

Globe trotting



With some planning, people with MS can travel anywhere in the world.

by Vicky Uhland

By any standard, Dave Bexfield's globe-trotting résumé is impressive. The 49-year-old Albuquerque, New Mexico-based founder of the nonprofit website ActiveMSers.org has traveled to more than 50 countries—30 of them since he was diagnosed with multiple sclerosis in 2006. In fact, in the seven years since his disease has progressed to the point where he regularly uses a wheelchair, Bexfield and his wife, Laura, have visited 17 countries, including places like Peru, Turkey and Russia that aren't known for their accessibility.



Dave Bexfield in Machu Picchu with his wife,

Laura. Photo courtesy of Dave Bexfield

Along with the usual travel woes like misplaced hotel reservations and flight cancellations, Bexfield has experienced an MS flare-up while on the road. In 2009, when he and Laura were in Venice, Italy, an exacerbation left Bexfield's legs so weak that he was unable to walk. He immediately called his neurologist and swapped his sightseeing plans for time spent relaxing in his hotel's garden, watching the gondolas go by. When Bexfield regained some mobility, his travel agent called the Italian MS Society, which arranged to lend him a wheelchair. With a few tweaks to their plans, Dave and Laura were able to continue—and enjoy—the rest of their three-week trip throughout Italy.

"I've learned that I can manage to go to any place on this planet—it just might take more planning and flexibility," Bexfield says.

But even an experienced traveler like Bexfield recognizes the potential perils of leaving home with MS—whether to a destination 10 or 10,000 miles away. "The night before I go on a trip, I'm always a ball of nerves, with all kinds of ideas about what can go wrong," he says. "But I've realized that not only can I travel with MS, there are even some advantages."

For instance, because he was using a wheelchair after his 2009 exacerbation in Italy, he and his wife were given free tickets to the Vatican—entry fees to tourist sites are often waived for people with disabilities—and whisked in through a VIP entrance. They arrived at the Sistine Chapel before it opened to the rest of the public, and viewed Michelangelo's masterpiece all by themselves.

Bexfield came up with his travel motto that day: *carpe diem*, or seize the day. Here's what he, other travelers living with MS, travel agents who specialize in trips for people with disabilities, and healthcare professionals advise that people with MS do to successfully seize their own travel moments.

Start small

Tarita Davenock, who was diagnosed with MS in 1995 and later founded Travel For All, an agency in British Columbia, Canada, specializing in accessible travel, says it's possible for people with MS to travel almost anywhere in the world.



Tarita Davenock owns a travel agency specializing in accessible travel. Photo by Riku Photo

"I've sent people who use a wheelchair to Nepal," she says. "I tell them don't let the fear of potentially having a new symptom or an exacerbation when you're away from home stop you from traveling."

That said, Davenock admits it's "still a little bit scary for me to travel," primarily because of mobility issues—she uses a wheelchair—and occasional brain fog.

But she believes one of the best ways to help reduce travel fears is to start small. While Machu Picchu or the Great Wall of China may be on your bucket list, you will feel more confident if you work your way up to challenging destinations.

"Try starting out with a weekend trip like a wine tour," Davenock says. "That gets you used to not sleeping in your own bed or having your home bathroom." Then consider a longer vacation in the U.S. or Canada, where the healthcare professionals speak your language and accessibility is less of an issue. In the U.S., the Americans with Disabilities Act guarantees equal access to transportation like Amtrak and public city buses, while the Air Carrier Access Act governs the rights of people with disabilities when it comes to air travel.

John Sage, who founded Houston-based Sage Traveling after he suffered a spinal cord injury in 2001 and began using a wheelchair, says when you're ready to go abroad, a Caribbean cruise can be a good first trip. The plane trip to your embarkation destination doesn't take long, cruise ships have accessible staterooms and elevators, they're relatively easy to navigate if you have cognitive or vision issues, there's a doctor on board, and if you're feeling fatigued, you can skip the shore excursions. A magnetic wristband or medication to prevent motion sickness can address minor vertigo.

If you prefer to be on land rather than the sea, Bexfield recommends taking one of your first

voyages to a city that has hosted the Paralympics. “Places like London, Barcelona, even Rio, are going to have a lot of accessibility features,” he says.

Bexfield tends to avoid group tours—even ones that specialize in disabilities—because of the unique nature of MS symptoms. “MS is such a funky disease. Some people do fantastic in the mornings but they crash in the afternoon, or vice versa,” he says. “A tour may not be set up to accommodate that.” One option is tours for seniors, which usually go at a slower pace. Sage and Davenock say they can also tailor tours to one’s specific MS symptoms.

Travel agents can be a good resource if something goes wrong. After Bexfield’s exacerbation in Italy, his travel agent called the hotel the Bexfields were planning to stay at in southern Tuscany, and the innkeeper went down to city hall to get a temporary handicapped parking pass so they could park virtually anywhere inside the walls of the hill town.

