

Advocates on your side



Navigating the complexities of MS-related healthcare can be daunting, but specialists can help you find your way.

by Marcella Durand and Paul Wynn

When questions arise about treatment options, care plans, medical bills or insurance claims, many people like to dig in and research the matter themselves. After all, individuals are often the strongest advocates for their own needs. But sometimes, the reality of living with multiple sclerosis, and managing all the clinical and financial aspects of it, can feel overwhelming. In those instances, people with MS may turn to doctors, family members—maybe even Google—for answers. But when that’s not enough, where else can you look for help?

More resources

If you need support in managing life with MS, begin with the following resources:

The National MS Society

MS Navigators at the National MS Society have an extensive list of resources and organizations that can help with specific needs related to health insurance or other matters. “Using information about a person’s unique situation, we can guide individuals toward the right agency or resource,” says Nicole Vasquez, an MS Navigator. To speak with a Navigator, call 1-800-344-4867, email contactusnmss@nmss.org or visit

MSconnection.org/discussions.

Pharmaceutical companies

To see a full list of companies offering financial assistance programs, visit nationalMSSociety.org/AssistancePrograms.

Health Insurance Marketplace

To find a local Affordable Care Act Marketplace navigator, visit localhelp.healthcare.gov.

Medicare

To find a State Health Information and Assistance Program (SHIP) counselor in your state, visit shipnpr.shiptalk.org/shipprofile.aspx.

Patient Advocate Foundation

For free professional case management, mediation and arbitration services by phone, email or live chat, visit patientadvocate.org or call 1-800-532-5274.

AdvoConnection Directory

To find contact information for hundreds of independent patient advocates, visit advoconnection.com.

Seeking support

As it turns out, there are numerous advocacy resources for people with MS. Each type of advocate may have a different expertise, but together, they can help you connect to financial, medical and wellness resources; find the right healthcare providers; research treatment options; participate more actively in your healthcare; manage medical bills; and navigate health insurance concerns, such as filing claims and challenging denials.

Chief among these sources of support are nonprofit organizations, such as the National MS Society, with staff and volunteers trained to field a range of inquiries. Others include nurses, nurse practitioners and social workers at MS centers or hospitals, and patient advocates for hire. Even some pharmaceutical companies offer patient assistance services, primarily to help people pay for a treatment or get it covered by health insurance.

Many people find these resources especially helpful when they are newly diagnosed, but these services also help to fill the gaps in America's complex healthcare system, according to Vicki Breitbart, director of the Health Advocacy Program at Sarah Lawrence College in Bronxville, New York. "With all of the significant changes happening in healthcare, most recently with the Affordable Care Act (ACA) and the national and state healthcare exchanges, there is increasing need for help to navigate these uncharted areas," she says.

A healthcare compass

For these reasons, more than 200,000 people living with MS call the Society's MS Navigator® program each year. Trained MS Navigators are ready to assist people in all stages of the

disease, from the recently diagnosed to those addressing life changes brought about by MS progression. Navigators are available not only to people with MS, but also to family members, co-workers, friends or anyone else affected by the disease.

“We can assist callers in their ability to self-advocate for their rights, and connect people with the agencies and organizations established to serve people living with a disability,” says Carla Turechek, an MS Navigator. Turechek says Navigators can help people access optimal MS healthcare now, and plan for the future.

In addition to helping people find healthcare professionals with experience in MS care, Navigators frequently handle questions about the complexities of employment, financial and insurance matters, such as Medicare and Part D plans; insurance appeals; the ACA and the insurance marketplace; Social Security Disability Income (SSDI) and private disability plans; and employment accommodations and discrimination.

In a recent call, a woman with MS who was new to Medicare had questions about which prescription drug plan she should choose and what supplemental policy would work best for her. An MS Navigator was able to help the caller narrow down her options and also directed her to several resources to help with her out-of-pocket costs. The woman later called back to say that not only did her new coverage meet her needs, but she was able to get assistance with premiums and medication costs. “She said she expected that her monthly healthcare costs would be cut in half,” Turechek says.

Making connections

MS Navigators also connect people affected by MS to other sources of specialized support. For example, if callers have questions about Medicare, or Medicare combined with Medicaid, they may be referred to their State Health Information and Assistance Program (SHIP). SHIP counselors can provide one-on-one assistance to help people understand insurance options, compare supplemental insurance products and apply for insurance or prescription drug assistance. The Health Insurance Marketplace created by the ACA also has a staff of “insurance navigators” to help consumers research and enroll in a health insurance exchange (see sidebar on [previous page](#)).



