

## In the beginning



### **What it's like when you're first diagnosed with MS.**

by Vicky Uhland

On the surface, Jennifer Ellinger, Bob Hermanson, Emily Reilly and Nicole White don't have much in common. They are different ages, genders and ethnicities. They live thousands of miles apart and have diverse lifestyles.



**When Jennifer Ellinger was diagnosed with MS in 2009, she tried to learn all that**

## **she could by researching the disease.**

What they do have in common is their multiple sclerosis diagnosis. And whether that diagnosis was more than a decade ago, in Ellinger's and Reilly's cases, or fewer than two years ago, in White's and Hermanson's cases, they all vividly recall what it was like their first year of living with MS.

They remember how they felt physically, emotionally and mentally. They remember the confusion and fear and depression. They remember when they finally realized that they had MS, but MS didn't have them.

"When I made it to the one-year mark, and I got my MRI results back and everything was stable, I thought, 'Wow, I think I've got it. I think I've got control of this,'" Ellinger says.

People living with MS, healthcare professionals and support teams agree that the first year after an MS diagnosis can be one of the most challenging. Adjusting to the "new normal" of living with a chronic disease varies from person to person, but there are some concerns that tend to be universal.

MS specialists and people living with MS identified the most common questions people ask in their first year after diagnosis. Although they approached the issues from different perspectives, they agreed on many things as well. Here's their advice for people grappling with a new MS diagnosis.

### **People living with MS**

Jennifer Ellinger, 46, diagnosed with MS in 2009, Huntsville, Alabama

Bob Hermanson, 46, diagnosed with MS in 2018, Boulder, Colorado

Emily Reilly, 32, diagnosed with MS in 2005, Alexandria, Virginia

Nicole White, 43, diagnosed with MS in 2019, Chicago

### **MS healthcare specialists**

Luydmila Jovine, licensed clinical social worker and psychotherapist who specializes in chronic illness, New York

Jacqueline Nicholas, MD, OhioHealth System Medical Chief of Multiple Sclerosis and Neuroimmunology, Columbus, Ohio

Susan Stuart, nurse practitioner and nursing director, Georgetown Multiple Sclerosis and Neuroimmunology Patient-Centered Specialty Practice, Georgetown University Hospital Department of Neurology, Washington, D.C.

## **National Multiple Sclerosis Society**

Chrissie Griffin, MS navigator and licensed clinical social worker, Raleigh, North Carolina

Steven Nissen, director, MS Navigator Services Delivery, Washington, D.C.

### **How do I get the best information about my disease? Should I just Google “multiple sclerosis?”**

Google is a great way to find reputable resources, such as the National MS Society. However, don't rely solely on “Dr. Google” for diagnosis or prognosis of your disease.

**Hermanson:** “I admit I spent too much time on Google after I was diagnosed. There's just so much gibberish. People were talking about their own experiences that may or may not have anything to do with me.”

Hermanson said he found some valuable, science-based information by doing searches on phrases like “cell depletion” and Rituximab, the disease-modifying therapy (DMT) he takes.

**Griffin:** Call the Society to speak to an MS Navigator like herself and connect via live chat, email, social media or through the [Society website](#).

“Newly diagnosed calls are my favorite because I'm able to provide people with the information and materials when they have the most impact. We have so much information to give and can tailor it to their individual needs.”

The Society also offers a wide variety of information and resources, including how to find local support groups, on its website.

**Nicholas, MD:** Make a list of questions for your healthcare providers. “Some patients don't want to feel overwhelmed with too much information on the internet and the challenges of knowing what is accurate, so they prefer to get information on MS when they visit their neurologists/MS doctors. That's appropriate, too.”

### **How is my disease going to progress? Will I end up in a wheelchair?**

Disease progression is one of the most common topics people ask about when they call an MS Navigator.

**Griffin:** “They have gone to Google, and they have read about people being in wheelchairs within six months after their diagnosis. I always tell them that people can live long, happy lives with MS.”

**Ellinger:** She learned about MS when she was studying to be a registered nurse in the mid-1990s. “The picture of MS at that time was bleak. That was before DMTs, and it was almost labeled a death sentence. I had a lot of fear when I learned I had MS.”

Ellinger countered that fear by doing research. She looked at the MS Society website,

analyzed statistics and figures on disease progression, and learned about the various MS medications.

“I was looking for a flowchart — your MS is going to go to this, then this, then this. I wanted to be able to look at somebody with MS and say: ‘I’m going to be just like that.’ I found that no two of us are alike.”

**Jovine:** “Every time the feet are numb, the migraine won’t go away, the vision is blurred, the thought is always creeping in that ‘this is it. Here’s that moment. I thought I was doing well, but it’s just a matter of when.’ We are primed to prioritize the negatives of life as a survival tactic.

So, it’s crucial to check in with yourself as often as possible and see if your beliefs about the future are accurate. Catastrophizing is a barrier to healthy living as opposed to a resource.”

