



Summer/Fall 2023

THE Motivator

Published by the Multiple Sclerosis Association of America

The Importance of Diet and Nutrition in MS





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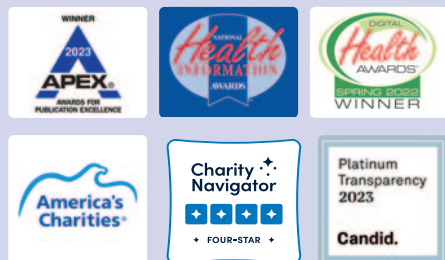
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Multiple Sclerosis Association of America

The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

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MSAA Embarks Upon a New Strategic Plan

By Gina Ross Murdoch
MSAA President and CEO

I hope that all of our readers were able to “weather” the dangerous heat waves and storms that impacted our country during the summer months. We can now look forward to cooler temperatures and all of the other things that the change in season brings.

When we think of the coming months, many look forward to the New Year approaching. And while most people think of the New Year beginning on January 1st, MSAA’s New Year actually starts on July 1st, at the beginning of our fiscal year. Frequently in our “Up Front” column, I talk about the current fiscal year and vital details of our strategic plan. On July 1st of this year, we not only started our new fiscal year, but we also began the

In our new strategic plan, our core values include compassion, dedication, teamwork, and creativity, as well as diversity, inclusion, and health equity.

implementation of our new 2024-2026 strategic plan.

The start of a new strategic plan is always an exciting time at MSAA. The purpose of a strategic plan is to re-examine the mission and vision, ensuring that the work of the organization continues to be focused on our core values. In our new strategic plan, our core values include compassion, dedication, teamwork, and creativity, as well as diversity, inclusion, and health equity. Our goals for the

next three years are as follows: increase activity addressing issues of health equity in the MS community; strengthen connections and expand actions to support living the best possible life with MS; champion the power of self-advocacy and shared decision-making; and lead in improving MS outcomes through implementation research.

Gina Ross Murdoch is a seasoned executive in non-profit management. Her career includes leadership positions with chapters of the Leukemia and Lymphoma Society as well as the American Diabetes Association. Earlier, she spent 14 years overseeing development activities at a large chapter of the National Multiple Sclerosis Society, leading explosive growth initiatives and ground-breaking strategic projects. An active member of the community, Ms. Murdoch has held several town positions and volunteers for her college alma mater, Drew University.

While our strategic plan serves to shape our programs, we depend on our generous donors and various fundraising events to support these urgently needed services. Our most successful fundraiser is our annual Improving Lives Benefit, which was held in May and consisted of two events: one in-person and one held virtually. This year's Improving Lives Benefit in-person event was once again held at the beautiful Barnes Foundation in Philadelphia, Pennsylvania, where we honored our Mission Honoree, the highly acclaimed actress and MS advocate, Selma Blair. We also recognized our Corporate Honoree, Polar Products President and CEO, Jacob Graessle. We are truly grateful to all of our devoted attendees and supporters.

Another amazing way of supporting MSAA is through our Team MSAA events. Team MSAA is once again participating in the Walt Disney World® Marathon Weekend presented by State Farm® in Orlando, Florida. I am thrilled to be alongside Team MSAA participants again this year for *runDisney* as we collectively raise funds for MSAA's vital programs. In early 2023, Team MSAA brought together our largest group ever with almost 100 participants fundraising for MSAA's free programs and services – and we're looking forward to an even larger impact in 2024! For more information on other ways to support MSAA, please visit our "Thoughts About Giving" column on page 32.

Before concluding this edition of "Up Front," I wanted to give my personal thoughts

on this issue's cover story, "The Importance of Diet and Nutrition in MS." While more research is needed, studies suggest that certain foods can have an effect on important functions, including our immune system, inflammation, and disease progression, as well as a number of MS symptoms. Often the foods that appear to have a positive effect on MS are healthy options for the entire family as well. With this in mind, families and friends may want to make meal preparation, cooking, and nutrition a fun group activity – all while socializing and encouraging good food choices at the same time.

Finally, I want to extend my wishes to all of our readers for good health and happiness throughout the upcoming fall and winter seasons. ■

MSAA Webinars and Videos

Check out MSAA's latest webinars and videos covering a wide range of vital topics. Several of these are available in Spanish. Please visit mymsaa.org/videos to learn more.

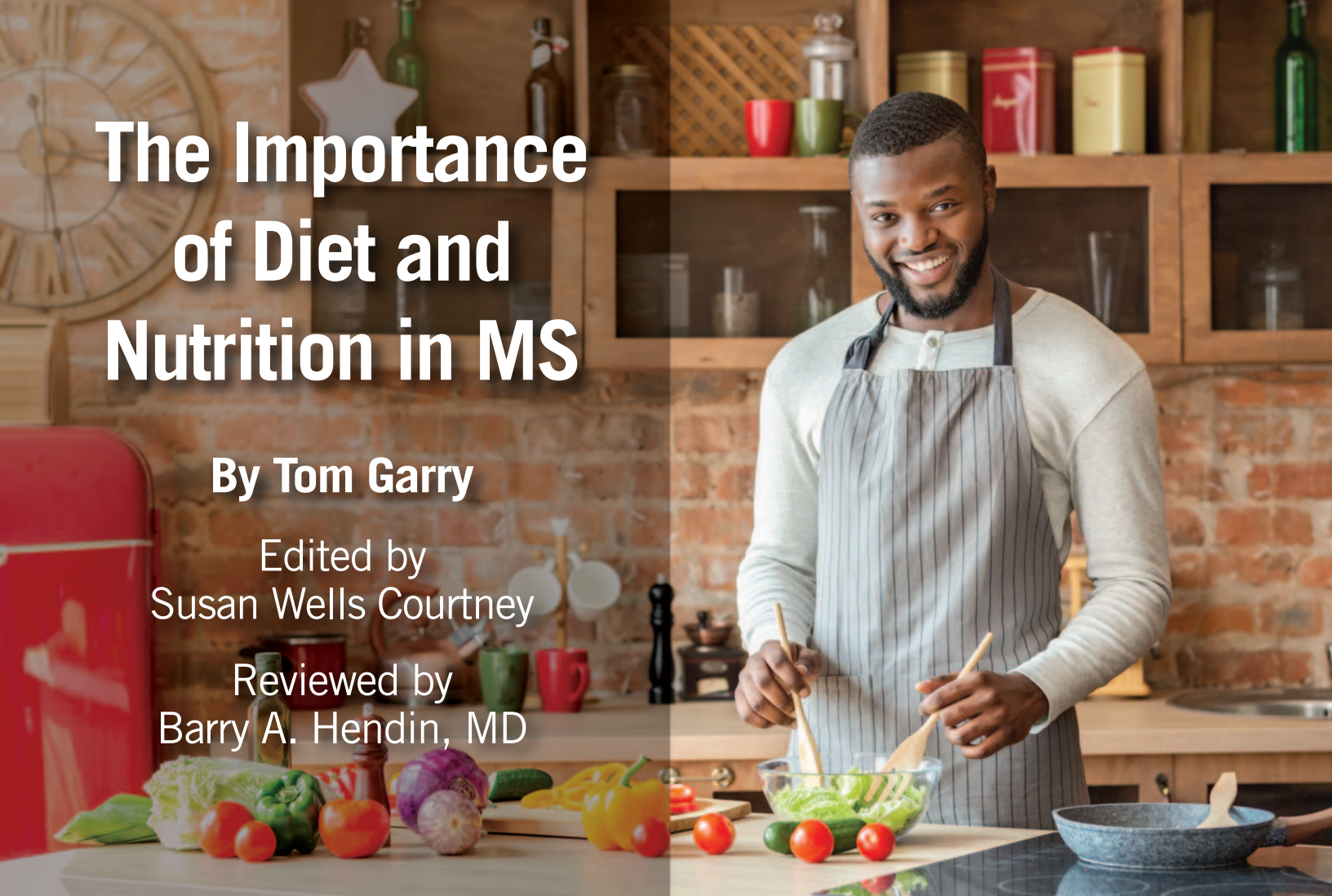


The Importance of Diet and Nutrition in MS

By Tom Garry

Edited by
Susan Wells Courtney

Reviewed by
Barry A. Hendin, MD



Although more research is needed, studies have shown that diet and nutrition appear to have a significant effect on the progression of multiple sclerosis (MS), as well as on the severity of certain symptoms. Additionally, eating a healthy diet and ensuring good nutrition promotes overall wellness, which is important for everyone – both with and without MS.

In this cover story of *The Motivator*, top experts provide their thoughts on what foods are best to eat and what foods should be avoided. These experts explain how diet can affect how you feel and provide guidance for improving nutrition. Specifics on certain diets are also included, but please look to our cover story in the next issue of *The Motivator*

for more detailed information on several popular diets, as well as research into how these diets may impact MS and why research has been lacking in the past.

