Telehealth proves promising for people with MS

Spurred by the pandemic, virtual doctor visits save time and trouble.

by Matt Alderton

Going to the doctor was always an ordeal for 63-year-old Deborah Miller, who has lived with MS for 23 years. Miller relies on her sister to take her to appointments and uses a manual wheelchair to get to and from the car. It’s time-consuming and exhausting.

In spring 2020, however, she discovered a new way to see her doctor: Instead of waiting for her sister to pick her up, Miller logs onto the internet from her computer and speaks with her neurologist via video chat.

Virtually seeing her neurologist saves time, helps Miller conserve energy and reduces her dependence on others. “That’s important because I’m fiercely independent, and I only have a window of about six hours during the day where I can be physically put to my limits,” says Miller, who lives in St. Charles, Missouri. “After that, I can’t think clearly, and my legs don’t bend because I’m overtired, which is a whole other fiasco.”

Miller is one of millions of Americans who has discovered telehealth — many for the first time during the COVID-19 pandemic. Although healthcare professionals have long recognized the potential benefits of virtual doctor visits, neither the Centers for Medicare & Medicaid Services (CMS) nor private insurers previously reimbursed them. That changed in March 2020, when CMS announced it was expanding access to telehealth on a temporary and
emergency basis so Medicare beneficiaries who were at risk of contracting the coronavirus could receive a range of services without having to visit a healthcare facility.

But even before the pandemic, telehealth has offered solutions for people like Miller who face challenges when scheduling healthcare visits.

**The virtues of virtual**
Because telehealth visits were so few before the COVID-19 pandemic, data about their effectiveness is scarce, particularly among people with MS. Still, what limited data exists is promising.

One piece of research, in particular, sheds some light: In 2018, the U.S. Department of Veterans Affairs (VA) Multiple Sclerosis Center of Excellence conducted a systematic review of 28 different studies into the efficacy of telehealth. The studies, spanning nearly two decades, produced “a range of outcomes with variable quality.” Overall, the studies demonstrated that telehealth is “beneficial, cost-effective and satisfactory for patients and providers,” according to the review.

Before COVID-19: 14,000
Medicare beneficiaries received a telehealth service per week.
Photo: iStock

For practitioners, the most substantial evidence so far is what they’ve witnessed firsthand since telehealth’s tipping point in spring 2020. Specifically, providers say they’ve noticed several benefits, the most significant of which is increased access to care.

“We in the MS community have always felt that telehealth is something that would make a lot of sense for our patients — especially patients who have mobility issues or who live far away,” says Dr. Nancy Sicotte, MD, chair of the Department of Neurology at Cedars-Sinai Medical Center in Los Angeles. “I have one patient who lives in Bakersfield, California, which is two hours away. He works full time and would have to take a whole day off from work every six to nine months to drive down and see me. Now he can turn on his tablet from his
office, talk to me for 25 minutes, then turn around and go back to work.”

Making visits easier
It’s more than convenience. Some patients can’t afford time off work, not to mention transportation and parking costs. Others, like Miller, are easily fatigued and have difficulty finding transportation, though she emphasizes that her appointments with her neurologist are well worth the effort she makes. Still, others live in areas that are prone to extreme weather, where driving on any given day might be dangerous.

Faced with many obstacles, some people with MS will opt to skip healthcare appointments altogether, forfeiting the positive health outcomes routine care might otherwise yield. This is especially true in specialties that require frequent visits. While a person with MS might see a neurologist only once or twice a year, for example, they might see a physical therapist or psychologist once or twice a month or even weekly. That can compound obstacles and increase the number of missed appointments.

“If you live with MS and have fatigue, you may wake up one morning and find that your body is not moving very well. Are you feeling able and motivated to get dressed and take transportation to come to see me in my office? It’s not likely,” says Kimberly McGuire, PhD, a clinical psychologist at the Kessler Institute for Rehabilitation in West Orange, New Jersey. “But if you’re not feeling well, can you make it over to the phone or the computer? It’s a lot more likely, and you’ll get the support you need on a day when you probably need it most.”