Travel agents can also advise you about the best trip cancellation or travel insurance should a medical issue keep you from going on your journey. They can help you find a healthcare professional at your destination or, worst-case scenario, get you airlifted home. If you don’t use a travel agent, find out before you leave home if the country you’re visiting has an MS organization that can provide assistance—most European and South American countries do. And if you’re in a real pinch, you can always contact the American consulate in any country.

While people with MS may have reservations about the demands of group tours, when you’re visiting a new city, Sage recommends booking a private guided tour the first day. Not only will you get an overview of the area, but you can also ask the guide questions about things like public restroom locations; accessibility of monuments, museums or restaurants; or even the best place to cool off on a hot day.

Healthcare on the go

When it comes to medical issues, a little preplanning can save a lot of potential hassle during your trip. Barbara Giesser, MD, medical director at UCLA’s Marilyn Hilton MS Achievement Center, says it’s best to inform your healthcare providers before you hit the road. If you’re traveling by plane, ask for a note from your doctor stating that you have MS and will have medication and injection supplies in your carry-on bag. It’s not a good idea to pack medications in bags you plan to check, in case your luggage is lost.

If you’re traveling to a region where you need a vaccination, it’s important to ask your doctor if your medications will interfere with the effectiveness of the vaccine. “In general, people with MS are advised to avoid live vaccines,” Dr. Giesser says. This may include vaccines for tuberculosis, measles or yellow fever.

Your doctor may give you a prescription for extra medication in case you lose some on the road or if your trip is extended. And Dr. Giesser says if you’ll be traveling in a remote region where healthcare isn’t readily accessible, some neurologists will give you a prescription for oral steroids in case you have an exacerbation.

You should also ask your doctor if any of your medications need to be refrigerated during your trip. Bexfield advises putting temperature-sensitive medications in a small soft-sided cooler that contains a gel ice pack. He recommends packing a few digital thermometers as well, to check the temperature in your hotel refrigerator or minibar so you don't inadvertently freeze your meds. Don't have a fridge? Bexfield says most hotels will deliver a portable one to your room if you ask.

If you have limited balance, strength or endurance, Amanda Rohrig, a physical therapist (PT) with Horizon Rehabilitation Centers in Omaha, Nebraska, recommends consulting with a PT prior to your trip. "A physical therapist who understands MS will help you to strategize—not dread—travel opportunities," she says.

And don't forget to make sure your health insurance has reciprocity in other states or countries, says Laura Kingston, an occupational therapist at Providence St. Vincent Medical Center in Portland, Oregon. If it doesn't, she recommends buying travel insurance from a reputable company like AAA. Bexfield is a fan of AIG Travel Guard. In fact, he had travel insurance during his exacerbation in Italy. "Calling my neurologist immediately after it happened turned out to be important to get reimbursed by my travel insurance," he says. "They needed confirmation that it was a medical emergency and not just a change of heart or oversleeping."

Travel hacks for specific symptoms

Because people with MS have varying symptoms, there are no one-size-fits-all travel recommendations. Instead, it's best to plan your trip to accommodate your main symptoms. Here's what experts suggest.

Fatigue or pain. When Pam Woods was diagnosed with MS in 2003 at age 38, she refused to let her disease interfere with her travel plans. "I truly believe wanderlust is part of my genetics," she says. So she and her husband, Darren, continued to travel around the U.S. and Europe despite weakness in her left leg, foot drop, fatigue and bladder issues. But in 2012, she had a big flare-up and went on disability. "I started thinking what happens if I'm in my 60s or 70s, and my MS gets worse and I can't travel?" she says. So she and Darren sold their house and traveled in Europe for a year.

Woods calls their journey, which was designed to accommodate her fatigue and mobility issues, "slow travel." She and Darren would pick a city they wanted to stay in and rent a place for a month through Airbnb or another vacation-home site. Then they would take day trips to nearby destinations. "By forcing me to slow down, MS allowed me to experience a place like a local," Woods says. She could also come home for naps and cook her own healthy meals.

Even when she's on a short vacation, Woods is still a fan of slow travel, although she admits it takes some mental adjustments. "I have to let go of my expectations that I need to see or do everything," she says. Instead, she will take a rest day while her husband goes

sightseeing. “It gives him a break from being a caregiver and lets him go at his own pace. While being left behind is hard, I enjoy hearing Darren’s stories of what he saw.”

Woods also uses her rest days to plan her sightseeing expeditions. For instance, she knows museums can be fatiguing, so she prioritizes what she wants to see. Many national and international museums have free wheelchairs for patrons, but Woods cautions that they’re usually first-come, first-served, so it’s best to arrive early.