As always, we caution readers not to make any changes to their diet without first consulting a medical professional. The information provided in this article should not be considered as medical advice. We recognize that individuals have their own specific requirements and preferences in terms of diet, and we hope that the details given by the specialists quoted can be of assistance in customizing a diet that not only promotes good health for each individual, but will also provide enjoyment and a better quality of life.

Early Research into Diet and MS

Neurologist Roy Laver Swank, MD, PhD, was a true pioneer in the study of the effects of diet on MS. Driven to learn how diet and nutrition play a role in MS, Roy Swank was able to identify patterns in diet and trends in disease severity. Following World War II, an epidemiological survey he had helped launch showed that for every 10 people diagnosed with multiple sclerosis (MS) in Norway, nine lived in the country's mountainous inland regions while only one lived along the nation's extensive coasts.

The neurologist and his colleagues spent time in Europe to gather additional statistics. He noted, "In the mountains, the rural families lived largely on meat, milk, eggs, and cheese, whereas along the coast, people consumed fish and other food sources found in the ocean."

This conclusion led Dr. Swank to believe that fat was a primary dietary culprit in the development of MS.¹ Upon returning to North America, Dr. Swank published his findings in *The New England Journal of Medicine* in 1952.² He continued to make diet a primary focus of his research into MS throughout his career, and in 1972, published a book detailing the first diet specifically formulated for people with MS.¹

Since Dr. Swank's pioneering work, many other diets have been evaluated for their potential to ease the symptoms and slow the progression of MS, and at least one other eating plan has been developed specifically to counter the effects of the disease. The author of that approach, Terry Wahls, MD, is

a physician and researcher like Dr. Swank, and also is a person living with MS.³

The Wahls Protocol™ diet emphasizes the consumption of vegetables (particularly leafy greens), berries and other brightly colored fruits, meat and fish, and omega-3 fatty acids and other fats from animals and plants. By contrast, people following this diet steer clear of sugar; dairy products and eggs; "nightshade" vegetables, such as tomatoes, peppers, potatoes, and eggplant; legumes, which include beans, peas, peanuts, and more; plus grains, such as wheat and rice.

The breadth of diets being investigated is matched by the depth of people's interest in the topic. When neurologists J. Nicholas Brenton, MD, and Myla D. Goldman, MD, MSc, surveyed 199 people with MS in 2015, 91.5% of respondents said they were interested in using diet modification as a way to address their MS, and 85% said they were willing to stick with diet therapy for three months or more.⁴

That desire to enlist diet in the fight against MS is supported by a wealth of encouraging evidence. (Additional studies will be cited in the next edition of *The Motivator*.)

For example, in 2018, a group of researchers in the United States and Canada constructed a "diet quality score" based on people's intake of four types of foods: 1. Fruits, vegetables, and legumes; 2. Whole grains; 3. Sugar obtained from sweetened beverages and desserts; and, 4. Red meats and processed meat. They then surveyed almost 7,000 people with MS on their eating

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 - feeling faint
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 - wheezing
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 - abdominal pain
 - throat irritation
 - redness of the face or skin

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IMPORTANT SAFETY INFORMATION (CONTINUED)

These infusion reactions can happen over 24 hours after your infusion. It is important that you call your healthcare provider right away if you get any of the signs or symptoms listed above after each infusion. If you get an infusion reaction, your healthcare provider may need to stop or slow down the rate of your infusion.

● **Infection:**

- Infections are a common side effect, and upper respiratory tract infections are one of the most common side effects of BRIUMVI. BRIUMVI increases your risk of getting infections caused by bacteria or viruses that may be life-threatening or cause death. Tell your healthcare provider if you have an infection or have any of the following signs of infection including fever, chills, a cough that does not go away, or painful urination. Your healthcare provider should delay your treatment with BRIUMVI until your infection is gone.
 - Hepatitis B virus (HBV) reactivation: Before starting treatment with BRIUMVI, your healthcare provider will do blood tests to check for hepatitis B viral infection. If you have ever had hepatitis B virus infection, the hepatitis B virus may become active again during or after treatment with BRIUMVI. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. Your healthcare provider will monitor you if you are at risk for hepatitis B virus reactivation during treatment and after you stop receiving BRIUMVI.
 - Weakened immune system: BRIUMVI taken before or after other medicines that weaken the immune system could increase your risk of getting infections.
 - Progressive Multifocal Leukoencephalopathy (PML): PML may happen with BRIUMVI. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These symptoms may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion, and personality changes.
- **Low immunoglobulins:** BRIUMVI may cause a decrease in some types of antibodies. Your healthcare provider will do blood tests to check your blood immunoglobulin levels.

Before receiving BRIUMVI, tell your healthcare provider about all of your medical conditions, including if you:

- have or think you have an infection.
- take or plan to take medicines that affect your immune system. These medicines may increase your risk of getting an infection.

- have ever had hepatitis B or are a carrier of the hepatitis B virus.
- have had a recent vaccination or are scheduled to receive any vaccinations.
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 - If you have a baby and you received BRIUMVI during your pregnancy, it is important to tell your baby's healthcare provider about receiving BRIUMVI so they can decide when your baby should be vaccinated.
- are pregnant, think that you might be pregnant, or plan to become pregnant. BRIUMVI may harm your unborn baby. You should use birth control (contraception) during treatment with BRIUMVI and for at least 6 months after your last infusion of BRIUMVI. Talk with your healthcare provider about what birth control method is right for you during this time.
- are breastfeeding or plan to breastfeed. It is not known if BRIUMVI passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take BRIUMVI.

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

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The most common side effects of BRIUMVI include:

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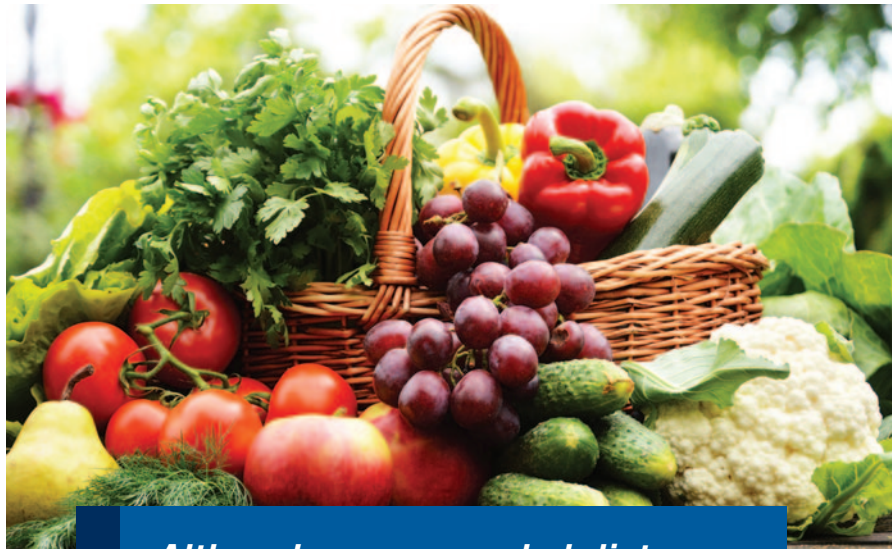
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habits and assigned each person a diet quality score. They found that people who ranked in the top fifth of the group for diet quality had lower levels of disability and depression than their counterparts who had lower scores, representing a lower-quality diet. The researchers also found that study participants who had a healthier lifestyle overall – one in which a high-quality diet was combined with a healthy weight, regular physical activity, and not smoking – were about one-third less likely than other people studied to report severe fatigue or cognitive impairment, and only about half as likely to report depression or pain.⁵

In a separate study, a team of Australian investigators monitored almost 1,000 people with MS over 7.5 years and found that those who followed a better diet (in general, think less meat and dairy, more fruits and vegetables) had a better quality of life in terms of physical symptoms than their peers who had a lower-quality diet. Meanwhile, meat consumption was associated with lower physical quality of life, and dairy consumption with lower physical and mental quality of life.⁶

Despite that evidence, only 17% of the people with MS surveyed by Dr. Brenton and Dr. Goldman in 2015 reported that they were attempting to use diet to impact their MS.⁴ Why such a low proportion? First, it's important to note that the question asked about what the study participants were doing when they answered the survey, rather than about past attempts or future plans. Looking at the larger picture, however, if people with



Although recommended diets may differ in their specifics, they universally emphasize the importance of including plenty of fruits and vegetables.

MS are uncertain about which diet is the best one for them to follow, it may be because many MS clinicians are, too.

Advocates of various eating plans and researchers assessing those plans tend to agree on two things:

- Avoid processed foods as much as possible
- Eat plenty of fruits and vegetables, although some diet plans carry important caveats about which types of vegetables to eat

Experts say that beyond these two major points, theories on diet are not likely to come together until further research has provided definitive guidance. They add, however, that this is not reason to despair, because there are plenty of steps people with MS can take right now to improve their health by making thoughtful choices about what they eat.

Adopting Practical Approaches while Awaiting Precise Answers

As a young neurologist, Ilana Katz Sand, MD, found that her patients were frustrated – and so was she.

