing the different portions of the same lesions, "it was very clear that gray matter has a greater repair capacity than white matter. Analyzing these lesions gives us the possibility to determine what inhibits repair and what enhances repair," he states.

Dr. Trapp and colleagues have now identified specific molecules produced in the white matter lesions that inhibit repair. If a therapy can be developed that stops the production of these molecules in the human brain, it could eventually be used in conjunction with immune-modulating therapies that inhibit damage.

Dr. Trapp will also investigate whether there are molecules in the gray matter that do the opposite—that is, promote remyelination. Perhaps, he theorizes, the slowdown in remyelination in MS is caused by both the production of molecules that inhibit repair and a reduction in the normal amounts of molecules that promote repair.

Removing a block

Larry Sherman, PhD, a professor of cell and developmental biology at the Oregon Health & Science University and senior scientist at an affiliated institution, the Oregon National Primate Research Center, was the first to identify the accumulation of a specific molecule, hyaluronic acid (HA), in areas of myelin damage in mice with an MS-like disease, called experimental autoimmune encephalomyelitis, or EAE. "Whenever it built up in areas of the EAE mouse brain, HA seemed to prevent precursor cells from becoming new oligodendrocytes [that are] necessary for remyelination to occur," Dr. Sherman explains. (Precursor cells are cells that can become oligodendrocytes under the right conditions.)

PHOTO COURTESY OF DR. LARRY SHERMAN

Larry Sherman, PhD

Further research in his laboratory revealed that the breakdown byproducts of HA, not the intact HA molecule, are responsible for slowing remyelination. In addition, the enzyme that breaks down HA is only seen in demyelinated lesions in brains from people affected by MS and in mouse brains affected by EAE, not in healthy brains. So Dr. Sherman decided to try to block the breakdown of HA by inhibiting the enzyme. His laboratory used a drug that does exactly this. When the researchers gave the drug to mice (using a different mouse model of MS), remyelination increased. "This was

Restoring the material that protects nerve fibers

Scientists are studying different ways the body can repair myelin, a process known as remyelination, as well as the mechanisms in the body that may prevent such repair.

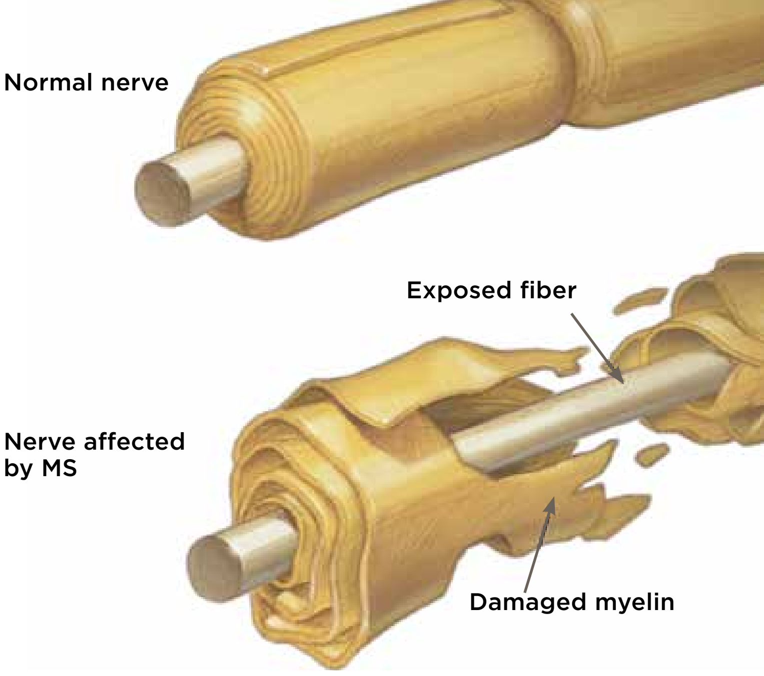


ILLUSTRATION COURTESY OF MAYO FOUNDATION FOR EDUCATION AND RESEARCH

remarkable—not only did we see myelin coming back, but we saw evidence of functional myelin with increased speed of nerve conduction."

Unfortunately, the drug that works in the mouse model would be too toxic to use in humans. The next phase of research, Dr. Sherman explains, is to identify other, less toxic agents that specifically block the enzyme that breaks down HA in MS lesions.

> **"This was remarkable—not only did we see myelin coming back, but we saw evidence of functional myelin with increased speed of nerve conduction."**

If the research team can identify a candidate medication that works in both mouse cells grown in tissue culture and in a live mouse model of MS, it will then be tested further in a novel model that looks very much like aggressive primary-progressive MS. Success would likely lead to human clinical trials, he notes.

