

Roll with it



Life looks different from a wheelchair. Here's how to manage it.

by Mike Knight

Everything should have been fine.



Mike Knight was diagnosed with MS in 2013. He writes that using a wheelchair takes time, energy and patience.

It was late in the afternoon, the end of the day at the medical facility where I had undergone diagnostic breathing tests. I was recovering from aspiration pneumonia courtesy of my multiple sclerosis-weakened respiratory system.

With my tests completed, my wife, Michelle, and I boarded an empty elevator.

Large medical facilities often mean parking garages, long hallways and lots of walking — walking I could no longer do, even with a rollator and multiple rests. Today, we'd decided to incorporate my new wheelchair into the trip. Though getting in and out of the men's room took some doing, it worked out pretty well and reinforced my decision not just to use the chair that day but to get it in the first place.

We boarded the elevator, turned around to face the door and pushed the button for the first floor. Then we moved back a couple of feet and waited for other passengers to get on.

We hadn't noticed another door behind us until it opened, and people began filing in. We turned to face the "correct" entry, with all those people now crowded into a packed elevator standing in front of us. Michelle stared at the backs of a bunch of heads and necks. Me? I had a different view. I was sitting in my chair "cheek to cheek" with my fellow passengers. And while the elevator hadn't yet moved an inch, I had clearly reached the "bottom" floor.

Life is different in a wheelchair. From opening doors to navigating bathroom stalls to transporting the chair to and from your destination, it can be challenging, chaotic and frustrating. The unpredictability of MS and its symptoms only adds to that mix. On top of that, there's all the emotional baggage that comes with it.

A wheelchair can get you from point A to point B a lot easier, which means less energy spent on the journey and more spent enjoying the destination, even if it's simply going to the kitchen to grab a snack before settling in for a Netflix binge. You don't have to worry about tripping and falling and the awkward, tension-filled drama that accompanies your every step with a cane or walker. And, like much of life itself, it gets a little easier with experience.

As with all things MS, getting the right chair for your needs, and learning how to live in — and with — it requires time, energy and patience. I asked mobility experts and MS-wheelchair users for insights, tricks, tips and advice that can help get you rolling faster and easier.

Chair today, tool tomorrow

The decision to transition to a wheelchair can be an emotional one. It's a milestone that marks the loss of a core function as well as the challenge of learning to live life forever strapped into a piece of equipment that announces your disability wherever you go. It also represents a piece of ground forever lost to MS — a disease bent on painting those who have it into ever-smaller corners.

Justin Kimrey is a mobility and seating specialist at Stalls Medical in North Carolina. He is also a certified assistive technology professional (ATP) who analyzes the needs of customers with disabilities, helps them select the appropriate technology for their needs and then trains them in how to use their devices. Kimrey says emotional turmoil often hinders our acceptance of transitioning into a chair and influences our decision-making later in the

process, too.

Kimrey, who began using a wheelchair after an automobile accident left him unable to walk, says there's a somewhat definable path users with MS take to a wheelchair. First, the cane-walker-rollator combo stops working for them. They frequently choose a scooter next, not because it's the best choice for their mobility needs, but because it's easier for them to accept.

Kimrey says many of his customers have MS. "They prefer to be in a scooter because it's less 'visually' disabling in our society," he says. Consequently, they often choose a manual chair over a power chair, and also because it doesn't require a conversion van to haul it around and because they can get some exercise by pushing themselves in it.

Rick Ebner followed much of that path himself. Diagnosed with MS in 1995, the 57-year-old is a former Division II collegiate athlete and traveling salesman from the Bloomington, Minnesota, area and is now on Social Security Disability Insurance. A broken arm suffered while using a cane convinced him to try a scooter. The decision was not without its costs. "I had a lot of holes in the doors and the walls," he says. "There's a learning curve with this whole thing."



Rick Ebner with his daughters Samantha (left) and Alexa. Diagnosed with MS in 1995, he now uses a power chair.

A driver's assessment gone wrong sped his transition to a power chair. "I was driving [for the assessment]," he says. "I was lifting my right leg [with my hand] from the gas to the brake, and as soon as he [the assessor] saw me do that, he said, 'You're done.'"