“They would say, ‘I know you want me to take this medication for my MS, and I’ll do that, but what else can I do? What foods should I be eating, or not eating? What diet should I be following?’ And it was very unsatisfying to me as their clinician and as a scientist, and very unsatisfying to them as people who wanted to take a proactive approach to their health, for me to have to tell them that I didn’t have good, evidence-based answers to their questions,” Dr. Katz Sand says of frequent conversations she had with newly diagnosed patients during her fellowship training in multiple sclerosis.

In the 10 years since she completed her MS fellowship, Dr. Katz Sand has devoted much of her time to pursuing those answers through rigorously constructed and conducted studies. Now an associate professor of neurology at the Icahn School of Medicine at Mount Sinai in New York City and a clinician at Mount Sinai’s Corinne Goldsmith Dickinson Center for MS, Dr. Katz Sand has emerged as a leading researcher on the impact of diet on MS disease progression and symptoms. Working with Mount Sinai colleagues and with physicians at other academic medical centers across the country, she has published many papers on the biological mechanisms by which nutrition influences the course of MS. In these writings, Dr. Katz Sand explains how various

approaches to eating appear to affect the symptoms often faced by people with MS, including fatigue and cognitive issues, as well as other symptoms.

Dr. Katz Sand says that much has changed for the better over that decade. Researchers know more about diet and MS than ever before, and intriguing findings from small studies and observational analyses are being put to the test in larger, prospective trials. There is also a growing realization that medical students and residents need more training in nutrition, and a greater emphasis on taking a holistic approach to the care of people with MS. One thing, however, hasn’t changed: “Patients still want to know ‘the big secret’ when it comes to diet,” the neurologist says with a smile.

The big secret to diet in MS, according to Dr. Katz Sand and other experts interviewed for this article, is that there is no big secret. Nor, they say, is there definitive evidence supporting a one-approach-fits-all diet or other nutritional remedy for combating the effects of multiple sclerosis.

A registered dietitian nutritionist, Mona Bostick, RDN, LDN, MSCS, explains, “When people with MS see me for a consultation, they often want to know how many blueberries they should eat each day for anti-inflammatory purposes or how much salmon they need to consume to reduce their spasticity.”

She continues, “A lot of my initial work with these individuals is to explain that there has been no research demonstrating that your nutritional needs change when you

receive a diagnosis of multiple sclerosis. People with MS do not absorb, metabolize, or excrete the food they eat any differently than other people. So, when people ask about specific foods and the quantities they should eat to have a specific impact on their MS, I

tell them that we just don't have the evidence we would need to endorse such precise steps. We are not anywhere close to that point."

While we await such answers, Ms. Bostick and other experts say, people with MS can benefit from taking five steps.

Recommended Dietary Intake: Start with These Five Ingredients

1 Take your nutritional advice (but not your meals) with a grain of salt.

An August 2023 internet search of the term "Diet and MS" yielded roughly 843,000,000 results. The problem, says Ms. Bostick, is that many of those "hits" are actually "misses."

"People with MS are being bombarded with nonsense. I would say that three-quarters of the questions I'm asked are based on misinformation that people have read on the internet, often from sources that are trying to sell them something," she explains. Ms. Bostick, who began her nutrition career working with cancer patients in an acute-care, inpatient setting, launched the MSBites website (www.msbytes.com) in large part to counter the abundance of questionable or just plain wrong information about multiple sclerosis that she found on the internet after she was diagnosed with relapsing-remitting MS in 2008. "I wish I had a megaphone that I could use to tell people: Talk with your clinician, talk with other healthcare professionals, but don't listen to Dr. Google!" she says.

Barry Hendin, MD, adds, "Beware fads. Beware anecdotes. Beware highly specific advice that makes highly specific claims." Dr. Hendin, a Phoenix-based neurologist and MS specialist who serves as the Multiple Sclerosis Association of America's Chief Medical Officer, says, "The broad outlines of healthy nutritional practices are known to us. Further, several recent studies have yielded encouraging results, and research under way now is going to provide us with great insights in the years ahead. But we're just not at a stage where we can say definitively that Diet X or Food Y will have Z Effect on multiple sclerosis."

2 Take out your insurance card and turn it over.

So where can people with MS find reliable information on nutrition? Ms. Bostick recommends that they start by reaching for their wallet instead of their laptop mouse. She doesn't want them to extract a credit card or cash to buy anything, however. Rather, she says, "Pull out your insurance card and find the number on the back that



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you can call to learn what benefits your plan offers. Find out if you're eligible for a certain number of visits with a registered dietitian each year or at least for an initial consultation. If so, take advantage of that healthcare professional's expertise." Other resources are available that are free of charge – including reputable websites such as the US Department of Agriculture's (USDA) website on nutrition at [nutrition.gov](https://www.nutrition.gov). A good place to start is by going to [nutrition.gov/topics/basic-nutrition](https://www.nutrition.gov/topics/basic-nutrition).

3

Take a look at what's realistic – over the long term and for everyday living.

Dr. Hendin explains, "When patients ask me what diet they should follow, I start by telling them that there's no single magic diet for MS. I then explain that whatever approach they choose should be well-balanced in terms of different types of healthy foods and should be relatively flexible. It should not be so restrictive that you can't follow it over time." Dr. Hendin adds, "My view is that eating should provide pleasure as well as nutrition. If a diet turns eating into a chore, you won't stick with that diet."

Ms. Bostick has a similar outlook, as she describes on her website. "As a general rule, I opt out of food fights and nutrition extremes or 'diets.' I believe that the way to optimal nutrition is through personalized, sustainable habit changes rather than strict, inflexible, and perhaps unrealistic dogma." In a recent interview, she noted that people can sometimes feel a sense of guilt or shame when

they're unable to adhere to a very restrictive diet, and may even believe that this somehow makes them responsible for their MS getting worse because of a lack of discipline or willpower. The sad irony, she adds, is that those negative emotions are induced by an inability to stay on a very demanding diet that has no foundation in the evidence.

Dr. Katz Sand notes that it's easier to eat poorly than it is to eat well, not only for people with MS but for everyone. "We're all so pressed for time that it's very tempting to just order take-out food, but the more we can make the effort to prepare our own meals, including healthy ingredients and avoiding things like added sugars, the better off we'll be."

One of the main ways registered dietitians can assist people with MS, Ms. Bostick notes, is by helping them identify obstacles to good nutritional practices and strategies for overcoming those obstacles. "Based on the available evidence, the principles of healthy eating are not different for people with MS than they are for other people, but healthy eating can be more difficult for people with MS than for others." This is because of issues with manual dexterity, swallowing difficulties, mobility, vision problems, cognitive issues, and other common manifestations of MS.

"Help the dietitian help you" by providing a complete, honest explanation of your abilities, challenges, preferences, and concerns, so that the dietitian can devise a personalized approach to meal planning and preparation that will work day-in and day-out, Ms. Bostick adds.

4 Take your eyes off the scale, at least at first.

“In counseling patients about diet, I used to focus on weight more than on healthy eating. Then my daughter counseled me,” Dr. Hendin says. He explains that he has three daughters, the oldest a psychologist, the middle one a neurologist, and the youngest a psychiatrist. It was that oldest daughter who convinced him that a change of emphasis was in order. Drawing on her knowledge of human behavior and motivation, she explained that having people concentrate on healthy habits gained rather than excess pounds lost was the better way to promote enduring change.

5 Take a step back to see the larger picture.

“I still encourage people to reach and maintain a healthy weight, but that’s not where I start. I begin by talking about healthy eating and encouraging the adoption of good habits. If people can do that, the weight loss generally will follow,” Dr. Hendin says.

In a similar vein, Ms. Bostick focuses on having people add healthy foods to their diets more than she does on placing restrictions on other foods. The idea, she explains, is to have people feel good about the positive steps they’re taking, rather than feeling badly about not immediately eliminating less-advisable (but often more desirable) items from their diets.

Dr. Hendin says that just as a healthy diet consists of many nutritious foods, a comprehensive approach to healthy living entails much more than eating well. He explains, “Diet has to be part of a larger effort to optimize health, one that includes regular exercise, obtaining sufficient sleep, and maintaining social connections, among other things.” Dr. Hendin adds that just as people with MS should not become overly focused on eating a particular food or losing a specific number of pounds, neither should they let their attention to diet detract from attending to other aspects of their well-being.



What Should People with MS be Eating, and Not Eating, and Why?

Outlining dietary principles and practices, such as those already noted, is all well and good, but it can leave people hungry for something more substantial in terms of which foods they should eat and which they should avoid. While the experts interviewed for this article did not endorse one diet over others for all people with MS, they did have recommendations about healthy eating.

Dr. Katz Sand says, “If there’s one piece of advice I would ask people to follow, it is to try to limit your reliance on processed foods, because so many things flow from that in terms of overall health. Limiting processed foods can be hard. It requires thought and time and preparation, so there’s a lot that goes into it, but the dietary research shows there are significant benefits.” One key to reducing processed foods in your diet is to work with a dietitian or other professional who can “walk through” your day or week with you and devise workable approaches, Dr. Katz Sand adds.

