

## Seeing MS from both sides



### **Healthcare professionals who live with the disease offer a unique perspective.**

by Vicky Uhland

In 2009, Lisa Whitty Bradley, MD, began having strange auras in her vision and other vague symptoms indicating that something wasn't quite right with her health. When she became pregnant in 2011, the symptoms disappeared. But within a year after her daughter's birth, Bradley began having balance issues, numbness on one side of her face, loss of taste and sensitivity to cold.

In 2013, Bradley was diagnosed with multiple sclerosis. She was a reconstructive plastic surgeon in private practice at the time, and she quickly realized that her diagnosis affected not only her private life, but her professional life as well.

"The first thing I encountered was that other healthcare professionals seemed very uncomfortable when I disclosed my disease," she says. "My perception was that they were thinking, 'How did this happen to you? You're supposed to be a gatekeeper, not a patient.' I felt there was a lack of empathy, like it was inconceivable to them that I had this diagnosis and was still interacting with the world."

Like other healthcare professionals living with MS, Bradley's diagnosis has given her a unique perspective on the disease. She says her new role as both a practitioner and a patient has taught her to "love healthcare in a different way."

"It's a drawback to have this diagnosis, but I think it's made me a better healthcare

professional in the long run,” she says. “We’re not just the gatekeepers of disease; we’re partners in the medical community. We’re partners with our patients.”

Over the years, Bradley has learned how to accommodate her disease both on the job and at home. Here’s what she and other healthcare professionals who have been diagnosed with MS have discovered — and what they’d like other practitioners and people living with MS to know.

### **Lisa Doggett, MD, Austin, Texas**

In 2009, Lisa Doggett, a family physician, was the mother of a toddler and a preschooler, the wife of a pediatrician and the director of a clinic for central Texas residents without private health insurance. She started feeling dizzy and had cloudy vision, but after she and her doctors couldn’t find a cause, she attributed her symptoms to a virus or her stressful job.



But the symptoms didn’t disappear, and Doggett also began having double vision and taste changes. She had an MRI, and was diagnosed with MS.

“One of the worst things early on was the uncertainty. In the first few years after my diagnosis, I had dizziness every day, and I didn’t know how long I could continue to work and raise my kids. I didn’t know what form the disease would take,” Doggett remembers. “MS doesn’t follow a playbook, and I’m a planner. To not know if I was going to be able to see or walk or have any energy was very difficult to cope with.”

After three MS flareups, Doggett started on Ocrevus and hasn’t had a relapse since 2017. She’s also learned how to manage her disease, which includes exercising every day — “I feel like it’s my antidepressant and anti-anxiety medicine,” she says — eating a mostly vegan diet, meditating, getting enough sleep and connecting with her support circle.

“I see MS as an opportunity to prioritize self-care,” she says.

To help lower her stress, Doggett stopped seeing patients full-time. She took a job as senior medical director with a company that designs and implements programs for people on Medicare and Medicaid with chronic health conditions. To stay connected with patients, she volunteers in a clinic for people experiencing homelessness. She also wrote a memoir, *Up the Down Escalator: Medicine, Motherhood, and Multiple Sclerosis*, set to be published by Health

Communications, Inc.

And in September, Doggett will combine her experience as both doctor and patient and begin working as a primary care and lifestyle medicine physician at the MS clinic at the University of Texas Dell Medical School.

“Having MS has shown me the importance of self-advocacy and increased my resolve to support my patients in ways that go beyond the prescription pad. I’m much more tuned into all the things you need, including the emotional component,” Doggett says. “Dealing with MS involves a lot more than just medication — you also need to address the anxiety, shame and embarrassment that can come with some symptoms. And you need to have a reason to get up in the morning and a sense of purpose — whatever that may look like for you.”

### **Lisa Whitty Bradley, MD, Chicago**

After Bradley was diagnosed with MS, she found that working her typical 10 to 12 hours a day exacerbated her fatigue and balance issues.



“The majority of what I do is breast-cancer and skin-cancer reconstructions or plastic surgery after facial or hand trauma, which takes a lot of time and effort. I had to make a decision that clinical medicine had to be sacrificed to a large degree,” she says. In the years since her diagnosis, she’s worked part time as a plastic surgeon in a hospital, and also teaches physicians about contract negotiations and other business topics.

Bradley says despite the reaction she received from colleagues when she first revealed her MS diagnosis, she always discloses her disease to patients, fellow practitioners and potential employers.

“When I apply for privileges at hospitals or for clinical jobs, I say my neuro will provide a physician’s statement listing any and all restrictions,” she says. “My first and foremost concern is patient care, so I want them to know I’m capable and safe to treat patients. I don’t want there to be any question of my capacity to care for my patients.”