Initial funding from the National MS Society in the form of a pilot research grant in the early 2000s, together with the Society's continuous support since, has enabled Dr. Sherman's current studies of remyelination.

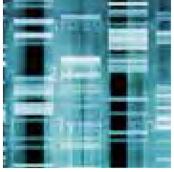
Promoting cell survival

Sharon Way, PhD, a Society-supported postdoctoral scholar working in the laboratory of Brian Popko, PhD, of the University of Chicago Department of Neurology, is researching a different approach to increasing remyelination—by promoting oligodendrocyte survival. Scientists have previously described an important protective process for maintaining cell health in response to several different stressors, including inflammation; this process is the integrated stress response (ISR). While the biochemistry is fairly complex, the key point for Dr. Way and her colleagues was that they might be able to harness this natural protective process. Enhancing the ISR, Dr. Way suggests, might improve oligodendrocyte survival during the inflammatory stresses of MS. Since oligodendrocytes are critical for remyelination, this might increase myelin repair.

Dr. Way is currently concentrating on a vital component of the ISR, a specific protein called eIF2-alpha. Dr. Way's team has found that inhibiting the activity of eIF2-alpha reduces oligodendrocyte death, and boosting it increases oligodendrocyte death.

"Now that we know the eIF2-alpha step in the ISR pathway is important, we are testing different drug therapies to see if we can pharmaceutically enhance this to protect oligodendrocytes," Dr. Way explains. If a candidate drug works in mouse oligodendrocytes grown in cell culture and then in mouse models of MS, it could move into clinical trials in humans. "We are protecting oligodendrocytes from inflammation using this approach," Dr. Way continues. "Since no known anti-inflammatory agent can completely block all inflammation in MS, this could be used in conjunction with current anti-inflammatory therapy" to stop the disease progression in complementary ways. ■

Mary E. King, PhD, is a freelance medical writer from Boulder, Colo.



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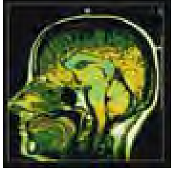
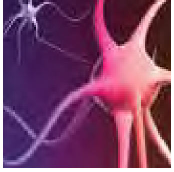




Movement for the mind

Studies suggest that physical activity helps improve cognitive function in people with MS.

by Donna Shryer

An estimated 50 percent of people with multiple sclerosis live with cognition challenges, such as problems with thinking speed and memory. For 5 to 10 percent of them, the difficulties are severe enough to interfere with everyday activities.

Diagnosed with MS in 1989, Gary Anzovino, 54, of Nutley, N.J., says he tries to soften the symptoms of cognitive deficit, or "cog fog," by adding more physical activity to his routine and by carefully organizing his days. "I exercise—religiously—because I do believe it helps me think more clearly," he says.

Anzovino may be on to something. Several independent studies have looked at various diseases associated with cognitive impairment, and data suggest that aerobic exercise may improve cognition and brain function in MS. A third, larger study, currently underway and specific to MS, may further strengthen that theory.

Exercise, cognition and MS

A small pilot study investigated the effects of exercise on memory in people with MS. The results suggest that aerobic exercise improves memory and increases the volume of the hippocampus, a region of the brain associated with learning and memory.

The study, led by Victoria Leavitt, PhD, and James Sumowski, PhD, and conducted by the Kessler Foundation in West Orange, N.J., followed two people with MS-related memory impairment. Over a three-month period, one study participant did stretching exercises and the other participant did aerobic stationary cycling. Each participant exercised three times per week, in 30-minute sessions. Participants were tested twice—before beginning the treatment to set a baseline, and then after completing the 12-week intervention.

Outcome measures included memory tests, functional MRIs (scans that measure real-time brain activity) and structural MRIs. According to the results, published in the October 2013 journal **Neurocase: The Neural Basis of Cognition**, the person assigned to aerobic exercise had an average 53.7 percent increase in memory for word lists and visual patterns. She also had a slight increase in hippocampal volume, along with increased hippocampal resting-state functional connectivity (RSFC), a relatively new measure of the integrity of the nerve connections that support a primary memory network of the brain. "Ours is the first study to ever look at RFSC after an aerobic exercise intervention," says Dr. Leavitt. "It aligns nicely with the increased volume of the hippocampus and improved memory, rounding our findings out to include a neurophysiologic measure as well."

Nonaerobic exercise resulted in minimal change in hippocampal volume and no changes in memory or functional connectivity.

While the study was quite small, its findings were significant enough to increase the buzz—and hope—that aerobic exercise boosts cognition.

