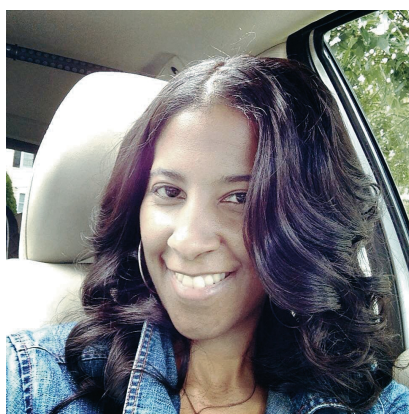


MS Rx: Rehab



This critical form of care helps you keep living your best life after diagnosis and through the years.

by Aviva Patz



Dawn Morgan, diagnosed with MS in 2000, says regular rehab has improved her mobility and strength.

Dawn Morgan, 47, ran four miles a day till she was diagnosed with multiple sclerosis in 2000 and lost the ability to “walk normally.”

“I was determined to get back to being able to walk unassisted,” says the Washington, D.C.,

resident. With regular rehabilitation — including physical therapy and occupational therapy — she improved her gait, mobility and leg strength, eventually leaving her cane, walker and motorized scooter behind. “I’m not running marathons, but I can walk,” she says.

MS can affect many aspects of everyday living, causing fatigue, pain, weakness, brain fog and low mood. “Medical treatments are good at limiting new events, but they don’t address the symptoms that affect people day to day,” explains occupational therapist Kathy M. Zackowski, PhD, associate vice president of research at the National Multiple Sclerosis Society. “Rehab kind of gives you your life back.”

Whether you’ve just been diagnosed with MS or are at a more advanced stage of the disease, rehab can help improve function in all aspects of your life. Read on to learn exactly what it is, the types of providers you might see and how you can overcome the most common obstacles to making rehabilitation part of your routine MS care.

What is rehab?

Rehabilitation involves working with a team of professionals to optimize function and reduce disability. “Rehab is about helping a person be as independent as possible, whether continuing school, work, recreation or raising a family,” explains Patty Bobryk, a neurological physical therapist in Steamboat Springs, Colorado. That might involve strengthening certain muscles, introducing assisted devices or adapting your environment to your needs. “The goal is to help people engage in whatever is most important in their life,” Bobryk says.



Armando Trinidad works with his therapist, Nick, from the NeuroBalance Center twice a week. Photo by Beto de Freitas

For 39-year-old Armando Trinidad, who was diagnosed with MS in 2014, doing rehab three times a week has meant the difference between weakness and stiffness with a walker and feeling strong on crutches. “I noticed quickly that physical therapy contributed a lot to improving my lifestyle — I got stronger, and my balance improved,” says Trinidad, who lives in Hoffman Estates outside Chicago. “Without that weekly movement, my legs feel heavier, and my arms are weaker.”

https://momentummagazineonline.com/wp-content/uploads/2023/12/armando_trinidad-momentum-540p.mp4

How rehab can help

Research is increasingly showing rehab to be a critical part of MS care. Not only can it help restore and preserve function, but it can prepare you to manage symptoms down the line.

Physical function

- A 2019 Cochrane Review of findings on the impact of physical therapy (PT) in MS found that people with MS who participated in exercise rehab with a team of professionals saw improved mobility and muscular strength, reduced fatigue and improved overall quality of life compared to people with MS who did not do rehab.
- Brett Fling, PhD, director of the Sensorimotor Neuroimaging Laboratory at Colorado State University, has found that people with MS who do a four- to six-week PT program see significant improvements in mobility. He’s now studying the use of wearable technologies (like a specialized Fitbit and biofeedback devices) to bring those benefits home. “We are able to translate those improvements into daily life by providing portable, wearable stimulation to muscles and nerves in the legs while folks go about their normal daily routine.”
- Eric Klawiter, MD, who works at Massachusetts General Hospital in Boston, is funded by the National MS Society to test whether a technique called Rhythmic Auditory Stimulation (RAS) — walking to a beat or music — can help people with MS improve their gait. In other populations, RAS has already been shown to improve walking speed, stride length and rhythm.

Mental function

- People with MS who engage in cognitive rehabilitation tend to improve overall cognitive functioning, according to Meghan Beier, PhD, adjunct professor of physical medicine and rehabilitation at the Johns Hopkins University School of Medicine. She cites a study from the Kessler Institute that looked at the ability of people with MS to purchase an airplane ticket or cookies online. “People who had rehab were better able to navigate

that task than people who had not," she says. "The neuropsychological skills learned in rehab translate to skills people use in their everyday lives."