And while we’re on the subject of foods to avoid, what about gluten? (Gluten includes wheat, barley, and rye.) “I think the biggest myth or misperception that I hear from patients is that we’ve determined that gluten is bad for people with MS. We definitely have not demonstrated that through any reliable research, despite what a number of websites may say to the contrary.” Dr. Katz Sand clarifies that she’s not endorsing gluten intake for MS, but rather is highlighting the lack of

evidence to support the bad reputation gluten has received in many corners of the internet.

Dr. Katz Sand says that another misperception she frequently encounters is the idea that the more restrictive or inflexible a diet is, the better it must be for you. Not true, she says, noting that variety, balance, and flexibility tend to be the keys to eating plans that are both beneficial and sustainable over time. She also cautions people against the notion that more expensive means more beneficial. “The frozen vegetables in the freezer aisle of your supermarket are a great alternative to fresh produce in the specialty food store,” she says. In addition to their affordability, frozen vegetables are more convenient to store and often easier to prepare, if experiencing challenges such as fatigue, weakness, and reduced manual dexterity.

With regard to the foods that people with MS should be eating, Dr. Hendin provides this advice. “I tell my patients to eat lots of fruits and vegetables. I advise them to eat more chicken and fish and less red meat and processed meats. I tell them to eat more nuts and legumes, and to avoid processed foods.”

If that advice sounds like it could be coming from a cardiologist, there’s good reason for that. Dr. Katz Sand explains, “We’ve seen in observational studies that people with MS who have certain other health conditions have a worse outlook for their multiple sclerosis compared to people who have MS but who don’t have those comorbid conditions.

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Diet and MS: The Gut Microbiome Connection

We all know that the digestive system is the mediator between what we eat and how those foods affect our bodies and health. More recently, however, scientists have begun to identify all the ways the gut microbiome – a vast reservoir of microbes within the digestive system – influences our immune system and its disorders, including multiple sclerosis.

Andrew Woo, MD, PhD, is a neuro-immunologist in private practice at Santa Monica Neurological Consultants in Santa Monica, CA, and Assistant Clinical Professor of Neurology at the David Geffen School of Medicine at the University of California – Los Angeles and Cedars-Sinai Medical Center. Dr. Woo is also a member of MSAA’s Board of Directors.

Dr. Woo explains, “You have about 39 trillion microorganisms in your gut – including bacteria, viruses, and fungal elements. By comparison, you have about 30 trillion cells in your body. The microorganisms in the intestines exist in a symbiotic community. Some support health; others are detrimental to health.

“Research has shown that the microbiota play a huge role in several autoimmune conditions, including not only MS but also rheumatoid arthritis, Crohn’s disease, psoriasis, and asthma. More recently, research in animal models has linked the gut microbiome to conditions such as Alzheimer’s disease, Parkinson’s disease, and even mood disorders.”

Dr. Woo adds that studies have shown

important differences in the gut microbiome in people with MS compared to the general population. “For example, levels of a microorganism known as *methanobrevibacter smithii* are six to seven times higher in people with MS than in other people. Similarly, people with MS tend to have relatively lower levels of other microorganisms, such as bacteria from the *porphyromonadaceae* and *faecalibacterium* groups. What is the significance of these differences? Researchers are still working out the mechanisms and processes involved, but we know that gut bacteria break down carbohydrates to produce short-chain fatty acids, which exercise an anti-inflammatory effect,” he notes.

Dr. Woo adds that three short-chain fatty acids – propionic acid, acetic acid, and butyric acid – support the immune system’s T-regulatory cells, which play a key role in controlling inflammation.

So can people with MS use dietary approaches to alter their microbiome?

Dr. Woo responds to that question with a resounding, “Yes!”

He explains that several foods are high in short-chain fatty acids, including oats, barley, lentils, apples, nectarines, asparagus, bananas, and garlic. A number of small and moderate-sized studies also support use of supplements as a means of obtaining short-chain fatty acids, Dr. Woo says.

He points to a 2017 randomized controlled pilot trial in which 51 people with secondary-progressive MS were assigned to

receive either 1,200 mg a day of alpha lipoic acid or placebo. After two years of follow-up, the 27 people who took alpha lipoic acid had significantly less loss of brain volume than people in the placebo group, although they had a higher incidence of gastrointestinal upset.¹

Dr. Woo adds that a 2020 study involving 91 people with MS found that 14 days of taking a propionic acid supplement altered the composition of the gut microbiome and changed those people's balance of the T-regulatory cells that fight inflammation and TH17 cells, another type of T cell that drives inflammation.² Other research, he notes, is examining the potential anti-inflammatory effects of bile acid supplements, such as tauroursodeoxycholic acid, or TUDCA, a substance long used by Chinese herbalists for a variety of purposes.

Looking beyond specific microorganisms and their availability from foods and supplements, Dr. Woo adds that a wealth of data has shown that intermittent fasting not only drives weight loss but also rebalances the gut microbiome in a way that decreases inflammation. By following an intermittent fasting approach such as eating only during an 8-hour period each day, "You literally change the bacteria in your gut into the good bacteria, the ones that produce more short-chain fatty acids. This comes from altering the timing of your eating, not what you're eating. It takes a lot of discipline, but it's crazy to me that you can have this effect just based on when you eat," he adds.

For this reason, he explains, he

sometimes recommends that patients adopt intermittent fasting to alter their gut microbiome and then transition to a Mediterranean-style diet.

The neuroimmunologist emphasizes that dietary efforts to improve the course of MS should be part of a comprehensive approach that also includes engaging in regular physical activity, obtaining adequate sleep, and taking disease-modifying therapy selected through a shared decision-making process with an MS clinician.

And his final piece of advice? Well, if you can find one, consider an occasional sardine brandy latte. He explains, "A Belgian study that followed more than 1,300 people with MS over the course of several years found that eating fish and drinking coffee and alcohol reduced the risk of progression in those with relapsing forms of the disease."³ Beyond counseling moderation with alcohol and caffeine intake, Dr. Woo urges, "So drink up. It tastes disgusting, I know, but maybe we can come up with a cool name for it."

References

- ¹ Spain R, Powers K, Murchison C, et al. lipoic acid in secondary progressive MS: a randomized controlled pilot trial. *Neurol Neuroimmunol Neuroinflamm.* 2017;4(5):e374.
- ² Duscha A, Gisevius B, Hirschberg S, et al. Propionic acid shapes the multiple sclerosis disease course by an immunomodulatory mechanism. *Cell.* 2020;180:1067-1080.
- ³ D'Hooghe MB, Haentjens P, Nagels G, De Keyser J. Alcohol, coffee, fish, smoking and disease progression in multiple sclerosis. *Eur J Neurol.* 2011;19:616-624.

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Indication

What is KESIMPTA (ofatumumab) injection?

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

It is not known if KESIMPTA is safe or effective in children.

Important Safety Information

Who should not take KESIMPTA?

Do NOT take KESIMPTA if you have active hepatitis B virus (HBV) infection.

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Important Safety Information (cont)

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

KESIMPTA can cause serious side effects such as:

- **Infections.** Serious infections can happen during treatment with KESIMPTA. If you have an active infection, your healthcare provider (HCP) should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections. Tell your HCP right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.
- **HBV reactivation.** If you have ever had HBV infection, it may become active again during or after treatment with KESIMPTA (reactivation). If this happens, it may cause serious liver problems including liver failure or death. Before starting KESIMPTA, your HCP will do a blood test to check for HBV. They will also continue to monitor you during and after treatment with KESIMPTA for HBV. Tell your HCP right away if you get worsening tiredness or yellowing of your skin or the white part of your eyes.
- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your HCP right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory, which may lead to confusion and personality changes.
- **Weakened immune system.** KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

Before you take KESIMPTA, tell your HCP about all your medical conditions, including if you:

- Have or think you have an infection including HBV or PML.
- Have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- Have had a recent vaccination or are scheduled to receive any vaccinations.
 - You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA. You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your HCP tells you that your immune system is no longer weakened.
 - Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.
 - Talk to your HCP about vaccinations for

your baby if you used KESIMPTA during your pregnancy.

- Are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your HCP about what birth control method is right for you during this time.
- Are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your HCP about the best way to feed your baby if you take KESIMPTA.

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

How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready pens or prefilled syringes.

- Use KESIMPTA exactly as your HCP tells you to use it.
- Your HCP will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars, or stretch marks.

KESIMPTA may cause serious side effects including:

- **Injection-related reactions.** Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. Talk with your HCP if you have any of these signs and symptoms:
 - **at or near the injection site:** redness of the skin, swelling, itching, and pain or
 - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, and tiredness.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your HCP will do blood tests to check your blood immunoglobulin levels.

The most common side effects of KESIMPTA include:

- Upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache.
- Headache.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see accompanying Consumer Brief Summary on the following page.

Consumer Brief Summary

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

To learn more about KESIMPTA (ofatumumab) injections, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.kesimpta.com.

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

KESIMPTA can cause serious side effects, including:

Infections. Serious infections can happen during treatment with KESIMPTA. If you have an active infection, your healthcare provider should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections.