Bradley says she’s never encountered a patient who’s had a negative response to her disease. “Nobody has ever said to me, ‘I don’t want you to operate on me because you have MS.’ Instead, they cheer me on. They thank me for being honest with them.”

To continue working while also caring for her family, Bradley has modified her lifestyle considerably. She sits down while sewing up skin during surgeries. She schedules mini breaks during her workday for snacks or to mentally and physically regroup. She does yoga to lower her stress levels. And she's become an advocate for patient care.

"Having MS has made me realize what my patients have to deal with — getting referrals, getting appointments and everything else associated with a chronic disease," she says. "I've definitely evolved over time in terms of my ability to advocate for myself and others, and the desire I have and the necessity I feel to do that."



**Mona Bostick, registered dietitian nutritionist, Greensboro, North Carolina**

In 2008, Mona Bostick was working full time as a board-certified oncology dietitian at a hospital, and was also the primary caregiver for her mother, who had lung cancer. So, it was understandable that Bostick was too busy to immediately consult a doctor when she developed numbness in the lower right quadrant of her face, mouth and tongue.

But when her symptoms persisted, she was referred to a neurologist and was diagnosed with MS. Today, "unless you're in my immediate family, you may not be able to tell I have MS," Bostick says. Her main symptoms are some spasticity in her lower legs and cognitive challenges made worse by lack of sleep.

When Bostick was diagnosed, she had two school-age children and a two-hour commute to work each day. Something had to give. She left her dietitian job in 2014 to start a private practice, Food Matters 365, and later launched a blog called MSBites.

"I hadn't considered the role of nutrition in MS until my neurologist asked if she could refer me to her patients," she says. "But soon it became really clear to me that Dr. Google had been filling the internet with less-than-credible information about food and MS."

Some of Bostick's MS patients thought that "eating copious amounts of one thing or avoiding a whole group of things entirely could alter the course of their MS," she says. "But isn't the unpredictability of living with multiple sclerosis challenging enough without being told the food you're eating will lead to you becoming disabled tomorrow? Much of my role is advocating for

nutrition science and research and how to navigate information on the internet.”

Currently, about half of Bostick’s patients have MS. She’s open about her MS diagnosis and believes that disclosing to patients can “get across the idea that I understand; I get all of those dark clouds and question marks.” But there are negatives to disclosure as well.

“In today’s world, there can be too much of a tendency to be a wellness influencer: ‘Mona has MS; this is how she eats so this is how we should eat.’ But there’s no value in that, at least according to science,” she says.

Instead, Bostick addresses whether a patient’s diet is working for them. “People have a lot of emotion invested in what they eat. Eating healthy should be both physically and emotionally nourishing. If beliefs behind our eating behaviors are causing emotional and physical distress or harm, they’re not worth it.”

Bostick also spends time educating healthcare practitioners about the role of diet in MS. “I’m trying to get RDs to become welcome members of the MS care team, so they can provide education to those who don’t have a wide nutrition base,” she says.

### **Jessica Thomas, licensed clinical social worker, High Point, North Carolina**



In 2005, when Jessica Thomas was a 26-year-old newlywed studying for a Master of Social Work degree, she began having optical and cognitive symptoms. Shortly afterwards, she was diagnosed with MS.

Thomas continued with her schooling, earned her certification as a licensed clinical social worker and began working as a therapist. Following a significant relapse three years after her diagnosis, Thomas’ symptoms have been relatively stable. But she can still get fatigued, which can lead to cognitive issues that affect how she feels at work.

“As a therapist, your day is very appointment driven. You can’t just cancel somebody’s appointment because you’re tired,” she says. “So, I discovered the power of closing my eyes for 15 minutes and resetting or going outside for 15 minutes.” During COVID, she learned

how to play the ukulele. “It gave me a mental shift and brought lightness into my day.”

Last year, Thomas was named the director of patient education for the Neuroendocrine Tumor Research Foundation. She also facilitates the MS Mental Wellness Chat for MS Views & News, a nonprofit patient-advocacy program. Disclosing her diagnosis is not an issue in her new career, but when she was a therapist, she also chose to tell her patients and employers about her MS.

“If it doesn’t benefit someone to know, I don’t disclose. But I’ve found that disclosing can create connection and some level of understanding, even for patients without MS,” she says.

“If I could take away having MS, I would,” she continues. “But what I do with it is the most important thing. I’ve chosen to look at my MS as a great benefit to the healthcare I can provide to people. It gives me empathy I wouldn’t otherwise have, and it gives me perspective.”