Cindy Merchan, 36, who was diagnosed with MS in 1996 and lives in Jersey City, N.J., was the participant assigned to aerobic exercise, and today she continues her workouts. "When the study was finished, I noticed that I was more alert," she says. Plus the 15 pounds Merchan shed as a result of the added exercise increased her energy level. "I think having more energy helps me think more clearly, too," she says. "I feel more awake and in the moment."

Research in motion

A similar but larger Society-supported study is being led by Dr. Barbara Giesser, professor of clinical neurology at the UCLA School of Medicine and clinical director of the MS program at UCLA. Dr Giesser says the study is slated to close this summer, and no preliminary data are available yet.

The study includes 34 people with MS-related cognitive

50% of people with MS live with cognition challenges.

For **5-10%** of them, the difficulties are severe enough to interfere with everyday activities.

dysfunction. Half the participants have been randomized to an aerobic protocol that involves riding a device similar to an exercise bike. The other participants are following a stretching protocol. Both groups are training three times a week, 20 minutes at a time, for a total of six months.

Dr. Giesser and her team are using two cognition tests to measure data. Both tests were performed on each participant when the study first began in order to establish a baseline. The tests are repeated every three months, and to see if there are carryover effects, the final tests will be performed three months after completion of the study.

> **“Having more energy helps me think more clearly, too. I feel more awake and in the moment.”**

The primary outcome measure involves performance on standard neuropsychological testing. “These are memory, learning and thinking tests with paper and pencil,” Dr. Giesser explains. The secondary measure is an auditory cognitive evoked potential, which assesses a person’s response to a novel or unusual sound in order to measure awareness and processing of auditory information. The noninvasive test begins by placing electrodes on a person’s head and recording his or her brain waves while performing a listening task.

“For our study, participants listen to a series of tones, and they have to count the number of different tones,” Dr. Giesser says. She adds: “You could say that the waves we’re recording represent the brain paying attention to the tones. The waves’ timing is delayed in persons with cognitive deficit. We want to see if exercise improves the timing.”

PHOTO BY DAN DELLAPIAZZA, BARNABAS HEALTH

Gary Anzovino, who has been living with MS for more than 20 years, exercises regularly to help lessen the symptoms of “cog fog.”

The next step

While preliminary data suggest that aerobic exercise may improve cognition in people with MS, Dr. Giesser stresses that these benefits are not yet conclusive. “Ours is one of the first large-scale, randomized, controlled studies to address this possible benefit. And if our data does tell us that aerobic exercise improves MS-related cognitive deficit, the next step is to ask if it has to be aerobic exercise,” she says. “Can any type of physical exercise improve cognition? What about resistive weight training and yoga?”

Because additional studies are needed, the Society recently launched a larger-scale, controlled clinical trial to compare impacts of two forms of exercise training on cognition in people with MS.

Another important step is to help all people with MS feel comfortable with exercise—as Merchan and Anzovino are. Because each individual with MS has different capabilities and limitations—which may change over time—a physical therapist experienced with the unique and varied symptoms of MS can be helpful in designing, supervising and revising a well-balanced exercise program.

There is a myth that exercise of any form is bad for people with MS, Dr. Giesser says. “The medical community was naive back when we said, ‘don’t exercise.’ Exercise benefits people with MS just like it does people who don’t have MS.” ■

Donna Shryer is a Chicago-based freelance writer.

Biking with MS

A new Bike MS program allows more people living with the disease to say, ‘I Ride with MS.’

by Marcella Durand

People who ride in Bike MS events may do it to support family members, friends or co-workers who have been diagnosed with multiple sclerosis. But there are also legions of participants who live—and ride—with the disease, despite challenges such as fatigue or weakness.

Now, anyone with MS who is interested in cycling to support MS research and programs can join the I Ride with MS program, which has been expanded to all 100 Bike MS events nationwide, thanks to the support of Genzyme, a Sanofi company, and Primal Wear.

At her own pace

“Bike MS was something I never considered,” says science teacher Rosemary Sieber, who was diagnosed with MS at age 19. Encouraged by her uncle, she began participating a year after her diagnosis. “It was scary,” the Pittsgrove, N.J., resident remembers. “I was still figuring out how my body responded to different things, but I bought a decent bike and just started training 10 miles at a time. I probably never would have gotten involved if not for my uncle.”

And involved she is. Bike MS turned out to be a doorway to a range of MS-related activities that Sieber participates in, including Walk MS and MuckFest MS. Last year, she added I Ride with MS, pedaling in

PHOTO COURTESY OF ROSEMARY SIEBER

Rosemary Sieber, right, shown with friend Melissa Love, participated last year for the first time in **I Ride with MS**.

the City to Shore Bike MS ride from Cherry Hill to Ocean City, N.J.