Woods likes to build in rest days before and after long travel days. Kingston also advises setting aside a few hours each day to rest, particularly during hot afternoons. And if personal grooming or bathing is fatiguing, Kingston suggests showering at night. “This helps you conserve some energy in the morning for other activities,” she says. Or consider scheduling sightseeing trips only in the afternoon, to allow you to recuperate from morning ablutions.

If your destination requires a long plane, train or car trip, Davenock suggests breaking it up into less-tiring chunks when possible. Fly for a few hours, for instance, and then stay overnight in a hotel before continuing on.

Mobility issues. Sage, who has navigated hundreds of miles of European cobblestone streets in his wheelchair, says virtually anywhere can be accessible if you do your homework. “To help alleviate anxiety, plan a trip that meets your highest level of accessibility needs,” he says. That includes scouting out transportation, hotels, restaurants, museums and other sights before you leave home. But because people have different definitions of “accessible,” ask for photos or, ideally, a video of hotel rooms, bathrooms, elevators and building entrances. A travel agent or tour guide that specializes in disabilities can also provide this information.

And don’t forget to research whether a hotel is in an accessible, centrally located part of town. Sage suggests using Google Maps’ Street View to see whether a property is surrounded by hills, stairs or other accessibility nightmares. Also consider choosing a hotel with room service for times you’re too fatigued to go out to a restaurant.

Once you find an acceptable hotel, Sage recommends booking it as much as six months in advance, especially if your trip is during the high season. “A lot of hotels in Europe have only one or two accessible rooms, and they get reserved quickly,” he says.

Rohrig says even if you don’t use a cane or walker at home, consider taking them with you on your travels. “They may be helpful in unfamiliar circumstances, and they can improve your ease, safety and mobility so you can concentrate on enjoying your experience.”

Bexfield likes to bring multiple walking aids in case he loses one or finds that it doesn’t work well on certain terrain. He’s also a fan of foldable wheelchairs for their portability. And don’t forget a bungee cord to secure the chair on public transportation such as a bus or train. If you need to navigate rough surfaces throughout your trip, Bexfield suggests all-terrain

wheelchairs equipped with off-road tires and even shock absorbers. If you prefer a scooter, Sage says they're usually easy to rent in advance through [Special Needs Group](#), which delivers and picks them up at your destination in the U.S. or abroad.

Above all, Bexfield says, check your ego along with your luggage. "I've taken a cab ride for 100 meters because I was just too fatigued to walk," he says. "I've hired porters to carry me at Machu Picchu. Is someone staring? Who bloody cares!"

Bladder or bowel issues. Woods and Bexfield agree that wearing protective undergarments and carrying an extra change of lightweight clothing are key when you're on the road. Smartphone or tablet apps like Flushd, SitOrSquat and Airpnp will tell you where the nearest restroom is. Sage has also been known to make a quick detour into an American fast-food restaurant, which will usually have an accessible restroom no matter which country it's located in.

For future trips, Woods is considering an RV because she would always have a bathroom with her. But for now, when nature calls and there's no public restroom nearby, she depends on the kindness of strangers. "I've found that in almost any place, if you appear desperate, they'll rush you to the bathroom even if it's not public," she says.

Heat sensitivity. This is one of Bexfield's main symptoms, so he's done quite a bit of research on cooling vests that perform well on the road. His favorite travel vests are those that recharge in an ice-filled cooler ([Glacier Tek](#) or [ThermApparel](#)) or at room temperature ([First Line Technology](#)).

Bexfield also likes to travel during the fall or spring because temperatures are cooler. If he does travel in the summer, he packs a sun-safe travel umbrella to provide shade and relief from the heat. ([Gustbuster](#) umbrellas are his favorite.)

And, of course, always look for hotels with air conditioning or, at the least, windows that open.

Cognitive issues. Whether you're traveling with others or alone, Davenock recommends making a copy of your itinerary and contact information, and putting it in a secure pocket in your clothing in case you get lost or forget where you're going. Taking photos of your hotel address, room number, street signs or other landmarks can also be a good memory aid. And Sage recommends having a backup plan in case something goes wrong. Hotel construction, train strikes or inclement weather can mean your original plan needs quick modification.

While it's helpful to know the language of the country you're visiting, English is so universal that even in the hinterlands you'll likely find someone who can speak enough to help you. Another option is to use a translation app like Google Translate or iTranslate.

Museums and other tourist attractions can be loud and overwhelming to the senses. Bexfield recommends visiting early, when most tourists are sleeping in, and only staying for a couple

of hours. In fact, consider planning your trip during the offseason, when there will be fewer tourists overall.

And finally, think positively. “What I would have loved to have heard when I was first injured was about all of the places that are possible, rather than impossible, for people with disabilities,” Sage says. “There are tons of places that someone with MS can visit.”

Vicky Uhland is a freelance writer and editor in Lafayette, Colorado.

Visit nationalMSSociety.org/travel for more tips and information.