

## Connected to care



**Remote rehab and exercise programs serve people with MS regardless of location, schedule or mobility.**

**by Matt Alderton**

Although she isn't a physicist, Susie Keith lives her life according to Newton's first law of motion: An object at rest stays at rest, while an object in motion stays in motion.



**Susie Keith, who was diagnosed with MS when she was 19, knows the**

## **benefits of staying active.**

**When she broke her foot and couldn't drive to the gym, she relied on a telefitness program for remote group exercise classes.**

Photos courtesy of Susie Keith

"I've always known how important exercise is," says Keith, 62, of Omaha, Nebraska, who fills her free time with activities like weightlifting, swimming and yoga. "The Lord blessed me with this body. If I just lay around not taking care of it, it's not going to stay healthy."

Staying healthy is especially important—and difficult—for Keith because she has Type 1 diabetes and was diagnosed with multiple sclerosis when she was 19. During 13 subsequent years spent in and out of exacerbations, her most pronounced MS symptom was her stiff, lumbering walk.

"I got better, but my left foot and ankle were never quite right," says Keith, whose gait eventually improved with the help of a physical therapist. That is, until she broke her foot in 2015, at which point she had to rely on a rollator (a walker with wheels) and lost confidence in her ability to walk.

Literally and figuratively, she found her footing again nine months later at Omaha's MSforward, a nonprofit gym for people with MS, where a combination of coaching and community had her walking independently within six months—until she experienced a seizure.

"For three months I couldn't drive and had to stay home," recalls Keith, who was determined to stay active. Her saving grace: MSforward provides a telefitness program where participants can join remote group exercise classes led by founder and owner Daryl Kucera, who also has MS. Five times a week, he livestreams personalized, MS-specific physical training to participants via their computer, tablet or smartphone.

"I survived those three months at home because of [telefitness]," says Keith, who continues to work out remotely once a week. "I can't say enough how much it's benefited me."

Telehealth advocates say remote exercise and rehabilitation can benefit a lot of people like Keith. Unfortunately, insurance in most cases doesn't cover it, which means programs for now are few and far between. But that's changing thanks to a growing body of research that's gradually making the case that "virtual" is valuable.

## **Remote rewards**

Although exercise and rehabilitation are not identical—exercise is supposed to be ongoing

and routine in pursuit of overall physical health, while rehabilitation is finite and targeted to help overcome specific symptoms or challenges—they offer similar benefits when provided remotely to people with MS. These benefits include convenience, comfort and quality.

Convenience is especially important for people who live in rural areas. “We are in a rural state, and it’s not uncommon for patients to drive two or three hours each way to see us,” says Dr. Gabriel Pardo, director of the Multiple Sclerosis Center of Excellence at the Oklahoma Medical Research Foundation (OMRF) in Oklahoma City, where he conducted a successful telerehab trial in 2016. “That may be OK for visiting your neurologist, whom you see once every four to six months. But for physical therapy, you may have two or three visits a week for six to eight weeks.”



**Tracy Tracy, clinical research coordinator at the Tanner Foundation.** Photo courtesy of Tracy Tracy

Commutes also can be challenging for urbanites, particularly those with physical disabilities, visual impairments, extreme fatigue or other limitations. “Even if you live in a large urban center ... if you have to use a rolling walker and negotiate transportation, that is a significant hassle,” Pardo says. Even if distance and mobility aren’t issues, time can be. “There are some people—moms like me, for example—who are busy and can’t or won’t take time for themselves to do [onsite physical therapy or exercise],” says occupational therapist Tracy Tracy, clinical research coordinator at the Tanner Foundation in Birmingham, Alabama. The foundation is studying the benefits of telerehab for people with MS.

Another consideration is quality of care. “Just finding physical therapists who have the right expertise and experience can be a barrier,” Pardo says.

There may be psychosocial benefits to remote rehab and exercise services, too—particularly in the case of remote group exercise programs like those offered by MSforward and Horizon Rehabilitation Centers, another Omaha-based organization that offers telefitness for people with MS. “Not only are we able to create an environment where participants can exercise safely with a professional who understands MS, but we are able to offer a sense of community and understanding between participants,” says Lindie Schreiner, a physical therapist assistant at Horizon. “The connections that are made in the class help participants with accountability and mutual support.”

### **Healthy data**

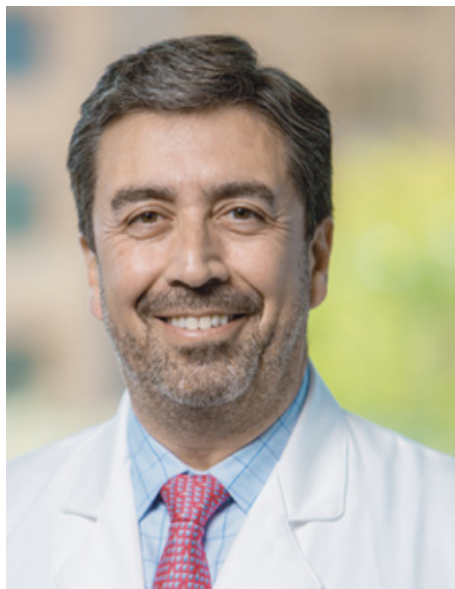
Sure, they’re convenient. But do remote programs actually work as well as in-person programs? Research suggests some might.