Sieber was careful to pace herself, however. “If I was feeling especially tired one day, I didn’t go out for a ride,” she says. Physical therapist Mandy Rohrig, PT, DPT, with Horizon Rehabilitation Centers in Omaha, Neb., agrees with that principle. “Remember that life happens and MS can happen,” she says. “Allow yourself some flexibility with your training when your MS causes you more challenges.”

Sieber also consulted with her doctor before beginning training, as people with MS should do when considering any new physical activity. “He had the same perspective I did,” she remembers. “He told me to listen to my body’s warning signs and to be smart about it.”

Rohrig recommends a consultation with a physical therapist as well. “A PT can provide a valuable pre-training step by helping you identify your physical strengths, as well as areas for potential improvement.”

A connection with roots

While Sieber is relatively new to biking, it’s long been a favorite activity for Marleigh Brown of Wrentham, Mass. “Since I was a young teen, my bike was my freedom, my mode of transportation. My brothers and I were always riding together,” Brown says. She recalls that after she was diagnosed with MS at age 36, “my brothers were the first ones to say, ‘We are still going to ride together.’”

Brown and her siblings began recruiting a Bike MS team almost immediately after her diagnosis in 2009, and

Spinning your wheels?

People with multiple sclerosis may wonder about the range of support available during Bike MS rides.

“At every start and finish line, and at every rest stop on every ride, we have shady shelters, accessible restrooms, and plenty of fluids and snacks available. We also have support and gear vehicles that can give a ride to anyone who feels [he or she] can’t continue,” says Paula Eichholz, national director for Bike MS. In addition, she notes, most rides have several mileage options.

Call 1-800-344-4867 to find a Bike MS event in your area.

PHOTO COURTESY OF MARLEIGH BROWN

I Ride with MS is a great opportunity to spread awareness about MS, says Marleigh Brown, shown here hugging her husband, Tim.

PHOTO COURTESY OF ROSEMARY SIEBER

Through Bike MS events, Rosemary Sieber, far right, has discovered a passion for cycling.

PHOTO COURTESY OF MARLEIGH BROWN

I Ride with MS participant Marleigh Brown didn't have to think about gear on ride day, thanks to a jersey supplied by Primal Wear, the official cycling apparel partner of Bike MS.

Visit **BikeMS.org** to learn more.

her brothers' support gave her the confidence to complete the event. "When I learned about I Ride with MS, it was an additional opportunity to spread awareness about MS," she says. This will be the first year participants can raise awareness even more, by wearing free custom jerseys provided by Primal Wear, the official cycling apparel partner of Bike MS.

Facing the challenges

Both Brown and Sieber face obstacles to cycling but have found strategies to manage them. To deal with heat, they time their rides for cooler parts of the day. "Our team is the first out in the morning," says Brown.

Both women rely on keeping their muscles limber, as well. Sieber notes that she stretches not just after rides but often during them. Brown says she is a "huge fan" of yoga. "The stretches, especially in the hips, are very helpful for cycling," says Brown, who had to learn to manage MS-related hip and leg issues in order to ride. Now she trains year-round, thanks to a stand she places her bike on during the long winters. "It creates a stationary bike out of your bicycle," she says.

Rohrig encourages riders to have their bikes professionally fitted, which can be done by a PT or an associate at a bike shop. "A properly fitted bike facilitates an energy-efficient cycling form" that can help counteract fatigue, she says. "Also explore other types of bikes, such as a lightweight recumbent bike, a three-wheeled bike, a tandem (recruit a family member or friend!), a handcycle or a bike with a power-assist feature. Participating in I Ride with MS does not mean you must use a traditional bike. Bicycling is for all ability levels."

Genzyme is a proud supporter of the Bike MS **I Ride with MS** program, and sponsored the pilot program in 2013. For information about how you can participate, visit **BikeMS.org**. ■

Marcella Durand is a frequent contributor to **Momentum**.

Passing the baton

Relay events prove that ordinary individuals can accomplish extraordinary things when they work together.

by Matt Alderton

To relax, most people read a book, watch a movie or listen to music. Ashley Kumlien isn't most people. She spends her spare time running—a lot.

"I can't remember a time when I didn't love running," says Kumlien, 29, a Milwaukee-based personal trainer whose mother, Jill, has been living with multiple sclerosis for more than 33 years.