**Valerie Stickel-Diehl,
MSCN, helps people with
MS understand their
personalized care plans.**

In addition, pharmaceutical companies “can be a wealth of knowledge,” says Valerie Stickel-Diehl, MSCN, an MS-certified nurse at the Mercy Ruan Neuroscience Center in Des Moines, Iowa. Many of these companies offer patient assistance programs. People with MS can enroll in these programs, or they can ask their healthcare provider to contact the company directly. “[Pharmaceutical representatives] know which insurance companies are covering what treatment and can assist with the process. They all have advocates on their staff whom I can talk to,” Stickel-Diehl says.

The ‘go-to’ person

Healthcare facilities may also have staff members designated to provide support services. Stickel-Diehl says she is the “go-to person,” or care coordinator, at Mercy Ruan. In fact, to be recognized by the Society as a Center for Comprehensive MS Care through its Partners in MS Care program, a facility must have a care coordinator on staff.

One of the most important things a care coordinator can do for people with MS is to help them understand their personalized care plans. “I meet with all newly diagnosed patients and give them my card with my direct phone number,” Stickel-Diehl says.

But it’s not a solo effort. “Patient advocacy is everyone’s role in our center,” Stickel-Diehl says. “My role is to make sure our patients leave here understanding the next step, the plan of care and whom to call. Newly diagnosed patients are starting a new journey in healthcare. They have many questions and may need assistance forming them. Many of their questions lead to more questions, which is expected. I help patients organize their thoughts and prepare for their appointments so they are able to receive the best care available. Providing the best possible care leads to healthier patient outcomes.”



Rachel Stacom

People who have been living with MS longer may find that care coordinators can be helpful with weighing changes in treatment plans, evaluating rehabilitation options and wellness strategies, understanding insurance issues, and even initiating a discussion about long-term care. “If a person [anticipates having complex care needs] for an extended period, he or she may want to identify a program that offers care-management services,” says Rachael Stacom, an MS-certified nurse and senior vice president of care management at Independence Care System in New York City.

Distance doesn’t have to be a barrier, either, because healthcare providers often consult with each other via phone or email to get the answers they or their patients need. Stickel-Diehl says the neurologist on her team gets many calls from general neurologists in the Midwest for second opinions on treatment and care, and similarly, she may call Society staff with people’s questions about disability benefits.

Advocates for hire

People living with MS can also seek out independent patient advocates—those not affiliated with any hospital or nonprofit organization. These advocates, who may or may not have in-depth knowledge of MS, offer their services for a fee. Often, independent advocates focus on helping their clients manage insurance claims and find the healthcare specialists they need. But advocates can do more, including arranging for transportation to and from medical appointments.

As a profession, patient advocacy is relatively new, and may be practiced by nurses, physician assistants, social workers, medical billers, insurance advisers and even caregivers whose personal experience motivated them to make it a career. There currently is no national or state certification or licensure for fee-based patient advocates, and no actual qualifications are required to hang out a shingle. However, a committee of practicing patient advocates and academics is working on national certification for independent patient advocates.

Committee member Trisha Torrey, founder and director of advoconnection.com and The Alliance of Professional Health Advocates (APHA), estimates it will take two to three years to develop that standard.

There’s no set fee for independent patient advocates, and payment will likely come out of your own pocket, as their services generally are not covered by health insurance. In addition, patient advocates are not yet designated as a qualified medical benefit by the Internal Revenue Service, and the IRS has not provided clear guidance on whether these services are tax deductible or can be paid for with a health savings account or employer-sponsored flexible spending account. However, some employers do offer patient advocates’ services—sometimes at no cost.

Fortunately for Perry Joyner of Angier, North Carolina, his employer was one such company. “After the shock of being diagnosed with MS settled in, it didn’t take me long to realize that my insurance company did not understand or appreciate the special needs of people with MS compared to people with other conditions,” he says. “For instance, they didn’t understand how MS can affect my vision and why I needed to have multiple eye exams done each year.” Joyner turned to his doctor and the Society for help, and the patient advocate that his company hired also eased some of the insurance headaches.

“People newly diagnosed with MS have questions; however, they don’t always ask them due to the fear of this diagnosis,” says Stickel-Diehl. “I help people organize and ask those questions, but we hope they always know where they can go for help and advice.”

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