Thomas encourages people living with MS to consider mental health counseling. But the therapist they choose doesn’t necessarily need to be an expert in MS, she says.

“You just need someone who knows and understands chronic disease and is interested in and engaged in the patient’s journey, because the themes of chronic diseases are very similar — loss, grief, and comorbidities of depression and anxiety.”

### **Vincent Macaluso, MD, New Hyde Park, New York**



In 1987, when Vincent Macaluso was a sophomore at Cornell University, he developed an infection that spiked his temperature to 105.9 degrees. He recovered, but his concentration dropped, his grades started going down and he became less patient and considerate towards other people.

Macaluso went on to Georgetown University School of Medicine, where he learned that he had one of the most common symptoms of MS: double vision. His mother encouraged him to see an ophthalmologist. After telling the doctor the story of his double vision and then being

evaluated, the doctor suspected Macaluso might have MS. He was referred to a neurologist, who sent him for an MRI. He and his parents took the films to see the neurologist for a follow-up. “I gave him the films and then watched him looking at them as he held each one up to a light bulb mounted on the ceiling,” Macaluso recalls. When he asked the doctor if the MRI revealed findings of MS, he replied by saying, “Do you want me to say what you want to hear?”

Then Macaluso says the doctor pretended that his pager went off and excused himself. A nurse came into the office and told Macaluso and his parents that they could come out and pay for the visit. When they left, Macaluso swore to himself that after he became a doctor he would never treat a patient the way he had been treated.

It wasn't until he was a medical resident at Georgetown's Department of Neurology in the mid-1990s that Macaluso finally got treatment for his MS.

Today, Macaluso is a neurologist who operates a private practice, Macaluso Medical, with his wife, Lauren Macaluso, MD. He also published *Multiple Sclerosis from Both Sides of the Desk* in 2015.

“Since we do not have a cure for MS, I know that I need to keep using my brain,” he says. “The saying in neurology is: ‘If you don't use it, you lose it.’ What that means is that if a nerve and its connections are not used on a routine basis, the nerves eventually die.”

Most of Macaluso's patients have MS, and he believes he provides care for them in a way that other doctors can't.

“A person who does not have MS cannot understand the chaos that goes on in the mind of an MSe,” he says. “Likewise, the friends and relatives — especially spouses — of my patients don't understand why their spouse acts the way they do. I try and teach them about the elevated pressure in the brain of people with multiple sclerosis and how it causes trouble with our thinking.”

**Twanna Monds, licensed clinical mental health counselor, Durham, North Carolina**



In 2003, during her first year of graduate school at the University of Cincinnati, Twanna Monds began having vertigo, tingles from her neck down, seizures, loss of feeling in her limbs, and difficulty walking and talking. She was diagnosed that May with MS, just two months after her wedding.

“My neuro said I was ‘lit up,’ ” Monds remembers.

When she was diagnosed, there were only five MS medications available, and Monds had antibodies to them all. She started on Novantrone, a chemotherapy drug, but managing her symptoms was a struggle for the first couple of years. Undaunted, Monds earned her master’s in counseling and began working as a public-school counselor.

At her first job, Monds had seizures while working and difficulty walking, and her colleagues didn’t react well. “I had to leave because I felt judged,” she says.

She took another school counseling job where she felt the staff was warm and understanding, and her supervisor encouraged her to become a licensed clinical mental health counselor. She eventually started taking Copaxone and today, her MS symptoms — extreme fatigue, numbness and tingles — are mostly invisible to others.

Monds worked in public schools for 15 years but didn’t use her clinician license until the pandemic lockdowns. She was asked if she could work individually with children, which spurred her to start her own practice, Monds Counseling & Consulting. She specializes in children’s and family therapy, and about 20% of her patients have MS.

“There’s something special about working with someone who knows you’re the same as them. I call it a family,” she says. “We’re all together in this journey, and it’s an honor to be a support person for people who identify the same way I do. I’m conscious they chose me because they may know I have MS and they trust me with their care in that way.”

That said, Monds is very selective about disclosing her disease to her patients.

“Everyone has a unique journey in terms of disclosure. In my practice, if someone tells me they have MS, I self-disclose that I have MS as well. But I don’t bring up my MS if they don’t say anything,” she says.

Monds also works with relatives and friends of people with MS — helping children navigate and understand MS in their parents or providing a sounding board for frustrated caregivers. The messages she gives them are relevant for healthcare professionals as well.

“I always tell my clients to embrace their journey. Whatever it is, wherever it is, that’s where you are. You don’t have to be OK every day.”

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