In 2009, Kumlien, who at that time had already completed three half-marathons, decided to combine her love of running with her passion for travel, while raising money for MS programs and research. So she created a nonprofit organization—MS Run the US—to support a 3,288-mile run from San Francisco to New York. She started running in March 2010 and became the 16th woman to run across America when she finished that September, having raised $56,000. But to her, that wasn't enough.

"I really wanted to be a significant fundraiser for the cause, and what I learned is: If you want to do significant fundraising, you've got to involve other people."

And so the idea of a relay was born.

Strength in numbers

After hearing from many endurance athletes who were interested in joining her event, Kumlien decided to split the route into 18 segments divided among numerous runners, who would each have a fundraising goal of $10,000.

"They would each run 160 miles over six consecutive days, which is a marathon a day, before handing off the relay baton," explains Kumlien, who commenced the first MS Run the US relay in Los Angeles in April 2013. By the time they reached New York in September, the relay's 16 runners—including Kumlien—had raised $185,000 for the National MS Society.

"Now, it's an annual event," says Kumlien, who has 17 runners in this year's relay, which for the first time includes a series of run/walk 5Ks in major cities along the route. "We'll eventually max out at three runners per segment, which is about 60 runners a year, but we'll be able to maximize participation by involving potentially thousands of other runners in these little 5Ks across the country."

Helping in person

For Don Fraser, the benefits of using a relay format to raise money took a while to crystallize.

In 2007, after graduating college, and inspired by stories of cyclists who had ridden their bikes across the United States, Fraser convinced his three roommates to join him on a 4,000-mile bike ride from Seattle to Bar Harbor, Maine. They didn't have a schedule or an itinerary—but they did have a cause: MS, a disease that Fraser's mom, Nina, has lived with most of her life.

"We created a Web page that had some information about what we were doing and a little donation button. Then we started passing out the URL," says Fraser, 30, now a watercraft operations manager at Virginia Tech in Blacksburg, Va. "Together, we raised about $20,000 for MS programs and research."

Just as impressive was their work helping people with MS along the way. During their two-month journey, the men frequently rode to people's homes to do volunteer service projects, such as cleaning gutters, repairing broken screen doors and moving heavy objects—or sometimes, just to visit. "We were trying to raise money for MS research to find a cure, but we were also trying to help people who are living with MS right now," says Fraser, who over the years has watched his mother go from walking to using a cane to using a wheelchair.

PHOTO COURTESY OF DON FRASER

Last summer, Don Fraser's Bike the US for MS team cycled from Yorktown, Va., to San Francisco, Calif. They celebrated when they reached their destination, near the Golden Gate Bridge, shown above.

PHOTO COURTESY OF ASHLEY KUMLIEN

Ashley Kumlien's MS Run the US relay runners and program ambassadors rejoice in New York at the end of the 2013 run. Kumlien is kneeling on the right of her mother, Jill Kumlien, who is seated in a modified wheelchair.

"There are a lot of people out there like my mom who need assistance," he adds.

Because his ride attracted attention from athletes and enthusiasts across the country who wanted to join, Fraser in 2009 founded Bike the US for MS, a nonprofit group that organizes transcontinental bike rides every summer for 60 to 100 cyclists, each of whom must raise $1 per mile if they ride more than 1,500 miles, or $2 per mile if they ride less.

"We realized not everyone could take the entire summer off, so we started incorporating the relay aspect into it. Now, people can join us for a day or a week or half the trip—whatever makes sense for them," explains Fraser, whose rides continue to mix fundraising with community service—just like his original ride did. So far, Bike the US for MS participants have raised nearly $1 million and completed more than 50 service projects, which often inspire people to become even more engaged with the cause.

"We're taking people who previously had no connection to MS and, through this life-changing adventure, turning them into lifelong advocates," Fraser says. "That's a huge win."

The finish line

Even the most ambitious goals—running or biking across the country, for instance, to support MS programs and research—can be achieved when individuals tackle them together. If everyone finishes his or her leg of the course, eventually the baton will cross the finish line, no matter who carries it.

"We are so grateful for this army of passionate fundraisers across the country," says Rachael Nuwash, director of emerging campaigns for the National MS Society. "They are reaching and connecting with so many individuals. It might be the person they meet while running through a small town, or the person with MS who allows them to stay overnight in their home. Those personal connections not only bring awareness to the cause, but also give people living with MS a sense of hope and community." ■

Matt Alderton is a Chicago-based freelance writer and editor.

PHOTO COURTESY OF ASHLEY KUMLIEN

This car, donated to Ashley Kumlien's organization in 2009, has traversed the country as a support vehicle twice—during both Kumlien's solo run and her team relay.