Emotional function

- A Cleveland Clinic study shows that people newly diagnosed with MS who see a psychologist for at least four sessions have better mental health outcomes than people who don't. "It helps people gain some education about this diagnosis and what to do if they experience new or worsening symptoms," Beier explains. She often sees people in panic mode because they never learned how to cope with the stressors or manage the uncertainty of living with this unpredictable disease. "Rehab lays the groundwork so people with MS feel more control," Beier says.
- A 2023 study in *Health Psychology Research* showed that people with greater psychological resilience — defined as ability to cope with and recover quickly from problems and difficulties — showed higher levels of social and professional functioning, especially when it came to relationships, communication, social activities and life skills. Resilience is one of two factors that predict the success of rehab, according to Zackowski. "Resilience is the belief that you can get better. It stimulates the nervous system to the point that it really makes a difference in recovery," she says. The second factor, neuroplasticity, is the brain's ability to adapt to change, which is key to compensating for the damage caused by MS. "But if you don't have the resilience piece, it diminishes the impact of neuroplasticity. You need both," Zackowski says.
- Psychological tools are a focus for Dawn M. Ehde, PhD, a professor of Rehabilitation Medicine at the University of Washington and a clinical psychologist in the UW Medicine Division of Clinical and Neuropsychology. In her research, she's exploring how two psychological interventions, cognitive-behavioral therapy (CBT) and mindfulness-based cognitive therapy (MBCT), can reduce chronic pain intensity in people with MS. CBT aims to reduce negative pain-related thoughts; MBCT also aims to minimize unhelpful thoughts and behaviors, but it adds measures such as attentional control and meditative behavior.

Why rehab should be part of your MS care

"There's no drug that can help you perform activity better," Zackowski says. Your rehab will look different depending on your type of MS and symptoms, and it will evolve over time.

"These are experts you will want to call upon throughout your life," she says.



Armando Trinidad journals about his rehab progress and other parts of life.

Photo by Beto de Freitas

Why rehab is important from the get-go

Many people with MS don't get diagnosed right away, and during that delay, disease progress marches on, causing disability. "Long-term accumulation of disability can have profound consequences," Zackowski says. "Going to rehab early can help prevent that."

Even if you don't have pronounced challenges, early intervention can help track progression. "If I see you 10 years into your diagnosis, I don't know where you started and I can't monitor the changes," Bobryk says. "Symptoms can change subtly, and you might not notice." For example, a slight change in ankle strength might affect how you walk and, if left untreated, could turn into an orthopedic problem. "There's a cascade of things that can happen," Bobryk says, "but when changes are picked up early, we can nip them in the bud."

Rehab can also keep your world big — it keeps you doing your activities and seeing friends and family, which have been shown to ward off depression and anxiety. "Rehab pros can identify tools that keep people engaged in the world around them," Beier says, "from learning computer programs like Zoom to stay connected, or using a mobility device, like a wheelchair, just for a day so your family can go to an amusement park."

Symptoms and issues that rehab can address

"Rehab covers pretty much whatever you're experiencing that isn't treated by medication," Bobryk says. That may include physical symptoms such as balance, weakness, gait issues and falls, problems with swallowing, speech, sight, hand coordination, bowel and bladder; cognitive issues such as brain fog and fatigue; and emotional issues such as loneliness and depression.

“The most important thing for people to understand is that the rehab team is a community,” says Kathleen Burgess, MD, a physiatrist (a physician who specializes in rehabilitation medicine) based in Seattle. “It’s a team to help you through a stressful time — understanding new information and what the future is going to hold.” Because, as Burgess notes, unknowns can trigger anxiety, and anxiety can worsen symptoms.”

What’s more, not managing symptoms can have a cumulative effect. Take the example of an exacerbation, Bobryk says. You have more fatigue, so you move less. You get weaker, so you’re less apt to engage in activities that are important to you. That can cause you to feel sad and depressed, which leads to more fatigue. “Rehab addresses the interrelationship of all these symptoms to stop that cascade of events from happening,” she says.

Different types of rehab and rehab specialists

Your core rehab team will likely consist of a physical therapist and an occupational therapist, and possibly a speech and language pathologist. Here’s what they do:

- Physical therapists address mobility issues — weakness, gait, balance and climbing stairs. “Depending on where you are, we’ll devise exercise programs to make sure you stay at the highest level of fitness,” Bobryk says.
- Occupational therapists address your daily routines — how you shower, dress, prepare meals, get around your home and get to work.
- Speech and language pathologists address swallowing and eating dysfunction and anything related to speech and language, such as slurring.