Tell your healthcare provider right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.

- **Hepatitis B virus (HBV) reactivation.** Before starting treatment with KESIMPTA, your healthcare provider will do blood tests to check for HBV. If you have ever had HBV infection, the HBV may become active again during or after treatment with KESIMPTA. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. You should not receive KESIMPTA if you have active hepatitis B liver disease. Your healthcare provider will monitor you for HBV infection during and after you stop using KESIMPTA. Tell your healthcare provider right away if you get worsening tiredness or yellowing of your skin or white part of your eyes during treatment with KESIMPTA.

- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion and personality changes.

Weakened immune system. KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

What is KESIMPTA?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including:

- clinically isolated syndrome
- relapsing-remitting disease
- active secondary progressive disease

It is not known if KESIMPTA is safe or effective in children.

Do not use KESIMPTA if you:

- have active hepatitis B virus infection.

Before using KESIMPTA, tell your healthcare provider about all of your medical conditions, including if you:

- have or think you have an infection, including HBV or PML. See **“What is the most important information I should know about KESIMPTA?”**
- have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations.
 - **You should receive any required ‘live’ or ‘live-attenuated’ vaccines at least 4 weeks before you start treatment with KESIMPTA.** You **should not receive** ‘live’ or ‘live-attenuated’ vaccines while you are being treated with KESIMPTA and until your healthcare provider tells you that your immune system is no longer weakened.
 - **Whenever possible, you should receive any ‘non-live’ vaccines at least 2 weeks before you start treatment with KESIMPTA.**
 - Talk to your healthcare provider about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your healthcare provider about what birth control method is right for you during this time.
- are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take KESIMPTA.

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

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

How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready[®] pens or prefilled syringes.

- Use KESIMPTA exactly as your healthcare provider tells you to use it.
- KESIMPTA is given as an injection under your skin (subcutaneous injection), in your thigh or stomach-area (abdomen) by you or a caregiver. A caregiver may also give you an injection of KESIMPTA in your upper outer arm.
- Your healthcare provider will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars or stretch marks.
- The initial dosing is 20 mg of KESIMPTA given by subcutaneous injection at Weeks 0, 1, and 2. There is no injection at Week 3. Starting at Week 4 and then every month, the recommended dose is 20 mg of KESIMPTA administered by subcutaneous injection.

If you miss an injection of KESIMPTA at Week 0, 1, or 2, talk to your healthcare provider. If you miss a monthly injection, give it as soon as possible without waiting until the next scheduled dose. After that, give your KESIMPTA injections a month apart.

What are the possible side effects of KESIMPTA?

KESIMPTA may cause serious side effects, including:

See **“What is the most important information I should know about KESIMPTA?”**

- **Injection-related reactions.** Injection-related reactions is a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. Talk with your healthcare provider if you have any of these signs and symptoms:
 - **at or near the injection site:** redness of the skin, swelling, itching and pain or
 - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, and tiredness.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your healthcare provider will do blood tests to check your blood immunoglobulin levels.

The most common side effects of KESIMPTA include:

- upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache. (See **“What is the most important information I should know about KESIMPTA?”**)
- headache

These are not all the possible side effects of KESIMPTA. Call your doctor for medical advice about side effects.

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

How should I store KESIMPTA?

- Store KESIMPTA in a refrigerator between 36°F to 46°F (2°C to 8°C).
- Keep KESIMPTA in the original carton until ready for use to protect from light.
- If needed, KESIMPTA may be stored for up to 7 days at room temperature, up to 86°F (30°C).
- Write the date taken out of the refrigerator in the space provided on the carton.
- If stored below 86°F (30°C), unused KESIMPTA may be returned to the refrigerator and must be used within the next 7 days. If this KESIMPTA is not used within those 7 days, then discard the medicine.
- Do not freeze KESIMPTA.
- Do not shake KESIMPTA.

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

General information about the safe and effective use of KESIMPTA.

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

You can ask your pharmacist or healthcare provider for information about KESIMPTA that is written for health professionals.

What are the ingredients in KESIMPTA?

Active ingredient: ofatumumab

Inactive ingredients: Sensoready pen and prefilled syringe: arginine, disodium edetate, polysorbate 80, sodium acetate trihydrate, sodium chloride, and Water for Injection. Hydrochloric acid may be added.

continued from page 14

Dr. Katz Sand continues, “In particular, high blood pressure, high cholesterol, and diabetes confer a worse prognosis for MS. But we don’t have a great understanding yet of why that is. It’s hard to know if, on a pathological basis, there is something that is very specific to MS that is happening, or whether the same biological process is at work and it is just manifesting in people with MS in a way that’s slightly different than in the general population. We have to get the research done so we can give people better guidance in this area.”

Until then, says Ms. Bostick, “Eat with those co-morbidities in mind.” She notes that the evidence base for diet and heart disease is much deeper and broader than the evidence available right now on diet and MS, and that the dietary approach outlined earlier by Dr. Hendin has been shown to be beneficial in avoiding or controlling the cardiometabolic conditions linked to worse outcomes in MS.

Dr. Hendin goes a step further. “Although I don’t endorse any one diet, I tend to like the Mediterranean diet, which emphasizes the vegetables, fruits, fish, nuts, and other foods that I recommend, along with whole grains and

olive oil. We know, from extensive research, that the Mediterranean diet reduces cardiovascular risk and improves general health, and we think, from early and continuing research, that it also improves MS symptoms. Actually, many of the diets that are of interest to people with MS right now, such as the Mediterranean diet or the Wahls Protocol, emphasize a lot of these foods, although each eating plan differs in important ways,” he says.

Dr. Hendin adds that while studies still need to establish the full benefits and potential drawbacks of specific diets in MS, the weight of the evidence supporting the advantages of healthy eating has changed the way he counsels patients. “I used to say that adopting healthy eating patterns would improve their prognosis over the long term, 10 or 20 years down the line. I still tell patients that, but now I’ve seen enough data to tell them that good nutrition also will help them feel better now, in terms of fatigue and other conditions.”

Ms. Bostick says that short-term improvements experienced by people typically have less to do with adding or excluding a particular food than with enhancing their overall nutritional status. “Someone with MS will come to me and say, ‘I’m experiencing a lot of fatigue, what food should I eat?’ The first thing I look at

Hear More Insights from Dr. Woo on Diet, MS, and the Microbiome

The Multiple Sclerosis Association of America (MSAA) recently featured Dr. Woo on a podcast titled “The 3 M’s of MS: Mangia, Microbiome, and Molecules.” On the podcast, the neuroimmunologist and member of MSAA’s Board of Directors provides greater detail on how the microbiome and diet affect MS, and on approaches people with MS can take to alter their gut microbiome. Tune in at mymsaa.org/msaa-podcasts or search “MSAA Podcast” wherever you listen to podcasts.

in such cases is whether the person is meeting his or her nutrient needs. This may sound like a strange thing to say when we're in the midst of an obesity crisis, but we need to institute malnutrition risk screening for people with MS as part of their regular outpatient care."

She explains, "While we await further answers on diet and MS, I would encourage people with MS to follow the approaches detailed in the "Dietary Guidelines for Americans" produced by the United States Department of Health and Human Services and available at [health.gov/our-work/nutrition-physical-activity/dietary-guidelines](https://www.health.gov/our-work/nutrition-physical-activity/dietary-guidelines). The document emphasizes nutrient-dense foods, a colorful variety of plant-based foods, and other choices that have been shown to be beneficial for all people."

Ms. Bostick concludes, "Eating is a really important component of health for every person, and when you have a chronic condition such as MS, it becomes even more important. As both a dietitian and a person living with MS, I understand the desire for very specific answers, very precise guidance. But that guidance has to be reliable and well-validated. We're moving in that direction, but

until we're there, I want people with MS to know that they don't need to wait to enhance their well-being – there are sound, sensible things they can do right here and right now to improve their overall health." ■

References

- 1 Swank MS Foundation. Swank MS Foundation: For Your Health, For Your Future. Available at swankmsdiet.org. Accessed August 13, 2023.
- 2 Swank RL, Lerstad O, Strom A, Becker J. Multiple sclerosis in rural Norway – its geographic and occupational incidence in relation to nutrition. *N Engl J Med*. 1952;246:721-728. DOI: 10.1056/NEJM195205082461901.
- 3 TerryWahls.com. My Story. Available at <https://terrywahls.com/about/about-terry-wahls/>. Accessed August 15, 2023.
- 4 Brenton JN, Goldman MD. A study of dietary modification: perceptions and attitude of patients with multiple sclerosis. *Mult Scler Relat Disord*. 2016;8:54-57.
- 5 Fitzgerald KC, Tyry T, Salter A, et al. Diet quality is associated with disability and symptom severity in multiple sclerosis. *Neurology*. 2018;90e1-11. doi:10.1212/WNL.0000000000004768.
- 6 Simpson-Yap S, Nag N, Probst Y, Reece JC, Jelinke GA. *Mult Scler Relat Disord*. 2022;60.doi:10/1016/j.msard2022.10371.