"I started crying," Ebner says. "My independence was now being threatened. It brought tears to my eyes."

It got harder. Affable by nature, Ebner began losing his temper with his daughters, something

he rarely did. He decided to make an appointment with a therapist for help.

"I remember going in to meet with [the therapist], and I remember the chair was by her desk, but I specifically remember seeing a box of Kleenex and I'm thinking to myself, 'What is that there for?'" he says. "And by the end of my meeting, I was using that box of Kleenex. She told me I was almost clinically depressed. I had no idea."

Ebner was prescribed an antidepressant that "took the edge off and made a big difference in my outlook." Ebner works out regularly on adaptive exercise equipment at the Courage Kenny Rehabilitation Institute in nearby Golden Valley. Sharing his story with friends at the Institute, he learned more about power chairs, adaptive hand controls that might make it possible for him to drive again, and about conversion vans he could wheel right into and ... go.

See and be seen

Ebner decided to get a power chair. While being measured for it, he began to see things differently. "The people that were fitting me to the chair told me, 'Rick, now people can see you. It's all you. It's not the steering column in front of your scooter. They see you,' " he says. "And I never thought about that. That helped me in my mindset. That gave me hope."

Not long after he received his chair, Ebner began volunteering at a senior home. "I needed to stop focusing on myself and to give back and to serve others," he says. "And that's what I did, and that's what helped me climb out of it. Today, Ebner credits his power chair for getting him "back in the game."

Alicia Vanek, an occupational therapist at the Fairview Achievement Center in St. Paul, Minnesota, says much of her job is educating patients about what a wheelchair can do for them and finding ways to incorporate it into their lives.

"My job is to help people realize that a wheelchair is another tool in their life that can increase independence versus increasing disability," she says. "A lot of people see a wheelchair as increasing their disability or that it looks bad," Vanek notes. "A lot of it honestly is that education piece and trying to just get people open to the idea of a wheelchair and what it could do for them."

Chair-curious but not sure where to turn? Chances are good your neurologist, physiatrist, primary care physician or physical therapist has noticed your diminishing abilities.

Ask for help. You may be able to find an assistive technology resource near you that will let you test drive a wheelchair before buying one.

Some home health equipment companies rent them. You might know someone who has a chair you can try, or talk to about their life in a wheelchair. Getting a wheelchair may be a tough decision to make, but it's an important one.

Choose your seat wisely

Your healthcare insurance policy likely covers some of the cost of a new wheelchair. Check with your provider to learn more. You will need a physician's order documenting what type of chair you need to receive coverage. Though that order typically comes from your neurologist or physiatrist, your primary care physician can write one, too. Your physical therapist may help your physician write the order for a wheelchair before it's submitted to your seating specialist.

But choosing the type of chair you want can get tricky, warns Meredith Linden, a clinical specialist at the International Center for Spinal Cord Injury at Kennedy Krieger Institute in Baltimore, Maryland. She understands some people's reluctance to choose a power chair due to social stigma.

Many insurance programs, including Medicare and Medicaid, she says, will only pay for a new chair every five to seven years — unless your diagnosis changes. So, choosing a manual chair for appearances' sake may come back to haunt you should you need the benefits of a power chair before five years has passed. Kimrey says a typical power chair costs about \$30,000 without insurance.

Though a manual wheelchair may be easier to embrace emotionally, a power chair may be a better long-term option, especially for people with MS battling fatigue and upper-body weakness, Linden says. However, that's often not what people want to hear. "It's tough for them to admit that they need to make the transition," Linden says. "And then to see the big picture from an insurance perspective and get the power chair is a challenging process and decision for them."

The best seat in the house

Almost as important as getting your chair is making sure your home will accommodate it. From ensuring doorways are wide enough to installing grab bars where needed to identifying potential trouble spots — steps, room dividers, accessing closets, etc. — they all play a role in everyday life in a wheelchair.



After experiencing falls while using a cane and rollator, Calvin Stroud, diagnosed in 1999, now uses a power wheelchair.

Photo: John Boal

It is a potentially long list. Arranging for a home visit from an occupational therapist or your seating specialist can help (though your seating specialist may also offer to sell home aid products to you). If you know someone in a wheelchair, you might consider asking that person for help, too.