Access to care is even more critical for those who live in small cities or rural towns away from MS centers of excellence. “It’s an equity issue,” Sicotte says. “We have some effective therapies for MS, but they require subspecialty expertise and have significant risks associated with them. [Telehealth] could help us address health disparities and ensure the best possible outcomes for people in places where there is a relative shortage of MS specialists.”

In July 2020, CMS reported a 4,300% increase in telehealth visits compared to pre-pandemic.
Along with its apparent benefits, telehealth has some unexpected advantages. One, for example, is the ability to interact with a person’s family member or friend.

“The most important part of an exam is taking a patient’s history, and we can do that just as well during a telehealth visit as we can in person — sometimes even a little better,” says Dr. Aaron Miller, MD, medical director of the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Hospital in New York. “That’s because there’s often a spouse or significant other at home who might or might not have been present at an in-person visit, and they can sometimes add useful information to the conversation.”

Telehealth also offers a unique window into a person’s environment and routine, allowing providers to tailor care to real-life circumstances. “As a physical therapist, patients will sometimes tell me, ‘I’m having trouble getting in and out of my bathroom’ or ‘I’m having trouble reaching this one cabinet where I store things,’” says Meredith Drake, a neurological physical therapist at Johns Hopkins Hospital in Baltimore. “With telehealth, I can actually see the weird stair they’ve been having trouble climbing and help them maneuver it.”

Cyber shortcomings

For all its benefits, telehealth also has its warts, according to Beverly Betz-Zachery of Crofton, Maryland, diagnosed with MS in 2010. When the pandemic began, she started virtually seeing her counselor every other week. When it came to her neurologist, however, telehealth didn’t seem like enough. “When I’m seeing the psychologist, it’s great. We’re just talking, so it works out fine,” says Betz-Zachery, 69. “However, my virtual appointments with the neurologist and other specialist seemed incomplete without the ability of the doctors to observe my issues with my drop foot and other mobility concerns.”

Some healthcare professionals share Betz-Zachery’s trepidation. “When you do exams remotely, it’s not as thorough as in-office exams because of limitations,” says Dr. Barry Singer, MD, director of the MS Center for Innovations in Care at Missouri Baptist Medical Center in St. Louis. “In the office, you can very easily check vision, sensation, reflexes and strength of different muscle groups. All of those things are harder or impossible to check remotely.”

Cognitive impairments can be challenging to address, as well. “You have to be able to figure out how to manipulate the technology to participate in a video visit, and that can be an issue for folks who are cognitively impaired,” Sicotte explains.

Pain management is yet another thorn, observes Jodie Haselkorn, MD, a physiatrist and MS
specialist at the VA Puget Sound Health Care System in Seattle. “What’s really difficult is doing hand or small-joint therapy, or addressing acute pain that requires specific modalities and skilled hands,” she says.

Though it works well for Betz-Zachery, even virtual psychotherapy has limitations. “When you see someone on video, for the most part, it’s like a school portrait: from the mid-chest up,” McGuire says. “As a mental health practitioner, when you’re sitting in a room with somebody, you see all their nonverbal cues — what they’re doing with their hands, how much they’re shifting in their seat, whether they are crossing their legs. Body language can be useful in helping a therapist establish an emotional and therapeutic connection with the client, and this is missing with a video session.”

Between mid-March through early July 2020: More than 10.1 million Medicare beneficiaries received a telehealth service.

Nevertheless, doctors can accomplish an impressive amount remotely. For example, Sicotte says she can easily review MRI scans and lab results with her telehealth patients, and she can look for signs of cranial nerve damage by examining facial asymmetry, listening for speech slurring and conducting basic eye movement tests. Miller likewise tests his patients’ coordination by asking them to put their finger to their nose, perform rapid alternating hand movements and sometimes slide their heel down their shin.

Singer has fine-tuned his virtual gait exams by asking patients to prop their phone against the wall on the floor, so he can observe their legs while they walk, including heel to toe. Even physical therapy can be effective from home, according to Drake. In the absence of specialized equipment, she has her patients do strength-building exercises with soup cans, milk jugs and other household items, as well as complementary resistance bands that her practice mails to their homes.
“We can’t do a full physical exam, but there’s a lot we can do,” says Patricia Melville, a nurse practitioner at the Stony Brook University Neurosciences Institute in Stony Brook, New York. “When a patient comes in for a follow-up, I may spend 20 or 30 minutes with them and spend only five minutes doing a neurological exam. I spend the rest of the time talking about their symptoms, strategizing ways to help ameliorate them and answering questions about new treatments or therapies. All of that can be discussed virtually.”

