

On the move



Assistive devices can help people with MS stay active. But learning to accept them can be a challenge.

by James Townsend



After experiencing falls while using a cane and rollator, Calvin Stroud now uses a power

wheelchair. Photo Courtesy of Calvin Stroud

Diagnosed with multiple sclerosis in 1999, Calvin Stroud was symptom-free for the first eight or nine years of living with the disease. “No one could tell unless I told them,” says Stroud of Montgomery County, Maryland. But in 2012, he began to have trouble with mobility and turned to a fold-up cane for help. “Then, I started to have more falls with a cane. By late 2013, I started to use a rollator (a walker with four wheels), but I even had falls using that.” Today, he uses a motorized wheelchair.

Yet, even now, coming to terms with using assistive devices is what Stroud calls “a work in progress.”

For people living with MS, assistive devices can make a big difference in staying active.

But learning to accept them can also be a big challenge.

“I worked for more than 20 years in the MS world, and people have many reasons for not wanting to employ assistive devices,” says occupational therapist Nancy Lowenstein, clinical associate professor at Boston University College of Health & Rehabilitation Sciences: Sargent College. “They may be young, for instance, and don’t want to be thought of as needing a device.”

Some of her clients thought that even using devices in private, such as a shower seat, was like giving in to the disease.

“Sometimes family members discourage the use of assistive devices too for this reason,” Lowenstein says. “But to remain as active as you can be, you have to save your energy, and assistive devices are important tools for this.”

Adapting to changing needs

It’s a point that Alexius Sandoval, MD, medical director of the Multiple Sclerosis Rehabilitation Program at Johns Hopkins University, also emphasizes. “When you have MS, particularly more progressive MS, you may have a limited amount of energy, which like a bank account, must be used wisely. Using an assistive device can significantly decrease the amount of energy you use to accomplish tasks.”

Dr. Sandoval is a physiatrist, a specialist in treatments for the neuromusculoskeletal system. He works with a team of physical, occupational and speech therapists, as well as psychologists and neurologists, to provide a multidisciplinary approach and individualized treatment for each patient. “MS is a moving target,” he says, “and individuals with MS have to adapt to changing needs as new challenges arise.



**Gina Daddazio and her husband
at MuckFest Philly 2018.**

**Daddazio came to terms with
using a cane after falling as well
as hurting herself on a
bike.** Photo courtesy of Gina
Daddazio

"Some individuals with more progressive MS may be in denial that they need an assistive device," Dr. Sandoval continues. "I've had some patients completely opposed to it, but coming from a rehab perspective, the patient's safety is my paramount concern. I ask them to walk, and if I see them dragging a foot, I ask if it has caused them to trip or fall, or if by the end of the day they have a hard time walking. One technique to help them overcome resistance to assistive devices is to let them see, hold and try the device. For instance, I let the patient try on a leg brace. Many of these are very lightweight and thin, and a number of them can be worn discreetly underneath their clothing," he says.

"One problem with MS is that it is largely an invisible disease," says Albuquerque, New Mexico, resident Caitlin Anderson, 52, who was diagnosed with MS in 2006. "Oftentimes you wouldn't have a clue that I have it until you see me try to walk."

People living with MS sometimes feel the sting of judgment from others. Diagnosed in 2008, Gina Daddazio, 39, of West Chester, Pennsylvania, is married and the mother of two young children. She and her family recently visited Universal Studios in Orlando, Florida. "I used a rental scooter in the park. It was challenging," she says. "I don't appear to not be normal, and I overheard people make fun of people using scooters. It took me a while to adjust to this

sort of thing, but it's a choice I have to make if I want to remain active."

The big difference: attitude

Coming to terms with how and why assistive devices may be useful for you is different for everyone. For Anderson humor has been a great ally. "If you don't have a sense of humor, it is going to be a long road." At first, she insisted on only using what she calls a "sexy REI walking stick." As she needed sturdier support, she graduated to "pretty canes," and a bright blue ankle/foot orthotic painted with butterflies that she sometimes uses. When eventually she needed a scooter, she says: "We named it Zippy and blinged it out with stickers. I'm approachable. People ask questions and I become an ambassador for any device I'm using. Kids will come up and talk to me about the ankle/foot orthotic, and I'll say things like, 'Sometimes my brain doesn't talk to my legs!'"



Caitlin Anderson and her service dog, Sunshine. Anderson was on a waiting list for four years before receiving Sunshine, who is now her constant companion. Photo courtesy of Caitlin Anderson

Anderson says she applied in 2013 to get on a waiting list for a service dog and waited more than four years before being selected. Though probably not technically an assistive device, Sunshine, half Golden Retriever and half English Labrador, has now been Anderson's constant companion for more than a year. Sunshine flies with her and picks up things for her when she can't feel her hands. "Sunshine loves movies, too, and will even get me popcorn."

Daddazio says she came to terms with needing a cane after she fell while holding her son in her arms and later hurt herself on a bike. "It was a lesson I needed," she says. "I've learned to accept [assistive devices] because they are what get me out of the house." And she gets out of the house a lot, leading TRX exercise classes for others with MS since September 2017. "[TRX] involves resistance training for the total body, using straps and one's own body weight to control exercise, either seated or standing. Some people have their walkers or wheelchairs

with them, and we do things to increase range of motion and strengthen the arms, such as reaching as high as possible.”

Her cane is also stylish. “People are going to stare at you one way or another,” she says, “and the cane is a psychological tool, as well. It helps me keep moving and keep smiling.” And although she says being diagnosed three days before her first wedding anniversary was sad, “now it’s a celebration.” Having her two children after being diagnosed has helped her realize she has to be an example for them and for others in the group. “Using assistive devices,” she says, “is not about feeling sorry for yourself, but about managing the disease.”



Gina Daddazio (right) leads TRX exercise classes for others with MS. TRX involves resistance training for the whole body, using straps and one’s own body weight to control exercise. Photo courtesy of Gina Daddazio

When Stroud began to realize that driving a car had become dangerous, he says he became “a little despondent that I’d lose some of my independence. But I was able to get another humongous assistive device: a vehicle with hand controls for steering, braking and acceleration, and a motorized transfer seat,” to move in and out of the vehicle. “It was a game changer!” he says. Getting remarried in 2016 was a big psychological boost and helped him figure out his choices. “I was having more falls, losing strength in my legs, and experiencing a lot of fatigue. My wife, who is a social worker in a hospital, really gave me a kick in the pants. She said, ‘You can’t keep doing this!’ So I started using the power chair around the house and, as of April 2018, I’ve now been to physical therapy three times. Also, I’ve just finished aquatic therapy, which has really helped me regain muscle strength.”

Dr. Sandoval says that people with MS often will minimize their problems, so it can be helpful if a family member comes to therapy with them. “The patient may say that they only fell once, while the family member might remind them that it was really 10 times. And I can ask

the family member how much assistance they have to provide for the patient. That kind of feedback can help the patient realize the need for these devices.”

A world of helpful tools

Countless other devices are on the market and can be useful to help with even small tasks. There are long-handled grabbers to pick things up from hard-to-reach places, kitchen devices to open bottles and cans, bathroom devices to increase safety in the shower or bath, leg lifters and adjustable beds, e-tablets on which users can trace the letters they want to type and, of course, numerous devices to help with mobility.

The first thing people with MS might need, however, is to weigh the options and this may lead to acceptance and increased use of assistive devices. “To be honest,” Daddazio says, “no one loves needing something to get around, but you don’t want to be locked up in your house.”

James Townsend is a freelance writer in Boulder, Colorado.

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