Or you can be like Mary Lamont and take matters into your own hands. Diagnosed with MS in 1981, Lamont lives near Fort Lauderdale, Florida, and has used a power chair for the past 20 years. Though she was offered a package of lessons when she received her first chair, she did the unthinkable and read the manuals that came with it instead.

Today, she knows where everything in her home belongs. Or doesn't. "All the furniture in my house, there is a certain place where I have room to get by the chair, or past the couch or TV or something," Lamont says. "I have it all situated where it's not in the way." She has also had three doorways widened, and she plans to have three doors removed, too.

Even with all the modifications, Lamont says using her chair remains a work in progress. "I'm still running into walls, and it's hard going around some corners in the house, but I'm doing the best I can," she says. She offers this piece of advice to new users: "They should not be discouraged when they get the wheelchair, because it can be very, very frustrating. You think, 'I'll never be able to master this chair, it's hopeless.' But you find that as you use it, within a few weeks, it's just routine."

Oh, the places you'll go!

Before you hit the open sidewalk, path or mall, it's essential to understand that using a wheelchair of any type isn't without its challenges. There are plenty of ways you can learn how to use your chair, including clinics and lessons at facilities like those where Vanek and Linden work and that Ebner attends. Linden recommends that if possible, new users should try to find such a place. (Search keywords "neurorehabilitation clinic/institute" or "adaptive/assistive technology clinic/institute.") Your doctors and therapists may be able to help, and your seating specialist may offer training lessons, though there may be a fee.

No matter who is giving you the lesson, if there are specific activities you need help with, such as getting in and out of the restroom, opening doors to that restroom, getting over curbs, or taking mass transit, don't just settle for practice in the clinic. Take a trip to a reasonably quiet coffee shop together and practice; real-world situations and conditions are always harder.

There are several videos on YouTube that you also might find helpful. Or you can do as Ebner did. Before he took his power chair with him and his family on vacation in early 2020, he asked other wheelchair users for advice.

"I talked to other people at Courage who travel and they're in chairs," Ebner says. "They traveled everywhere, and they came over to my house, and we talked about it. So I got the inside scoop on what I should do." Besides learning to let airlines know about his disability and power chair when purchasing his tickets, his friends also explained how to best tag and prepare his chair to minimize damage to it during flights.

Vanek recommends trying online resources if you don't have access to other wheelchair users in person. (See links at the end of this article.)

Calvin Stroud turned to his twin brother, Alvin, for help. Alvin, who also has MS and uses a power chair, was diagnosed a few years earlier than Calvin, who was diagnosed in 1999. His brother's MS has been more aggressive, which gave Calvin a sense of what might be on his horizon. "I kind of had a built-in roadmap, because I was able to go off of my brother's experiences," he says.

Using his power chair, Stroud can reach kitchen counters and pots and pans, which lets him do some cooking, and though the sidewalks aren't in the best shape in his neighborhood, he's able to navigate them while walking his beagle terrier, Simpson. Like Ebner, he purchased a conversion van and still drives. Stroud and his wife, Kim, are also fans of portable ramps, installing a series of them around their Washington, D.C., area home so he can go in and out and roll onto their deck.

They've learned to call ahead before going out to ensure their destination is accessible and to carry extra ramps with them — just in case. "You never know how accessible places are," Stroud says. "You ask them if their restaurant is accessible and they say it is, but then there's

a two-inch, three-inch step up that you have to navigate somehow,” he says.

Like Stroud, I’ve learned contacting the venue ahead of time is critical to minimizing frustration, which makes everything so much more fun. But there’s more to it than that. My wife and I love music, and we tend to enjoy bands that play smaller venues. We also like to dine out at independent, locally-owned restaurants that are often in older urban locations. All are often barely accessible.

I’ve taken to emailing ahead, explaining my needs, and I can tell everyone is eager to help. I ask if there is a table that I can roll right up to in my chair. There always is, and everyone who helps us is always wearing the biggest smile — just like we are.

Mike Knight is a writer in Indianapolis, Indiana. He was diagnosed with MS in 2013.

Watch [a video of writer Mike Knight](#) sharing how MS affects his life.

To connect with other wheelchair users, [join a local support group](#) or contact [MSFriends](#).