### **Should I get a second opinion about my diagnosis? How do I find a good healthcare team?**

**Nicholas:** “If you don’t feel you are getting the best care or answers to your questions, patients shouldn’t be afraid to get a second opinion for MS care.”

It’s important to feel comfortable with your providers, including their level of experience and bedside manner.

She recommends visiting a specialized MS center if one is convenient for you. These centers, which are usually offered through university hospitals or large healthcare systems, have MS fellowship-trained neurologists, physical therapists, urologists, psychologists, social workers and other clinicians trained in MS.

“Not all neurologists are familiar with these centers, so you may need to suggest it,” Nicholas says.

Another option is to consult with an MS specialist. Doctors at specialized centers have completed a four-year medical residency in neurology, and then an MS and neuroimmunology fellowship that lasts between one to three years. Ask your neurologist if there’s an MS specialist near you. If there isn’t, one option is to travel to visit a specialist annually or communicate through telemedicine.

### **Should I start a DMT? How do I find and afford the right medications for me?**

**Hermanson:** His mother was diagnosed with MS when he was in fourth grade, and now, three decades later, she’s in hospice care. As a former physiology and anatomy instructor at the University of Colorado, he’s done plenty of research into his mother’s disease.



**Bob Hermanson, diagnosed with MS in 2018, discussed disease-modifying therapies (DMT) with his doctor and opted for infusions.**

“I always told myself MS wasn’t hereditary, so there’s no way I would get it.” When his right arm went numb, he ignored it. When he had balance issues, he blamed it on getting older.

But the symptoms persisted, and he finally had a brain MRI.

“When I was told I had a demyelinating disease of the CNS (central nervous system) and 30 active lesions, my [jaw] just dropped.”

But after quizzing his doctor about DMTs, he learned that the drugs could make his prognosis much better than his mother’s. He opted for Rituximab. “When I got my first MRI after my first infusion, it showed that I had no more active lesions. I was encouraged that maybe we can just hold it here.”

**Nicholas:** One of the keys to MS care is not to delay treatment. “When somebody is newly diagnosed, research shows that treating the disease effectively early has the greatest impact on how you will do throughout your life with MS. DMTs are an investment to protect your physical and cognitive health in the long term.”

It’s common for people who are newly diagnosed not to want to take a DMT. Often, they’re worried about the potential side effects, risks or insurance coverage. The key to choosing a DMT is identifying one that will be effective enough for your MS and that fits into your lifestyle.

“I work with patients to find out what DMT options we believe will be effective for them and then to select one that they feel comfortable taking and one that is an acceptable mode of

administration for them. Sometimes, insurers will ask us to use an alternative DMT first, but often with appropriate documentation, we can get the DMT that both we as the MS specialist and the patient feel is the best approved.”

But DMT approval is not an exact science, and sometimes she has to appeal an insurer’s decision. “This is where it’s important to have a physician who’s invested in fighting for what their patients need.”

**Nissen:** With many DMTs costing tens of thousands of dollars a year, financial considerations are a top concern. “MS Navigators get many calls from people concerned about copays. They may be embarrassed to talk to their doctor about it or feel uncomfortable reaching out for help.”

For people who have private health insurance, pharmaceutical companies have patient-assistant programs that may help with drug costs. For those on government insurance, such as Medicare, some nonprofits may offer assistance with DMTs, but they can quickly run out of funds. MS Navigators can provide referrals to programs that might be available.

### **How do I find support groups or individuals? Whom should I talk to about my disease?**

**White:** As an African-American, she had particular trouble finding support groups in the months after her diagnosis, and that contributed to her fear and depression.



**Various therapies have helped Nicole White manage her MS and mental health.** Photo: Scott Thompson

“The one person I knew who had MS died from it at an early age. I could not find representation of anyone who looked like me who battled with MS. Where was the group for people who are 42, professional and African-American?”

White loathed asking for help. “I was independent to a fault. I had to exercise my ability to be

vulnerable with my family and friends. This is not a disease you want to manage by yourself. I had to understand that allowing your loved ones to help and support you makes you more able to do the things you want and need to do. Support is a lifeline.”

A friend who researched support groups and resources on her behalf reached out to White. While the resources were helpful, White longed for building a connection with a support group. Eight months into her diagnosis, White joined the Facebook group We Are ILLmatic, an African-American support group for MS warriors.

**Hermanson:** He found some useful Facebook groups that suit his irreverent approach to the disease, including “The MS-kateers: A Band of MiSfit MSers.”

Other options include groups and support offered through MS organizations like the National MS Society, the [Multiple Sclerosis Foundation](#) and the [MS Association of America](#).

**Stuart:** When deciding to join a support group, it is important to choose a group that will meet your needs, whether you are newly diagnosed, have had MS for years, or if you experience some level of disability. “Some people need time to accept and understand their diagnosis and MS treatment.”

**Jovine:** The way you tend to cope with life, in general, is how you will approach dealing with and communicating about your diagnosis. “The last time you had a cold, what was that like? Did you lock the door, go under the sheets and stay there; did you take a lot of medicine and go to work, or did you ask people to take care of you? Do you reach out to everyone you know when you’ve lost a job, a relationship or a pet? Or do you get stronger by going inward?”

