

Weathering the storm



When disaster strikes, people with MS face unique challenges. Here's how to find help.

by Vicky Uhland



Lisa Heitkemper, who uses a power wheelchair, took precautions and evacuated with her family as soon as they

learned that a fire was close to

home. Photo courtesy of Lisa Heitkemper

In the early morning of Oct. 8, 2017, Lisa Heitkemper's husband woke her up with a message anyone would dread: "Our hill is on fire!"

Although the fire was large and dramatic, it was still a couple of miles west of their house in Napa County. Normally, the Heitkempers would wait to see if the fire moved closer before leaving their home. But because Heitkemper, who was diagnosed with multiple sclerosis in 2012, uses a power wheelchair, they decided to evacuate immediately.

"Had I not had MS, if I had been able to run and jump in the car at a moment's notice, we probably would have stayed and watched the fire from home," she says.

Heitkemper only had enough time to wake her 20-year-old son and grab the family's 13-year-old labradoodle. "I didn't have my medication or our important papers," she says.

"I didn't even get a chance to get some clothes on. As I was slowly trying to get changed, my husband said, 'Are you kidding me? We need to go now!' So I just brought some clothes and shoes with me, and got in the car in my nightgown." She remembers looking at their wedding album up high on a shelf where she couldn't reach it and realized she had to let it go.

The Heitkempers drove to a vantage point where they could overlook the hills surrounding their house. "It was basically a fire horseshoe—we could see three different wildfires to the east, west and north," Heitkemper says. She didn't know it at the time, but they were in the midst of the 2017 Northern California firestorm—the most destructive wildfire in the history of the state.

After a couple of hours watching the fire and wind progress, the Heitkempers decided they would be safe if they returned home. Although they lost power and cellphone service for more than three days and at one point were under an evacuation advisory, they and their property made it through the wildfires unscathed.

But the fire taught Heitkemper a lesson. "You talk about what to do in an emergency, but once it's happening, you're like a deer in the headlights," she says. She realized that because she lives with MS and uses a wheelchair to get around, natural emergencies pose added challenges. Whether it's a fire, earthquake, tornado, flood, hurricane or blizzard, extreme weather events require extra preparedness for people with MS.

Here's what the Heitkempers and others with MS who lived through last summer's wildfires and hurricanes learned, along with tips from experts about how to deal with natural emergencies before, during and after they happen.

Be prepared

[Ready.gov](https://www.ready.gov) is a good resource for disaster preparedness plans. But if you have MS, you'll need to add other items to the emergency checklist this website recommends.

Experts recommend signing up for alerts from your local office of emergency management. Most counties have one—Google your county name and “emergency management,” or find a statewide organization at [fema.gov](https://www.fema.gov). They advise contacting your local police and fire departments and ambulance service and telling them ahead of time you have a disability. You may also want to inquire about a registry in your locality for people who may need extra help evacuating in an emergency. The registry will provide vital information for local emergency planners and responders about any special needs you may have.

“It gives you peace of mind,” Debbie Fagan says. “You can give them your phone number, address, contact information for relatives and where you would be in your home if they need to come in. All of that is added to the database that comes up if you call 911.”



The Fagans also recommend that you check with your local electricity provider to see if it maintains a registry of people with health conditions that require electricity-related aids like air conditioning or refrigeration for medications. People on this registry can get status updates and priority for power restoration during an emergency. Michael Fagan, who was diagnosed with MS in 1993 and uses a wheelchair, and his wife, Debbie, have weathered three major hurricanes since they moved to the Houston/Galveston, Texas, area—Rita, Ike and last summer’s Harvey. The Fagans invite guest speakers from emergency-management organizations to their area MS support group to provide programs on emergency and hurricane preparedness.

Inside your go-bag

- A medical alert tag or bracelet
- A list of all your prescription drugs, including the dosage, prescription number and pharmacy name, address and phone number
- First aid kit
- Flashlight
- Batteries
- Portable radio
- Important documents like birth and marriage certificates, insurance inventories, deeds, IDs, stocks and bonds, and bank information

Shelter. Since 2010, the Red Cross and Federal Emergency Management Agency (FEMA) have committed to providing general-population evacuation shelters that also have accommodations for people with disabilities. The reason, says Mary Casey-Lockyer, Red Cross senior associate for disaster health services, is to keep people with disabilities and their families or caregivers together. You can find the closest shelters at [DisasterAssistance.gov](https://www.fema.gov/disaster/assistance). You can also find a list of hotels that participate in FEMA's Transitional Sheltering Assistance program at [femaevachotels.com](https://www.fema.gov/hotels). FEMA may pick up the tab for your stay at these hotels, but availability is limited. Call in advance, especially if you need an accessible room, since hotels usually only have a few of these rooms.

But some states, including Florida, have statutes mandating that people who want to use special-needs shelters must register with their local facility first.

Susan Struder, who was diagnosed with MS in 1992 and uses a scooter, registered at her Hudson, Florida, shelter even though she didn't intend to evacuate her sturdy condo building when Hurricane Irma hit her hometown last September. But her friend, who also has MS and was alone during the storm, wanted company. The shelter, which was full at that point, directed Struder and her friend to a backup shelter at an elementary school, which was able to not only accommodate Struder's scooter, but also her friend's two cats. The lesson? Don't panic if you can't get into a shelter specifically geared toward people with disabilities.