To learn how you can turn any race or endurance event into a fundraiser, visit **finishMS.org**.

Reel life with MS

A young filmmaker focuses his sights on making the world more accessible.

by Alison Dale

Documentary filmmaker Jason DaSilva was only 25 when he was diagnosed with primary-progressive multiple sclerosis, a disease course in which a person experiences no relapses or remissions. In the span of just a few years, his symptoms rapidly worsened, and he went from using a cane to a walker, then a wheelchair, and now, a scooter.

With these drastic changes, DaSilva quickly discovered his previous fast-paced lifestyle was no longer an option. "It's hard being 25, living in New York City and getting a debilitating disease. All of a sudden you're not going to clubs and parties like you used to," he says. "And friends don't stick around."

So the young filmmaker decided to turn the camera on himself to make sense of what was happening to him through the art of cinema. The result is "When I Walk," a feature-length documentary that details the progression of his disease, the difficulties he faces as a result and how he copes with them. The film premiered at the 2013 Sundance Film Festival and had its theatrical release later that year.

The decision to film himself didn't come easily for DaSilva. "It took me about two years from diagnosis to really ramp up. I mean, I started just filming bits and pieces, but I really didn't want to start filming this film. You can see why," he says, hinting at the difficulty he had in coming to terms with his progressing symptoms. But his passion for filmmaking won out and he committed himself to documenting the changes that MS was causing in his body, his career, his relationships and his life.

The show must go on

As DaSilva's mobility challenges increased, so did his first-hand knowledge of how difficult the world can be for people who have disabilities, especially in New York City.

"When I Walk" follows DaSilva as he tries, unsuccessfully, to accomplish tasks that many people take for granted. For example, he's unable to use the subway system because of the stairs that lead down to most stations; and he also can't depend on taxis because most can't accommodate wheelchairs or scooters. Even when he could get to where he wanted, he found many businesses inaccessible because they had steps and no ramps. As he wrote in an opinion piece in **The New York Times** last year: "It's not the MS that exhausts me. It's the barriers that prevent me from conducting my daily activities."

After a while, DaSilva realized that he was becoming housebound and isolated. In an effort to get out and connect with others who had MS, he ventured out to an MS support group, a decision that would change his life forever.

There he met Alice Cook, who was in the group because her mother lives with MS. Before long, Cook became DaSilva's collaborator, co-writing, co-producing and co-starring in the film, which was already underway, and eventually performing the editing tasks his own fingers no longer could. After completing the film, the pair developed an even deeper partnership: They married in 2010, and are now the parents of a 1-year-old son, Jase.

Cook says they were able to collaborate so successfully because they shared the same vision. "We were both really adamant about not wanting it to be a medical film. We

PHOTO BY MICHAEL VARHOL

Jason DaSilva recently addressed an audience about his film, "When I Walk," which he says is about overcoming challenges with triumphs.

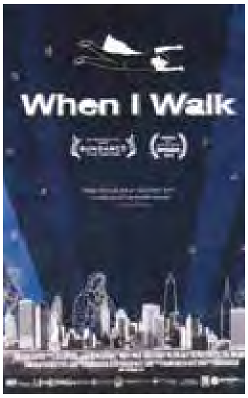


PHOTO COURTESY OF JASON DASILVA

"When I Walk" (**wheniwalk.com**) premiered at the 2013 Sundance Film Festival.

Catch **When I Walk** on the PBS series "POV" when it is broadcast on June 23. Check local listings for times.

wanted to focus on the emotional aspects of living with MS."

"At the end of the day, my film isn't just about MS. It's about disability and overcoming challenges with triumphs—big ones and little ones," DaSilva points out. "I really hope it's going to make people start thinking about the disabled community as being the same as everyone else."

> **"It's hard being 25, living in New York City and getting a debilitating disease. All of a sudden you're not going to clubs and parties like you used to. And friends don't stick around."**

Advocating for the rights of people with disabilities has become DaSilva's mission. "People who have disabilities should be able to live their lives like everyone else," he says emphatically.

Mapping progress

That concept sparked an idea in DaSilva. What if people everywhere could share information about all the accessible places that they know—businesses, restaurants, subway stations, restrooms and more—and that information was available on a mobile device?

PHOTO BY MICHAEL VARHOL

Happy family: Jason DaSilva met his wife, Alice, at an MS support group. She eventually became DaSilva's collaborator on the movie. They married in 2010 and have a 1-year-old son, Jase.