It’s important to honor your communication style. But at the same time, if you have trouble accepting help, you might need to work on that and accept that some things will simply be beyond your ability due to your disease.

“As you discover what works for you and your MS, share that with people close to you. People think that others will just intuit what they need, but that’s not the case. It’s helpful to have another perspective to see the big picture, to invite other opinions and thoughts. Maybe with some support and resources, the burden can be lightened.”

### **Should I quit my job? Should I tell my employer I have MS?**

**Nissen:** “Sometimes (with people who are newly diagnosed) their healthcare provider or their loved ones say: ‘You’re going through so much stress, you should just quit your job and go on disability.’”

Nissen generally encourages newly diagnosed people to “breathe and take a step back. Don’t make rash decisions without thinking about the long-term consequences. In addition to a paycheck, there are benefits to working, including contributing to society and having positive self-worth.”

Of course, not everyone can continue their job or perform it as they did before their MS diagnosis. MS Navigators help people understand their legal rights and responsibilities that apply to employment, including disclosure and accommodations that can be requested under the Americans with Disabilities Act (ADA).

**Jovine:** There are psychological issues that may need to be addressed as well. “Ask yourself, ‘Is it time to start thinking about your job right now? Are you making a decision based on fear?’”

### **How do I handle the mental and emotional aspects of my disease?**

**White:** For eight to 10 years before her MS diagnosis in February 2019, she suffered from chest tightness, numbness in her legs for weeks at a time, paralysis in her face and optic neuritis.

“Over and over, I was told that the reason I was having all of these issues was that I was obese.”

Another reason was that she is Black. “No one ever talked to me about MS being a possibility, not even the neurosurgeon. I was never tested for it, and it was never considered. So, when I got diagnosed with MS, I had no reference or preparation, and I thought my life was over. I went into a severe depression. I had no clue about MS, and I didn’t want to fight. I felt that if God gave it to me, then this is what I’m supposed to have.”



**Emily Reilly, diagnosed in 2005, manages her MS with the help of exercise, diet, stress management and self-care.**

As an elementary school principal, White is dedicated to serving others. “I had nurtured a life



where people depended on me for support, and I was very concerned about being less-abled because of my MS. I thought: 'How can I serve people if I can't even serve myself?' "

It took White five months to admit to her doctor that she was depressed and to begin medications for depression. But it wasn't until she had a relapse in October 2019 that sent her to the hospital for 15 days that she addressed her other thoughts and feelings. "I finally understood that I was heartbroken and that I needed to mourn the life I had lost."

In rehab after her hospital stay, White began physical, psychological, occupation, vocational and speech therapy. "I had thought, 'I don't need to go to therapy. I'm not that sick.' But all those forms of therapy changed my life. It got me to realize I can manage this disease, that I have some control over this thing."

**Jovine:** For people who aren't used to self-reflection, "take note of the natural resources in your life: family, a dear friend, a good neighbor, a pet, a beautiful garden, a houseplant, a great song or painting, a book that really speaks to you."

Yoga and Pilates are good self-reflective options for people who prefer more active pursuits. She also recommends journaling, including writing down your symptoms throughout the day. "Then you can look back and see patterns. It creates a grounding experience, helps you feel more empowered and gives a little bit of predictability."

### **How can I live well with MS and manage the disease, so it doesn't become my sole identity?**

**Reilly:** She was 17 years old when she was diagnosed with MS, only a month after she had signed a scholarship to play soccer at Dallas Baptist University. "When my parents came to me with the results of my MRI, I experienced all of these emotions all at once — fear, anger, frustration, denial. I was so afraid that my MS would keep me from accomplishing things in life — playing soccer, finding a husband, having kids. To accept the fact that there's not a cure for what I have was hard."

She learned how to manage her disease with a combination of knowledge and faith. She visited an MS specialist in Arizona who helped her take ownership of her diagnosis and be an active participant in her treatment. With the combination of having a teammate with MS and a coach who was willing to learn and help modify her training to accommodate her MS, Reilly was able to learn how to listen to her body and manage her energy levels. Reilly learned those lessons so well that she became an All-American goalkeeper at Dallas Baptist.

"Faith also played a huge part in my journey. I've learned to be grateful for the little things, to give myself a lot of grace, keep moving and celebrate the little victories."

Diet, exercise, stress management and self-care are all part of managing MS as well. Resources are available on the Society website.

**Jovine:** MS as an unwanted partner you need to figure out how to live with.

“It’s important to become more curious and aware of your habits, and that might help with managing and mastering this unwelcome intrusion that is MS. Give yourself a year to know your MS and what it means in your life.”

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

Find [resources and information about MS](#) on the National MS Society website.

Contact an MS Navigator by calling 1-800-344-4867, emailing [ContactUsNMSS@nmss.org](mailto:ContactUsNMSS@nmss.org), or visiting [nationalMSSociety.org/navigator](http://nationalMSSociety.org/navigator).