Support system. The Red Cross suggests you identify a minimum of three people who can assist you during an emergency, or who can simply check to make sure you're OK. You should also include someone outside of your immediate area who you can stay with or who can relay information to your family and friends.

And don't forget your pets. The Fagans say many shelters during Hurricane Harvey were pet friendly. But it's wise to make a plan for your pets' care just in case. The [Humane Society of the United States](https://www.humanesociety.org/) and the [Centers for Disease Control and Prevention](https://www.cdc.gov/) offer tips for caring for animals during an emergency, along with a list of pet-friendly hotel websites.

If an emergency happens while you're at work, the bad news is that your employer is not required to have an evacuation plan. However, the Job Accommodation Network (JAN) notes that employers covered under the Americans with Disabilities Act that do have evacuation plans must include people with disabilities in those plans. If your employer hasn't established evacuation procedures, you can consult materials like [JAN's emergency evacuation checklist](#).

Documents. Any basic emergency preparedness plan calls for taking important documents like birth and marriage certificates, insurance inventories, deeds, IDs, stocks and bonds, and bank information with you.

It's also important to include your medical records, health insurance cards, contact information for your healthcare providers, names and model numbers of your medical devices, and a list of all your prescription drugs—including the dosage, prescription number and pharmacy name, address and phone number. Heitkemper recommends making an extra copy of this list and giving it to a member of your support network. And make sure to wear a medical alert tag or bracelet.

Equipment and medications. If you use a motorized wheelchair or scooter, consider having a lightweight foldable manual chair as backup. Ready.gov suggests having an extra battery for your wheelchair. You should also include a patch kit or a flat-tire sealant, along with an extra inner tube, in your emergency bag. And make sure to teach your support network how to operate your wheelchair or other equipment.

If you're in an area that's frequently in danger of power outages, consider buying a gas- or battery-powered generator. And it's a good idea to store a second set of mobility devices like canes or walkers at your workplace or a friend's house in case you need to evacuate without them.

Most experts also recommend packing at least a week's worth of medications in your bag.

Get out safely, and stay safe

Along with checking weather reports and information from local emergency preparedness offices, also keep the following in mind during an emergency.

Transportation. The Red Cross doesn't offer emergency transportation, but local law enforcement and emergency management services do. These services will usually transfer you to shelters or a hospital, if needed. If you want to go elsewhere, you'll need to make private transportation plans.

National MS Society resources

Visit [Emergencies & Disasters](#) for an extensive disaster preparedness plan and emergency resource list. Although the Society is not a crisis agency, MS Navigators are available before,

during and after emergencies to help you connect with disaster-related resources and services. Angela Taylor, one of the managers of the Society's MS Navigator Services Delivery, says MS Navigators can help you, your family or your caregivers find solutions for a wide variety of needs.

Call 1-800-344-4867 or visit [Ask an MS Navigator](#).

Basic needs. Casey-Lockyer says Red Cross and FEMA shelters provide food, toiletries and emergency needs like incontinence supplies. They also have medical equipment like wheelchairs, walkers and canes, and can work with pharmacies and public health facilities to replace medications you were unable to bring with you. "There could be a gap of two to three days, though, depending on the state of the infrastructure," Casey-Lockyer says. Some pharmaceutical companies will replace MS medications that have been lost or destroyed in a disaster.

There will usually be a power source for recharging a wheelchair battery, but "we can't guarantee air conditioning," Casey-Lockyer says. If heat is an issue, pack a cooling vest in your go-bag. Struder recommends bringing a pillow and inflatable air mattress, as you may be sleeping on the floor. Red Cross shelters also offer physical and mental health services, and can transport you to a hospital if you need advanced medical care.

After the disaster

Even if you aren't hurt or your home isn't damaged during a natural emergency, there can still be a psychological and financial toll. Fortunately, there are a variety of resources available at no charge.

General assistance. Dialing 211, or visiting 211search.org, connects you with your local United Way, churches and community organizations that offer financial assistance, counseling and other forms of help.

The Disaster Assistance Improvement Program (DAIP) is designed to make applying for federal funds easier. DAIP administers DisasterAssistance.gov, where you can find more than 70 forms of assistance from 17 federal agencies, including emergency housing and food.

The federal government's multilingual Disaster Distress Helpline provides counseling and emotional support 24 hours a day. Call 1-800-985-5990 or text TalkWithUs to 66746. Casey-Lockyer says the Salvation Army, Red Cross or other federal agencies and partners operate multiagency resource centers. "They're like a one-stop shop" for financial, medical and mental health assistance, she says. For instance, after hurricanes Harvey and Irma, Medicare and Medicaid waived the usual three- to five-year waiting period for people who needed new wheelchairs. You can find resource centers in your area at redcross.org.

Salvation Army Disaster Relief Services provides meals, hygiene kits, social services, and emotional and spiritual care to disaster survivors. Check disaster.salvationarmyusa.org to see

what's offered in your area.

There's no getting around the fact that natural emergencies are traumatic—especially if you have MS. But preplanning can help lessen the impact. “I have terrible spasticity, and the stress during last summer's fires caused my legs to go straight out and stiff as boards,” Heitkemper says. “But I learned that if you're organized, prepared and have an emergency plan, that really helps minimize the stress.”

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See more [resources for disaster preparedness and emergencies](#).