The idea became a reality when DaSilva partnered with Google and launched an app, called AXSMAP (pronounced Access Map), about a year ago. "It allows people with canes, walkers or wheelchairs, even moms with strollers, to instantly find accessible places wherever they are," he explains. DaSilva hopes to begin to change the world of accessibility. "There are a million people like us. That adds to the urgency." ■

Alison Dale is a Los Angeles-based writer who has lived with MS for more than 30 years.

fired up
Perspectives on MS

Man of steel

by Ellen Robare

When ‘positive’ comments are kryptonite

A couple of years ago, we bought my husband, a comic book fan, a hat. On the front is the Superman logo, and on the back it says “Man of Steel.” He wears it often, and at times I can’t help but think just how appropriate it is for him to wear that label.

Yes, my husband has multiple sclerosis. Yet despite the ever-present and unpredictable company of severe numbness, stabbing pain and crushing fatigue caused by this disease, he manages to maintain a schedule at an unforgiving job that would exhaust a healthy person—and still finds time to do things at home and spend time with his teenage son. His alarm goes off at 4:30 a.m. each day, and it is rare that he gets home before 4 p.m.

It’s been my observation that many people who have MS are like him—tough as nails. In fact, they manage to function so well that others don’t have any idea what they are going through. I can’t count the number of times that people have said to me, upon learning that my husband has MS, “My aunt/uncle/friend/cousin/acquaintance has that, and is doing fine.” Or, “Isn’t it great that they have all kinds of new medicines for that now?”

> **“The real reason so many people know someone with MS who is doing ‘fine’ is because so many people who have MS are putting forth a Herculean effort on a daily basis to stay active, to not lose ground, to stay in the game.”**

Ever felt others don’t understand what it’s like to live with MS? Share your story at **MSconnection.org**.

People think they’re being helpful, or cheering me up—and I honestly do appreciate the attempt—but sometimes I wonder if nodding and smiling isn’t perpetuating the idea that MS isn’t that big of a deal. I wonder if these folks believe that MS is more or less just an inconvenience, that medical science just about has it beat, or even that it’s not a cause that still needs funding for research.

Unfortunately, the truth is that there is still no cure for MS. While research indicates we are tantalizingly close to figuring it out, it’s a long road from promising research to a commercially available cure. Certainly, new medicines can aid with symptoms and even slow disease progression, and I hesitate to call them anything less than fantastic (who knows where we'd be without them). However, they still are strong drugs with sometimes unpleasant delivery systems (such as stabbing yourself with a 2-inch needle) and sometimes scary side effects (would you like a side of heart damage with that?) that are intimidating to say the least.

I've come to the conclusion that the real reason so many people know someone with MS who is doing "fine" is not because we have it nearly beat, but because so many people who have MS are, like my husband, putting forth a Herculean effort on a daily basis to stay active, to not lose ground, to stay in the game. Man of Steel? Damn straight. In fact, now that I think about it, it's probably an understatement. People with MS could probably show Clark Kent a thing or two.

So, I'd like to make a suggestion. The next time a friend tells you that she or a loved one has MS, consider ditching the "people with MS do just fine" speech. Your friend probably knows that appearing fine on the outside is a small part of a much bigger picture. Maybe curb your praise for those new medicines. Unless you're a neurologist, your friend can probably school you on the latest available treatments—and their downsides.

Minimizing the situation won't make someone with MS feel better. But empathy just might. How about trying instead something as simple as, "I'm sorry, that has to be rough. How does he manage?" Better yet, ask that "fine" aunt/uncle/friend/cousin/acquaintance a little about what he or she really deals with on a daily basis, and you might find yourself adding, "I know someone who has that, and I am in awe of how he deals with all of it—I think he must be a superhero or something." ■

Ellen Robare lives in Portage, Mich., with her husband, Randy, who was diagnosed with MS in 2003, and their son.