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Questions from Our Readers

By Dr. Barry Hendin

MSAA's Chief Medical Officer

Q: I suffer from achalasia, similar to dysphagia. I have difficulty swallowing and have to have my throat stretched once a year during an endoscopy. I wanted to ask if you have any specific recommendations for people with this problem.

As a sidenote, I wanted to let you and your readers know that I received a tip through a chatline, and I am so grateful that I did. Anything that has fizz to it helps food to go down – and I choose sparkling mineral water because I only drink water. Whether it's chicken, yogurt, or an apple, when I drink the fizzy water, it helps everything to go down and within seconds I can swallow normally again.

A: Thank you for your question regarding achalasia. As you point out, both achalasia and dysphagia have similarities, since both refer to problems swallowing. There are some important differences, however, which I will describe. In addition, I wanted to note that “dysphagia” (ending with “gia”) is often confused with “dysphasia” (ending with “sia”), which refers to problems with conceptualizing and understanding speech.

Regarding the differences between the two types of swallowing disorders, dysphagia is relatively common in MS due to weakness or incoordination of the muscles involved in swallowing, including the mouth, tongue, palate, and pharynx (throat). Achalasia, on the other hand, is due to structural problems in the distal esophagus; its association with multiple sclerosis is uncertain.

Achalasia is generally treated by the gastroenterologist with treatments that include stretching. The most useful clinician for the treatment of dysphagia is usually the speech therapist, who can educate and instruct regarding safer and more efficient swallowing techniques. And in your case, I'm especially pleased that you have found a simple technique to help you with your swallowing by drinking fizzy water!

Q: I will be 65 in a few weeks and was diagnosed with clinically isolated syndrome (CIS) in 2016 – when I was in my late fifties – after having optic neuritis (an ongoing symptom) in 2015. No one believed it could be MS. I was considered "too old" to have my first symptom. I had a relapse in 2019, which changed my diagnosis to relapsing-remitting MS (RRMS).

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I am still fairly new to living with MS. I am finding it difficult to figure out what is MS and what is normal aging. I would be interested in hearing about patients who were diagnosed late in life. Have there been any studies on this topic?

A: Your experience with clinically isolated syndrome and MS is indeed instructive to the medical community. You are a living example of the fact that MS can occur in people in a wider age range than is considered typical. We have diagnosed MS in young children as well as in people in their 50s, 60s, and 70s. Studies show that 5% of MS diagnoses occur in people over the age of 50.

Although the diagnosis is usually made in young adults, people with MS will get older and ultimately have to deal with issues of

aging. Distinguishing between the effects of aging and possible MS progression is difficult for patients and for clinicians. It is currently a hot topic in the MS world. Cognitive issues (such as prolonged processing speed) and motor issues (such as weakness and imbalance), while often associated with MS, also occur naturally in older age, independent of MS. In late MS, in general, the concern is less about acute inflammation, such as relapses, and more about possible progression.

Although separating the effects of natural aging from multiple sclerosis in later years can be difficult, the actions that we should be taking are more straightforward. People with multiple sclerosis, as they age, should be maintaining an exercise program, eating a healthy diet, staying active socially, and giving attention to general mental health as well as

to the treatment of comorbidities, i.e., other health conditions.

You also asked about studies that have been done on the topic of individuals diagnosed at an older age. An article titled, “Clinical Features of Late-Onset Multiple Sclerosis: A Systematic Review and Meta-analysis,” appeared in the May 2021 edition of *Multiple Sclerosis and Related Disorders* (Naseri A, Nasiri E, Sahraian MA, et al.) and provides a good deal of information about late-onset MS, along with citing other relevant articles.

Q: I was diagnosed with MS in 2006, and at that time, I had 21 lesions. About a year ago, two more lesions “lit up.” Prior to this finding, another doctor told me I did not have MS, but could not tell me the cause of the lesions. I have several symptoms, including dizziness and balance problems. I would like to ask what other conditions might cause lesions and what suggestions you may have.

A: You bring up several important points: MS diagnostic criteria, symptomatic treatment of MS, and disease-modifying therapies (DMTs). I will try to address each one of these issues.

The diagnosis of MS is based on the appropriate history and examination, along with laboratory confirmation. We refer to the diagnostic criteria as the revised McDonald criteria. The discovery of brain lesions alone is insufficient to diagnose MS, although the number

*Please submit questions
for Ask the Doctor via
email to askdr@mysaa.org*

of entities that can create brain lesions is vast.

For most people who are diagnosed with multiple sclerosis, we suggest a DMT. Since there are more than 25 types and brands of DMTs approved by the FDA for the treatment of MS, we can generally find one that is appropriate and does not cause excessive side effects or risk. These DMTs reduce the likelihood of MS relapses and progressive disability.

For issues such as dizziness and imbalance, it’s appropriate to turn to symptomatic treatments. These symptomatic interventions can be medications, but more often they are evaluations and treatment by physical therapists.

Improving the quality of life for today, and maintaining function for the future, are the ultimate goals of MS therapies.

Q: In a recent cover story of *The Motivator* on aging, the term, “immunosenescence,” was used. I have only heard of “senescent cells,” which I understand are old cells that won't die and affect the immune system. I am now 64 and I know that the turnover of cells slows down as we age. I want to ask how these cells affect the immune system and if there is anything we can do to get rid of the old cells more quickly.

Immunosenescence has become an increasing focus in MS. The term immunosenescence refers to the natural aging of the immune system. The general population is aging, but there has also been a specific increase in longevity in

people with MS due to increasingly effective disease-modifying therapies (DMTs). As the immune system ages, the consequences can include an increased susceptibility to infections and tumor, a decreased effectiveness of vaccinations, and inflammation. This is not unique to multiple sclerosis. Immunosenescence occurs in the general population, but it has special importance in people with MS. For example, the risk/benefit ratio of our DMTs changes with aging, and similar to the consequences of the aging of one's immune system, infections become more likely and the effectiveness of vaccination diminishes.

Immunosenescence is incompletely understood, and immunology is always complex! (I don't think in terms of old cells that won't die, but rather changes in the immune cells, such as T cells and B cells and natural killer cells.) Older cells do lose some of their immune capabilities, and fewer new or naïve cells are produced. The organs that generate immune cells, such as the thymus, diminish. As we try to understand this phenomenon better, we have also begun to ask what strategies we can employ to rejuvenate the immune system. Stay tuned! ■

Check out MSAA's PODCAST

Featuring episodes on:

- Young adults and MS
- Pediatric MS
- Relationships and MS
- Care partner needs
- Diversity and MS
- Choosing the right MS therapy
- Nutrition

Please visit MSAA's website to listen to our podcast, or search for "**MSAA Podcast**" on any of the major podcast distributors.

mymsaa.org/podcasts

Barry A. Hendin, MD, is a highly accomplished neurologist who specializes in MS. He is the chief medical officer for the Multiple Sclerosis Association of America (MSAA) and has spoken at several of MSAA's educational programs. After 45 years as a neurologist with Phoenix Neurological Associates, Ltd., Dr. Hendin is now director of the Arizona Integrated Neurology MS Center. He is also director of the Multiple Sclerosis Clinic at Banner University Medical Center and clinical professor of neurology at the University of Arizona Medical School.

Recent News and Study Updates in MS Research

By Susan Wells Courtney

Reviewed by Dr. Barry A. Hendin

MSAA's Chief Medical Officer

FDA Approves the First Biosimilar to Treat MS

On August 24, 2023, the United States Food and Drug Administration (FDA) approved Tyruko® (natalizumab-sztn), the first biosimilar to be approved for the long-term treatment of multiple sclerosis (MS). Marketed by Sandoz, Tyruko is a biosimilar to Tysabri® (natalizumab), a disease-modifying therapy for MS that was originally approved in 2004 and is given via IV infusion every four weeks. The advantages of having generic, biologic, and biosimilar products available often include greater accessibility to the medication, potential savings, and continued product development through competition.

According to the FDA, “A biosimilar is a biological product that is highly similar to, and has no clinically meaningful differences from, a biological product already approved by the FDA (also called the reference product). This means patients can expect the same safety and effectiveness from the biosimilar as they would the reference product.”

As with Tysabri, Tyruko is approved to treat relapsing forms of MS, which include clinically

isolated syndrome (CIS), relapsing-remitting MS (RRMS), and active secondary- progressive MS (SPMS). Because it is a biosimilar, Tyruko is given at the same dosage and via the same administration as Tysabri, while also carrying the same benefits and risks.

Tysabri's benefits – when compared to placebo over a two-year period – include a 67% decrease in the number of relapses, a 92% reduction in lesions, and reductions in disability progression (42% and 54% over three and six months, respectively). Common potential side effects include headache and fatigue, infections such as upper respiratory tract infection (URTI) and urinary tract infection (UTI), as well as infusion reactions.