Take Pardo’s 2016 trial. Completed over eight weeks, the study of 30 participants with MS compared one group that completed supervised remote physical therapy via videoconferencing twice weekly to another that completed in-person physical therapy, also twice weekly.

“The patients who underwent telerehab performed pretty much the same as the ones who received in-person physical therapy,” says Pardo, who evaluated patients’ gait, balance and self-reported health. “Our conclusion: Telerehab for most parameters is as beneficial as in-person rehab.”

A 2016 study by German researchers found similar benefits for remote exercise: Among 59 people with MS who received physical training via the internet for six months, it observed positive gains in muscle strength, lung function and physical activity.

During a 2017 pilot project, University of Alabama at Birmingham physical therapy professor Robert Motl found that even virtual education can be helpful. He divided 47 people with MS into two groups: a control group and an intervention group. For six months, the latter received behavioral coaching by video chat and education via an e-learning website, the goal of which was learning strategies for increasing physical activity. Compared to the control group, they not only exercised more, but also experienced less fatigue, depression, anxiety and pain, as well as improved quality of life, walking, cognition and body composition.



**Dr. Gabriel Pardo, director of the Multiple Sclerosis Center of Excellence at the Oklahoma Medical Research Foundation.** Photo courtesy of Dr. Gabriel Pardo

Motl is part of an effort to gather “the strongest evidence to date” on the effectiveness of telerehab for people with MS. The multiyear “Tele-Exercise and Multiple Sclerosis,” or TEAMS, study will include 820 participants who will receive a tablet preloaded with video exercise routines to follow unsupervised at home, which makes the program more inclusive of rural populations that lack high-speed internet connections.

“We don’t have any results yet, but so far we’ve recruited 516 people out of 820—which tells me that people are actually very interested in this type of program,” says Tracy, who is working on the study with Motl.

A systematic review conducted in 2018 by the U.S. Department of Veterans Affairs (VA) Multiple Sclerosis Center of Excellence shows that results span more than just a few studies. Researchers reviewed the results of 28 different studies conducted between 2001 and 2018 and concluded that—despite “a range of outcomes with variable quality”—telehealth overall is “beneficial, cost-effective and satisfactory for patients and providers.”

### **Tele traction**

Although the TEAMS study is exploring the potential benefits of unsupervised programs—self-guided, home-based exercise or rehab using recorded videos—the secret ingredient in many remote programs is live video chat with a therapist or trainer who can coach, observe and direct participants in real time.

“With MS, everybody’s illness is so different, so a recorded video is not going to address your

unique needs,” says MSforward’s Kucera. “When you’re live, you can make the program specific to the individual, not the illness.”

But even the most tailored remote programs can have drawbacks. People at home typically have limited equipment, for example, and lack the benefit of a therapist’s physical touch.

“[In order to] reinforce quality movement patterns and correct exercise form, tactile or physical cues are most helpful,” says Mandy Rohrig, a physical therapist with Schreiner at Horizon Rehabilitation Centers.

Then there’s cost. Currently, Medicare does not cover telerehabilitation, although private insurers and Medicaid in some states do. In its most recent analysis, published in 2017, the American Telemedicine Association indicated that while Medicaid plans have some type of coverage, only 26 states reimburse for telerehabilitative services, each with varying degrees of coverage. Because reimbursement is so limited and inconsistent, telerehab programs for people with MS so far consist principally of pilots and trials.

Although participants must pay for them out of pocket, options are greater in the telefitness area, according to Rohrig. In addition to her program at Horizon, which costs \$30 per month, and MSforward, which costs \$14.95 per month, she cites MS Workouts and My MS Gym as options. Both cost about \$30 per month, or \$288 per year.

Whether you’re interested in rehab or exercise, Schreiner says your neurologist or physical therapist can help you find a remote program that suits you. And if they can’t, Rohrig adds, “there are other online exercise programs for yoga, Pilates or seated exercises—just to name a few—that are not specific to people with MS but are still quite valuable.”

One thing is certain: More options are just around the corner. “Legislators are taking notice, and policy is catching up,” says Shane Chanpimol, a physical therapist at the VA Multiple Sclerosis Center of Excellence, where he is administering a telerehab pilot program for veterans with MS. “I think this trend will accelerate as the benefits become clearer, clinicians become more comfortable using the technology and processes for reimbursement are standardized.”

**Matt Alderton is a Chicago-based writer and editor.**

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