“They’re usually the team leaders, but the network is much bigger,” Bobryk says. They also work with neurologists and physiatrists (a blend of primary care, neurology and orthopedics), neuropsychologists, health psychologists, counselors, therapists, social workers, pharmacists and orthotists (they fabricate bracing and supportive devices). At some major MS centers, “they’re all part of the team,” Bobryk adds.

What you can expect in rehab

Typically, at the first session, you’ll answer questions about your routines and impairments. “We’ll ask: ‘How do you take care of yourself? Do you have trouble dressing, toileting? Can you still clean your house, pay your bills? How do you do your job? What do you enjoy?’ ” Zackowski says.

The specialist will then do an evaluation to assess any functional challenges and get a baseline measurement of your abilities. Finally, you’ll discuss your personal goals and any recommendations for continued therapy, either at home or in-office, and possibly with other professionals. All recommendations will be tailored to your specific needs and goals.

For example, to help recover muscle strength in her legs, Morgan did weekly water therapy for a year. She walked from one side of the pool to the other and did flutters and kicks while holding onto the edge. “Working in the water helped me regain muscle control in my legs and

build strength,” she says.

For attention challenges, Beier might have a person do a cognitive task while playing their favorite music in the background. She’ll see how the person performs and practice ways to refocus attention if the person gets distracted. “We’ll talk about skills and practice again until we see improvement in the person’s ability to stay engaged,” she says.

Speech pathologist Rachel Haines, an MS-MS-certified specialist at the Multiple Sclerosis Comprehensive Care Center of Central Florida, explains how she works with a person whose speaking volume is low. She might recommend training on breath work for speech, a voice amplification system or alternate communication tools — a writing board, a text-to-speech app or a dedicated device that supplements or replaces communication if speech becomes more limited.

In-person vs telehealth rehab

Telehealth is here to stay, according to Burgess, and for good reason. “You don’t have to drive. You don’t get exposed to infections. And when things are stable and we’re just checking in, telehealth is great,” she says.

Bobryk says rehab via telehealth solves a few key problems, namely transportation and fatigue. “Think about the energy it takes for someone to shower and dress and get into a car and drive to a therapy center,” she says. And some people live a great distance away on top of that. “Telehealth is a great way to stay connected and manage symptoms because we can do things remotely that people wouldn’t otherwise be able to do.”

Telehealth rehab may be especially helpful when it comes to exercise, since traveling to a gym can be challenging for people with MS. Physical therapist Deborah Backus, vice president of research and innovation and director of MS research at the Shepherd Center in Atlanta, Georgia, is co-leading a study with Robert Motl, PhD. The study is comparing the effectiveness of an exercise program delivered via video conferencing against the same program at a rehab facility. The program is designed to improve walking, mobility, symptoms and quality of life for people with MS who have a walking impairment. If the at-home version proves valuable, more people with MS will be able to take advantage of the benefits of exercise.

Telehealth does have limitations. It can be difficult for people who aren’t computer savvy, and not all insurance carriers cover it. It’s also not useful if there needs to be a physical exam, like to check bladder volume, spasticity, weakness or muscle strain, or if the specialist needs to make an official diagnosis, according to Burgess.

It can also complicate physical assessments, says Bobryk. “To get a complete evaluation, I need to lay my hands on someone and feel what their muscles are doing,” she says. “And if they have balance issues and I’m trying to test their balance, there might be a fall risk and I’m not there to spot them.”

Barriers to rehab

MS symptoms can make rehab extra challenging, but there are often workarounds. Top obstacles may include:

- **Transportation.** Getting to and from the therapy center — whether it's far to drive, you lack the energy or you can't get someone to take you — can be challenging. Bobryk suggests looking into medical transportation that some communities, insurance companies and even church or synagogue groups offer.
- **Lacking a support system.** "You need a support system to not only get you to your appointments but to believe that this is worth the effort," Zackowski says. Engage friends and family and consider joining local support groups. Your rehab providers may be able to recommend care partner support resources as well.
- **Fatigue.** "It's not like you can take a nap and feel better because that doesn't work with MS," Zackowski says. She recommends booking appointments early in the day when you're less likely to be fatigued and planning rest breaks. Work with your rehab specialists on strategies to manage your daily tasks, work and other responsibilities.
- **Bowel or bladder issues.** Bobryk suggests emptying your bladder beforehand, stopping for breaks as needed, identifying bathrooms along your route and wearing absorbent products. You might also bring an extra set of clothes just in case.
- **Extreme weather.** Good options include canceling and rescheduling for when air temperatures are more moderate, using cooling products to manage heat and layering clothing to keep warm.
- **Limitations in insurance coverage.** Some insurance plans won't cover rehab or approve only a limited number of visits. Talk to your therapist about any limitations so you can work around them as much as possible. Bobryk also recommends reaching out to support agencies that might assist with coverage, looking into universities with rehab programs that may offer free clinics, asking your facility if they have out-of-network payment plans that might work for you, and asking your insurance carrier whether more coverage might be available from a different provider or facility (a private clinic vs. a hospital, for example).
- **Attitude.** Not understanding or appreciating the value of rehab therapy can prevent you from making it a priority. Talk to your main healthcare provider about the areas of your life that rehab could potentially improve.
- **Time.** Life is busy and having a chronic illness makes everything more complicated. Guidelines from the Society suggest finding therapists who offer evening or weekend appointments and asking your rehab team to prioritize your therapy sessions when you don't have time to do them all.

How to find a rehab specialist

Speak with your main healthcare provider about your physical or emotional challenges and ask for a referral or prescription to a rehab therapist. Or use the [Society's Find Doctors & Resources](#) tool to:

- Locate a rehab specialist with MS expertise
- Find a physical therapist, occupational therapist or speech-language therapist
- Search for Partners in MS Care – Centers for Comprehensive MS Care, which provide coordinated multidisciplinary care.

Need help using the tool? Contact an [MS Navigator](#) at 800-344-4867.

Resilience and rehab



Armando Trinidad and his mother, Sonia M. González

Photo by Beto de Freitas

Armando Trinidad has had a rough decade. In October 2014, after a torn meniscus wouldn't heal, an MRI showed lesions on his spinal cord that indicated he had multiple sclerosis. He knew little about MS at the time. "I try to find the humor in things," says Trinidad, 39, of Hoffman Estates outside Chicago. "I was like, 'I don't even know how to spell multiple sclerosis!' "

Then he got laid off from his job at a retail baby clothing store. In 2017, he suffered a grand mal seizure lasting 45 minutes that resulted in him having to relearn how to speak, eat and use his fingers. "That took away the little strength I had," he says. The following year he suffered a freak accident — a lit cigarette ignited something flammable on the floor and left him with third-degree burns on his legs that led to seven surgeries with skin grafts. In 2021, he developed pneumonia. At some point during this time, his marriage fell apart.

How did he get through all this adversity? Determination — and rehab.

“I have big faith in the lord above — he got me here for some reason,” says Trinidad, who never thought his legs would hold him up again after the burns. “All these things happened, but my attitude is: As long as I’m waking up every day, I’m winning.”

Trinidad’s unfailing resolve and love of life drove him to write a book, “Resilience: The Autobiography of Mando Trinidad,” published in 2022. “I’ve got a story to tell. Life is hard but when you give up, it gets even harder. We’ve just got to keep going.”

The counterpart to Trinidad’s positive attitude has been regular rehabilitation therapy, recommended by his neurologist. Though Trinidad still deals with leg weakness, stiffness and spasticity, he credits his three-day-a-week workouts to helping him transition from a scooter, wheelchair and walker to crutches, and allowing him to rebuild his strength and skills after each setback.

“Rehab has changed my life,” Trinidad says. “I’m walking again, and that itself went against a lot of odds. I wouldn’t be where I am at this point in my life physically and mentally if it wasn’t for rehab. Every day, in every way, I get better and better.”

Trinidad’s weekly rehab routine entails 10 minutes of cycling, seated strength-training using resistance bands, crunches using an exercise ball, and walking with crutches. The exercises strengthen his core, back and legs, giving him the muscle power to walk and balance.

The work is taxing, and he still sometimes stumbles and falls. “I get frustrated, but I let that heated moment last for 5 to 10 minutes at the most; then I say, ‘let’s go,’ ” says Trinidad, who believes that giving in to anger and negativity drains his metaphorical batteries. Instead, he challenges himself, “What are we going to do about it?”

Trinidad has posted more than 500 YouTube videos of his rehab sessions with the hashtags #Mindovermatter, #Noexcuses, and #Endurance. In one video, he splashes text across the screen: “Sits to stands!” Building on his [YouTube channel](#), which has about 12,000 subscribers, he is training to become a life coach.

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