Tysabri is a monoclonal antibody that acts against a molecule involved in the activation and function of lymphocytes, which are immune system cells produced to fight infection and disease. It also acts against the passage of lymphocytes into the central nervous system (CNS). Tysabri increases the risk of progressive multifocal leukoencephalopathy (PML), a rare but potentially fatal brain infection caused by the JC virus. Given that natalizumab products increase the risk of PML, all such medications are required to have dedicated Risk Evaluation and Mitigation Strategy (REMS) programs.

Positive Results Shown in Study of 10-Minute Subcutaneous Administration of Ocrevus®

People with MS who take Ocrevus® (ocrelizumab) may be able to switch from twice-yearly intravenous infusions of two hours or longer to 10-minute subcutaneous (under the skin) injections, if the results of the recently completed OCARINA II trial prompt FDA approval of this easier and shortened route of administration. The injections would be given twice a year.

Approved by the FDA in 2017, Ocrevus is indicated for the treatment of relapsing forms of multiple sclerosis, including CIS, RRMS, and active SPMS. Further, it is the only medication approved to treat primary-progressive MS (PPMS).

Currently, Ocrevus is infused intravenously, with initial doses of 300 mg given over 2.5 hours or more two weeks apart, followed every six months by 600 mg typically administered over 3.5 hours or longer. Based on post-approval studies, the FDA sanctioned shortening the infusion time for the 600-mg dose to two hours or longer in people who had no prior serious infusion reaction with any previous Ocrevus infusion.

OCARINA II is a Phase III randomized trial conducted at study sites in several different countries. Its purpose is to assess the pharmacokinetics (or drug activity and availability), safety, and radiological and clinical effects of Ocrevus injected subcutaneously compared with Ocrevus infused intravenously in 236 patients with relapsing forms of MS or PPMS.

FDA Accepts New Drug Application for GA Depot Treatment

On August 7, 2023, Viartis and Mapi Pharma announced that the New Drug Application (NDA) for their product, GA Depot, had been accepted by the FDA for the treatment of relapsing forms of MS. The FDA's decision on the approval of this treatment is scheduled for March 2024.

GA Depot is a long-acting injection version of Copaxone® (glatiramer acetate [GA]) and is designed to be administered as an intramuscular injection once every four weeks. FDA-approved in 1996, Copaxone is given via daily, or three-times weekly (depending on the dosage), subcutaneous self-injections. It is approved to treat relapsing forms of MS, including CIS, RRMS, and active SPMS, in adults.

Results from a Phase III clinical trial evaluating the efficacy, safety, and tolerability of GA Depot compared with placebo were used as support for the application to the FDA. More than 1,000 individuals with relapsing forms of MS participated in this international study and results include fewer injection-site reactions than with other GA products and a 30% reduction in annual relapse rate compared to placebo. A Phase II trial is currently evaluating GA Depot in people with PPMS.

For More Information

To speak with a Client Services Specialist, please call MSAA's Helpline at **(800) 532-7667, ext. 154**, or email **MSquestions@mymxaa.org**. ■

MSAA's Vital Programs and Services Improve Lives Today

By Susan Wells Courtney

MSAA's Toll-Free Helpline

Do you have questions about MS, its symptoms, or its treatments? Each year, several thousand members of the MS community reach out to MSAA's trained and experienced Client Services Specialists to ask questions, learn about helpful resources, or to find comfort and reassurance with whatever challenges or concerns they may be experiencing.

If you are in need of assistance, please contact **MSAA's Helpline** via phone or email. Helpline hours are Monday through Friday, 8:30 AM to 8:00 PM (ET). We invite you to call our toll-free number at **(800) 532-7667, ext. 154** or connect with our Helpline Specialists through email at **MSQuestions@mymsaa.org**.

To reach a Spanish-speaking Client Services Specialist, please call **(800) 532-7667, extension 131**. Para comunicarse con un Especialista de Servicios al Cliente que habla español, llame al **(800) 532-7667, extensión 131** o envíe un correo electrónico a **MSQuestions@mymsaa.org**. El horario de la línea de ayuda es de lunes a viernes, de 8:30 AM a 8:00 PM, hora del este.

Equipment Distribution Program

Equipment designed for mobility, safety, and comfort can greatly improve quality of life and enhance activities of daily living. Unfortunately, not everyone has access to the

equipment needed, and cost can often play a role. If this is the case, MSAA's **Equipment Distribution Program** may be the answer. This program offers products designed to improve safety and mobility while also providing greater opportunities for exercise and wellness. MSAA distributes these products at no charge to individuals with MS who qualify for assistance, and items are shipped directly to the client. Products provided through the program range from grab bars, shower chairs, and walkers, to wide-grip utensil sets and yoga mats. Please visit **mymsaa.org/equipment** for more information.

MSAA's Informative Videos, Webinars, and Podcasts

At MSAA, we know that providing urgent information on a wide range of topics – from diagnosis and treatments to healthy lifestyles and family relationships – is critical to the health and well-being of the entire MS community. MSAA conveniently provides this information through videos, live and recorded webinars, as well as podcast episodes, all featuring MS healthcare professionals.

MSAA's digital educational programs are free and available on our website. Some of our recent recorded webinar topics include brain health and MS, managing stress with MS to improve mental well-being, living with MS as

an LGBTQ+ person, and aging with MS.

To access these programs, please visit:

- Videos and webinars: mymsaa.org/videos
- Podcasts: mymsaa.org/podcasts (or search for “MSAA Podcast” on any major podcast distributor)
- To view our schedule and to register for any upcoming programs, please visit our calendar of events at mymsaa.org/calendar

My MSAA Community Online Forum

My MSAA Community is a free peer-to-peer online forum (hosted by HealthUnlocked.com) for individuals with MS, their families, and their care partners to share information and their experiences with multiple sclerosis. As a member of this friendly, supportive, and safe online community, you can:

- connect with other people affected by MS
- contribute to ongoing conversations
- start your own conversation with a question or a post about your journey

To join our online community, please visit healthunlocked.com/mymsaa.

Stay on Track with My MS Manager™

My MS Manager™ is MSAA’s mobile phone application, provided free of charge to individuals with multiple sclerosis (MS) or their care partner to use on their Apple iOS or Android mobile device. Developed in conjunction with @Point of Care, My MS Manager offers individuals a convenient and effective tool to easily track symptoms, access

helpful MS information, connect with one’s healthcare team, and more.

My MS Manager includes several features such as:

- Journal for logging symptoms, blood pressure and weight, physical activity, and personal notes.
- Health measurement scales that track fatigue, depression, bladder patterns, and cognitive abilities.
- Option to connect with one’s healthcare professionals to securely share medical progress and reports.
- Educational resources from MSAA within the Learning Center of the app
- And more!

For information about the My MS Manager app, please visit mymsaa.org/mobile.

MRI Access Program

Do you need financial assistance to help pay for magnetic resonance imaging (MRI) – either in the near future or one already done within the past six months? MSAA’s MRI Access Program assists with the payment of cranial (brain) and c-spine magnetic resonance imaging (MRI) scans to individuals meeting eligibility requirements.

Assistance is provided to qualified individuals who have no medical insurance or cannot afford their insurance costs and require an MRI to help determine a diagnosis of multiple sclerosis or evaluate current MS disease progression. Please visit mymsaa.org/MRI or call **(800) 532-7667, extension 142** for more information. ■

Ways to Support MSAA

By Susan Wells Courtney
Senior Writer

Improving Lives Through Art®

For more than a decade, MSAA has recognized and cultivated the artistic talents and expressions of the MS community through MSAA's Art Showcase. Immersed in artwork using a variety of mediums, individuals with MS often find inspiration, happiness, and hope for the future through their artistic endeavors. Given the success of this program and the inspirational stories associated with these works of art, MSAA has built upon this foundation of artwork to create "Improving Lives Through Art®," which promotes two exciting types of virtual, fundraising events.

The first type of program is a "paint-along," which is led by an artist with MS and the necessary art supplies are shipped directly to the participant. On the specific date of the event, online instruction is provided to the participants in the comfort of their home. In the Improving Lives Through Art Fall Series, we still have one date remaining this year for which individuals may register and participate.

Featuring MSAA Art Showcase artist Omayra Rivera-Filardi, the November Paint-Along will take place on Tuesday, November 14, 2023 from 7:00 to 9:00 PM, ET. The deadline to



register for the November 14th event is November 9, 2023.

The second type of program is a virtual art tour, led by art enthusiast and docent Joe Caliva. As with the paint-along program, we have one date remaining this year for which individuals may register and participate. Our December Tour features both the visual and musical arts from Poland, and will take place on Tuesday, December 12, 2023 from 7:00 to 8:30 PM, ET.

For more information or to register for either program, please visit engage.mymsaa.org/fall2023.

MSAA DIY Fundraisers

These days, many of us opt for a Do-It-Yourself approach to several of our tasks – from home improvement and car repair to cooking and gardening. So, if interested in supporting MSAA's vital mission, why not create your own Do-It-Yourself fundraiser?

Our supporters have hosted basketball tournaments, golf outings, runs/walks, swimming competitions, Halloween costume contests, holiday pie sales, and more! This is a great way to raise much-needed funds for MSAA, while getting together with friends and family – and having fun in the process!