PHOTOS COURTESY OF ELLEN ROBARE

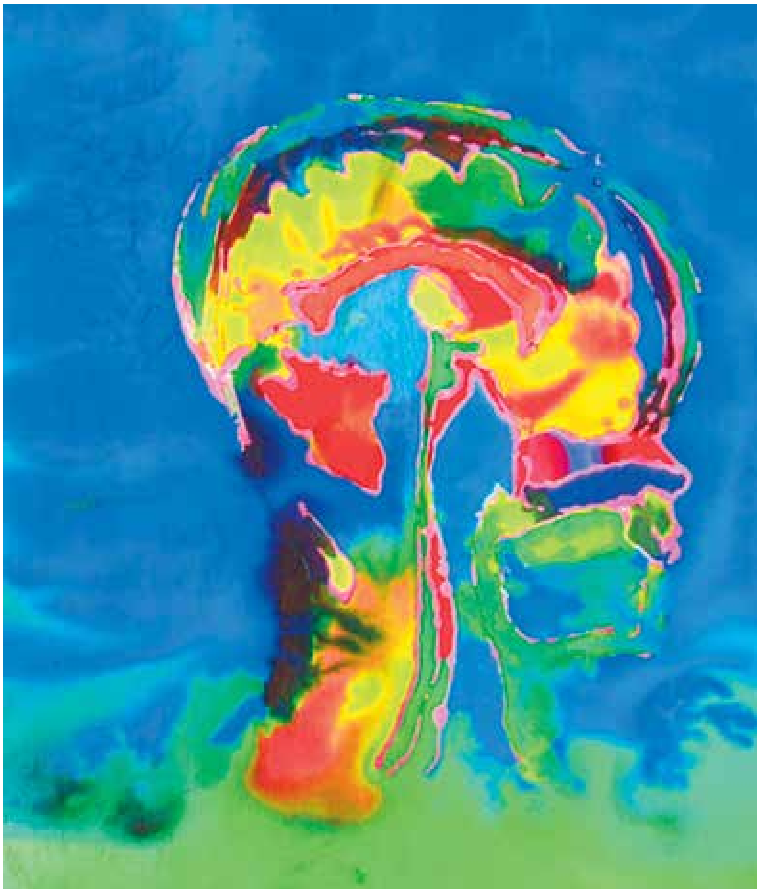
Not your average guy: Randy Robare looks like everyone else but, like many people with MS, he fights hard to appear that way.

Beautiful brain

by Elizabeth Jameson

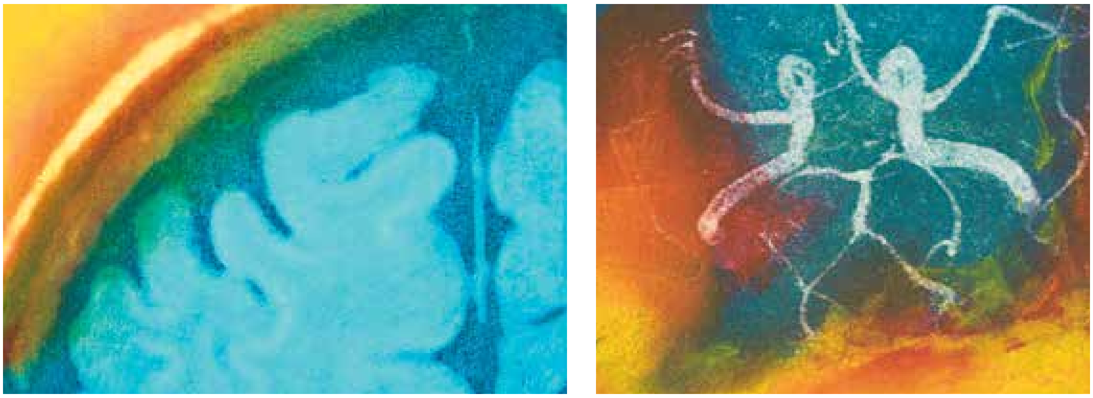
Neurologists diagnose and track the progression of multiple sclerosis through MRIs of the brain. My diagnosis of MS in 1992 initiated a fascination with these eerie images, which I found frightening yet mesmerizing. I felt a strong urge to reinterpret my brain scans—to use them in my art to explore the wonder and beauty of all brains, including those with disease.

My life with MS includes being constantly confronted with scans of my changing brain. Because of this, I am familiar with the vulnerability that is associated with having scans of my naked brain—being exposed from the inside out. Through my art, I attempt to capture the feelings and emotions this technology evokes. My passion lies in creating art engendering the acceptance of illness as a part of being human. At some point in our lives we all become patients, and my art serves to explore and redefine this experience for the medical community and for the patient. My artwork forms a new kind of visual imagery, one that interprets a structure in which creativity, personality and selfhood reside alongside disease—reminding viewers that this gray tissue and the body that shelters it represent far more than illness and human imperfection. ■



IMAGES BY ELIZABETH JAMESON

In "Self Portrait of the Artist's Brain I," artist Elizabeth Jameson saturates an MRI with vibrant colors of French dye on silk, to portray herself as a person with energy and passion, despite having a brain disease that threatens those qualities.



"Emerging" (above left) and "Celebration" (above right) were created through a process known as solar etching, in which a digitally cropped MRI and angiogram, respectively, were etched onto a photosensitive metal plate using the sun. Jameson then applied vibrant inks to the plates.

See more of Elizabeth Jameson's work at **jamesonfineart.com** and **MomentumMagazineOnline.com**.