‘Here to stay’
Its limitations mean telehealth isn’t for all. Still, its benefits mean it’s definitely for some, according to Drake, who says people with MS who are stable and know their bodies can thrive in virtual environments. At the same time, those who are newly diagnosed or coping with new or worsening symptoms might prefer hands-on care.

That resonates with Jennifer Stuart of St. Louis, who’s had MS since she was 17. So far, she’s had two telehealth visits with her neurologist. “I wouldn’t mind continuing to do telehealth visits going forward for regular checkups, but if there were something I was more concerned about, I would probably want to go into the office,” says Stuart, 34. “I definitely like it, though. You’re at home, and there’s no waiting at all, which is really convenient.”

Still, doctors need to see their patients in person eventually. In the future, Melville foresees a hybrid care model. “At some point,” she says, “I think patients will come in annually for an in-person visit, so we can do a full, thorough neurological exam with blood work and an MRI. And those who want to will then be able to do their follow-up visits via telehealth.”

From an insurer standpoint, prospects look bright so far: Although CMS began widely reimbursing telehealth only on an emergency basis because of COVID-19, it has since proposed changes to permanently expand telehealth coverage.

Concludes Sicotte, “It’s going to evolve. I think we’re going to see more regulations and requirements around what makes sense to do virtually and what doesn’t. I think telehealth is here to stay.”

**How to prepare for a telehealth visit**

A successful telehealth visit is as dependent on the patient as it is on the provider. Here are healthcare professionals’ top tips for preparing:

- Check your internet connection. The most critical thing in telehealth is a reliable internet connection, says Patricia Melville, a nurse practitioner at the Stony Brook University Neurosciences Institute.
- Make sure other programs on your computer are closed. Free up bandwidth by exiting unused programs.
- Do a technology test run. Different healthcare providers use different platforms for
telehealth. Some may use consumer platforms like Zoom or FaceTime, while others may use proprietary solutions. Likewise, some may allow you to connect via your smartphone, while others might require a computer. Find out ahead of time what your provider uses, then take it for a test run before your appointment, Melville advises. If your provider uses Zoom, try doing a Zoom call with a friend or family member beforehand to ensure you’re familiar with the technology and don’t waste precious appointment time learning it. If you’re not comfortable with technology, it’s a good idea to have available someone who is — a spouse, a friend or a child, for example — so they can help troubleshoot any glitches.

- Make sure you’re visible. When you do your test run, be sure to check your camera angle, cautions Meredith Drake, a neurological physical therapist at The Johns Hopkins Hospital. Your provider may want to see your full body, not just your face, so learn ahead of time to position your phone or computer appropriately. Also, she says, be mindful of lighting; if you do your telehealth visit in front of a bright window with a lot of glare or a dim room with little light, your provider won’t be able to see you adequately.

- Create a safe, private, well-lit and quiet space. If your telehealth visit will have a physical component — if you’re doing virtual rehab, for example, or even a virtual neurological exam — ensure that you can do it safely in your home or office, or wherever you’re conducting your telehealth visit. If you’re at risk of falling from balance issues, for example, it’s a good idea to have a chair or walker available to lean on and to have someone nearby who can help you if you need it, says Drake. If required, you also should clear space ahead of time where you can do physical therapy exercises.

- Provide your location and phone number to the provider.

- Set goals. Finally, you should prepare not only your space but also your plan, according to Jodie Haselkorn, MD, MPH, a physiatrist and MS specialist for the VA MS Center of Excellence and the VA Puget Sound Health Care System in Seattle. It’s easy to get lost in a teleconference by distractions when you’re connecting from home, she says, so it’s a good idea for patients and caregivers to write down essential objectives and questions ahead of time. When preparing your plan, remember the top three or so issues of personal concern are more likely to be discussed thoroughly in one visit rather than a large number of problems. Multiple large concerns may need additional visits.

Matt Alderton is a Chicago-based writer and editor.