For more information on how you can host your own Do-It-Yourself fundraiser, please visit mysaa.org/DIY.

Year-End Giving

As we approach the end of the year, people frequently think about the importance of supporting causes that are meaningful to them. This is an ideal opportunity to help support MSAA's urgent mission of Improving Lives Today.

MSAA's website mymsaa.org provides a variety of ways to support our mission. One option is our Monthly Improver program, which gives donors the opportunity to set up monthly payments that are both convenient and less of an expense than one large donation. While monthly donations may be smaller than an individual large donation, these 12 payments over the course of a year add up to make a significant difference in someone's life! For instance...

- **\$10/month** = shower chairs for two individuals with MS
- **\$15/month** = a wheelchair for an individual with MS
- **\$25/month** = cooling vests for two individuals with MS
- **\$60/month** = an MRI exam for an individual with MS

As you can see, being a Monthly Improver for MSAA can provide safety, comfort, and even vital MRI scans for those with MS. To become a Monthly Improver, please visit engage.mymsaa.org/improver. To make a direct donation, please visit mymsaa.org/donate or call **(800) 532-7667, ext. 172**. We thank you for your generosity! ■

SPECIAL THANKS to the MSAA 2023 Anniversary Challenge Community Connection Sponsors

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Still Upright

By Debbie Oelke

Disease progression is not welcome, predicted, or encouraging. Instead, it is difficult, random, and unrelenting. It is forever on my mind. Fear of the future is an hour-by-hour challenge to overcome.

I often wonder:

Will I be a burden to my family?

When will my physical care require specialized nursing?

How long will I be able to remain in my home?

I'm only forty-eight years old, but my life experience of adversity has matured me. Don't mistake my tears for a lack of strength. My forbearance is relied upon every day.

When I received a multiple sclerosis diagnosis at the age of 25 in 1999, after two years of intermittent symptoms, I was not completely surprised. My grandmother had the disease in the 1950s and 60s, dying at the age of 39 from heart failure after needing to use a wheelchair for the last eleven years of her life.

Having to rely on a wheelchair was a terrifying thought. But during the next eighteen years of living with an MS diagnosis without disability and with very few symptoms, the scare became almost nonexistent.

Then June 2017 hit. It's a time in my life I will never forget. Progression that seemed arbitrary began. I fast-forwarded through cane and four-wheeled walker stages, and then,

because of worsening leg weakness, I graduated to a wheelchair. Gone were the hours spent typing for a part-time medical transcription job. Gone were the kayaking, half-marathon running, and jumping on the trampoline with my kids. Instead, I entered a world of bed rails and wheelchair-accessible ramps, seating, and restrooms. All of a sudden, handicapped parking, elevators, and grab bars were noted and mattered. I had to adjust to brushing my teeth and showering while sitting. I soon found out, besides my eight-inch makeup mirror, there was not a mirror in my house I could see into.

Disability wasn't new to me as a trained school social worker, but it had never been personal. Now, it was. How was I going to attend my kids' athletic games and school events? What about coffee dates with friends? Thankfully, my husband, children, and friends helped me make these desires a reality. But then I often had to prepare for windy, extreme Kansas heat and rough terrain. After successfully navigating that hurdle, it became obvious that stares and unknowingly insensitive comments were difficult to ignore. As my very small community became accustomed to my sudden disability, I realized that putting my thoughts on paper was therapeutic for me.

My words tumbled out, and they turned into a book. It took six months to write a 256-page book, *Still Standing: Hope Beyond Disability*, which was published in late August 2022. An expression of my new normal was now public. My deepest feelings and fears were on display.



Debbie Oelke finds writing to be therapeutic, helping her to cope with the changes that occur with MS. In her new book, she chronicles the sudden onset of multiple sclerosis symptoms while balancing contentment with hope for healing – all from her viewpoint in a wheelchair. Debbie is a student of God’s word and loves to serve through teaching and hospitality. Even as her diverse background in small business, social work, and medical transcription took a turn when symptoms of MS began to impact her life, she has turned that struggle into yet another ministry. Debbie thoroughly enjoys small-town Kansas life with her husband and three children.

But the furthering of my disease continues amidst book publication excitement. A launch party, book signings, and selling out at a local fair are only temporary emotional relief.

Fear and wariness of what’s ahead loom on the periphery of my mind. Physical therapy exercises, activities intended to improve cognition, and even long-term care financial details now require my discernment. I find it’s best to stay distracted by other interests.

Though physically walking is not an option, I can still enjoy nature outside using my motorized wheelchair. Though spending long hours antique shopping is no longer doable, I can be grateful for friends who accompany me on short day trips to explore new places. Though spontaneously spending a weekend away is out of the question, I can be thankful for family members who purposely install safety bars in their own homes in order to encourage visits.

But my main distraction is also one of my

biggest interests. Writing continues to be therapeutic. Though it does nothing to slow disease progression, it does everything to meet my emotional needs...my fear of withstanding yet another loss, such as the inability to pick my left foot off the ground, doesn’t stand a chance when I am distracted by wordsmithing. It’s tempting to remain home and feel sorry for myself, but I refuse. I am determined to participate in activities as much as I possibly can. I have lost too much in the past five years. Whatever I am able to do, I will do it. My independence is now seen as a gift!

Having a husband who denies his own needs is unparalleled. Having three early adolescents who don’t remember a time their mom was not disabled is a blessing because life with a wheelchair is now quite natural for our family. But having a deep friendship with the God who made me and loves me is essential; it trumps even the hardest of days. ■

Become an MSAA Monthly Improver!

MSAA Monthly Improvers are a generous group of donors making automatic, monthly gifts to improve the lives of people with MS.

Recurring donations make it easy for you to support MSAA's free programs and services – while also providing MSAA with a reliable stream of revenue each month.

Questions?

Contact Donor Relations at
(800) 532-7667, ext. 172, or
MonthlyGiving@mymsaa.org



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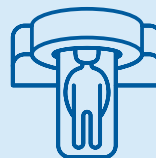
\$10/month (\$120/yr)
provides shower chairs for
two individuals with MS



\$15/month (\$180/yr)
provides a wheelchair for
an individual with MS



\$25/month (\$300/yr)
provides cooling vests for
two individuals with MS



\$60/month (\$720/yr)
provides an MRI exam for
an individual with MS

Submit Your Best Work for MSAA's 2024-2025 Online

Art Showcase



Memories – by Hope Angel

Submissions will be accepted until January 5, 2024.
For guidelines, visit mymsaa.org/artshowcase

NOW ACCEPTING SUBMISSIONS

MSAA welcomes paintings in oil, watercolor, and acrylic, as well as pastels and drawings in pencil and ink. MSAA also accepts digital artwork, including graphic design and photography. All submissions must be sent electronically.

MSAA will accept **3 pieces** of artwork per artist. Artwork will only be accepted from individuals who have MS and are 18 years of age or older. Sculpture, pottery, and other types of three-dimensional works cannot be accepted.

Submissions will be featured on MSAA's website beginning March 2024, in recognition of MS Awareness Month. MSAA will highlight 12 artists and their artwork throughout the year.

For more information, please contact:
Email: showcase@mymsaa.org
Phone: (800) 532-7667, ext. 117

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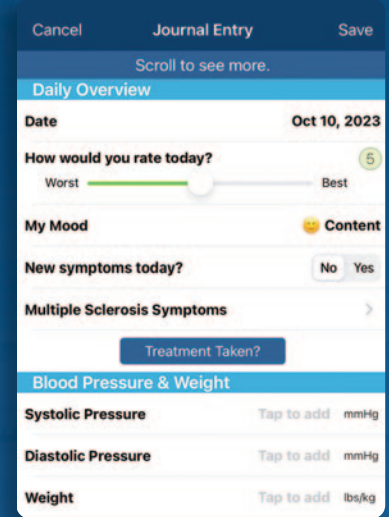


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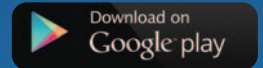
- User-friendly navigation, making it easy to effectively track the ever-changing course of one's MS.
- Body Location feature to report exact location of physical symptoms
- Dr. Appointment feature, with calendar integration, to help prepare for upcoming doctor visits with a snapshot of notes and charts, plus options to log or recap past visits.

Download My MS Manager™ and register your account today

to join the tens of thousands of people already using the app to help stay on top of their MS symptoms.



tinyurl.com/MyMS-apple



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Multiple Sclerosis
Association of America

Volunteer-driven fundraising is the foundation of MSAA's community of champions, raising funds to support MSAA's free programs and services for the MS community.

CREATE YOUR FUNDRAISER TODAY!
Please visit mymsaa.org/DIY



Connect with others and find support on **My MSAA Community**

Join more than 8,000 members who have similar experiences with multiple sclerosis in this online peer-to-peer forum.

- Get advice and support while connecting directly with people affected by MS
- Feel more confident managing one's own health or family's health
- Solve day-to-day challenges

Join My MSAA Community today:
healthunlocked.com/msaa

