

Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical Devices

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This emergency power planning checklist is for people who use electricity and battery dependent assistive technology and medical devices. Electricity and battery-dependent devices include:

- breathing machines (respirators, ventilators),
- power wheelchairs and scooters, and
- oxygen, suction or home dialysis equipment.

Some of this equipment is essential to your level of independence while other equipment is vital to keeping you alive! Use the checklist below to make power-backup plans.

This document also contains:

- how to establish a support team,
- how to mastering the skill of giving quick information on how best to help you,
- advice from users, and
- sources for more information.

Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical Devices*			
Complete	Date	Does not Apply	Item
			Planning Basics
			Create a plan for alternative sources of power.
			Read equipment instructions and talk to equipment suppliers about your backup power options.
			Get advice from your power company regarding type of backup power you plan to use.
			Regularly check backup or alternative power equipment to ensure it will function during an emergency.
			Teach many people to use your backup systems and operate your equipment (see below <i>Establish a Support Team</i>).
			Keep a list of alternate power providers.
			<ul style="list-style-type: none"> Ask your nearby police and fire departments and hospital if you could use them as a backup for your equipment power if your backup systems fail.
			Label all equipment with your name, address, and phone number. Attach simple and clear instruction cards to equipment and laminate them for added strength.
			Keep copies of lists of serial and model numbers of devices, as well as important use instructions in a waterproof container in your emergency supply kits.
			Life-Support Device Users
			Contact your power and water companies about your needs for life-support devices (home dialysis, suction, breathing, machines, etc.) in advance of a disaster.
			<ul style="list-style-type: none"> Many utility companies keep an emergency list and map of the locations of power-dependent customers. They will put you on a “priority reconnection service” list. Contact the customer service department of your utility company (ies) to learn if this service is available.
			<ul style="list-style-type: none"> Even if you are on the “priority reconnection service,” list, your power could still be out for many days following a disaster. It is vital that you have power backup options for your equipment.
			Let your fire department know that you are dependent on life-support devices.
			All ventilator users should keep a resuscitation bag handy. The bag

		delivers air through a mask when squeezed.
		If you receive dialysis or other medical treatments, ask for your provider what the plans are in an emergency and where you should go for treatment if your site is not available after an emergency.
		Oxygen Users
		Check with your provider to determine if you can use a reduced flow rate in an emergency to extend the life of the system. Record on your equipment the reduced flow numbers so that you can easily refer to them.
		Be aware of oxygen safety practices:
		<ul style="list-style-type: none"> • Avoid areas where gas leaks or open flames may be present.
		<ul style="list-style-type: none"> • Post "Oxygen in Use" signs.
		<ul style="list-style-type: none"> • Always use battery powered flashlights or lanterns rather than gas lights or candles when oxygen is in use (to reduce fire risk).
		<ul style="list-style-type: none"> • Keep the shut-off switch for oxygen equipment near you so you can get to it quickly in case of emergency.
		Generator Users
		Make sure use of a generator is appropriate and realistic.
		Operate them in open areas to ensure good airing.
		Safely store fuel.
		<ul style="list-style-type: none"> • The challenge when you live in an apartment is knowing how safely to safely store enough gasoline.
		<ul style="list-style-type: none"> • Store a siphon kit.
		Test it from time to time to make sure it will be work when needed.
		<ul style="list-style-type: none"> • Some generators can connect to the existing home wiring systems; always contact your utility company regarding critical restrictions and safety issues.
		A 2,000 to 2,500-watt gas-powered portable generator can power a refrigerator and several lamps. (A refrigerator needs to run only 15 minutes an hour to stay cool if you keep the door closed. So, you could unplug it to operate other devices.)
		Rechargeable Batteries
		Create a plan for how to recharge batteries when the electricity is out.
		Check with your vendor/supplier to find alternative ways to charge batteries. Examples include:
		<ul style="list-style-type: none"> • Connecting jumper cables to a vehicle battery.
		<ul style="list-style-type: none"> • Using a converter that plugs into a vehicle's cigarette lighter).
		<ul style="list-style-type: none"> • Substituting a vehicle battery for a wheelchair battery but it the charge will not last as a charge for a wheelchair's deep-cycle battery
		If you use a motorized wheelchair or scooter, if possible store a lightweight manual wheelchair for emergency use.

		<ul style="list-style-type: none"> • Stored extra batteries require periodic charging even when they are unused. If your survival strategy depends on storing batteries, closely follow a recharging schedule.
		Know the working time of any batteries that support your systems.
		When you have a choice, choose equipment that uses batteries that are easily bought from nearby stores.
		Other Backup Plans
		When Power is Restored
		Check to make sure the settings on your medical device have not changed (medical devices often reset to a default mode when power goes out).
* Review and update this checklist every six months (one way to remember to do this is when you set your clocks forward in the spring and back in the fall).		

Establish a Support Team

Build a support team of people who will help you in an emergency if necessary. They should be people who are regularly in the same area as you. The real first responders in an emergency are often your neighbors, friends and co-workers. These people, not professional first responders, make 70% of rescues in major disasters.

When you train many people, you create a universal team. When everyone knows what to do, everyone can help!

Build support teams with many people at every place where you spend a large part of your day: at work, home, school, or volunteer site. This is especially important when it is hard to predict who will be where you are at any given time.

Practice with different people to figure out who will best be able to help you. Traits to look for may include people who are:

- Strong,
- Calm,
- Listen well,
- Communicate clearly,
- Can guide you safely, and
- Attend to important details.

Work with people who are dependable and have the physical and emotional ability to assist you reliably.

Buddy Systems and Attendants: Do Not Rely on One Person

Do not depend on any one person. Buddy systems (choosing and training one person to assist you in an emergency) have weaknesses. You and your buddy may not be able to contact each other quickly in an emergency.

If you rely on personal assistance services (attendants), they may also not be available when you need them. Therefore, it is important that your support team include other people.

Plan Multiple Ways to Give and Get Information

Different communication systems work differently. In an emergency, some may work when others fail. The more systems you have available to you, the more likely it is that you will be able to contact other people. How many of these systems do you have?

- E-mail
- Internet
- Pagers
- Text messaging
- A standard phone that does not need electricity (most new phones, including cordless ones, need to be plugged into an electrical outlet)
- Cell phone
- Low cost two -way radios
- Ham radio

Master the Skill of Giving Quick Information on How Best to Help You

In spite of your best planning, sometimes you have to build a support team on the spot. Think about what you will need, how you want it done and what kind of people you want to work with if you have a choice.

Be ready to give people who may not know you all the information they need to be able to help you without causing injury. Be clear, specific, and concise with your directions. Think about how much detail is necessary. Be ready with additional instructions if necessary. Practice giving these instructions using as few words as possible. For example:

- “Connect the battery by the window to my vent by following the instructions attached to the battery.”
- “Take my oxygen tank; right side of green bookcase. I can breathe without it for 15 minutes.”
- ”Take my communication device from the table by the wall.“
- “Take my manual wheelchair.”

- “The traditional "fire fighter's carry" is hazardous for me because of my respiratory condition. Carry me by “
- “You have to carry me out. Get an evacuation chair hanging at the top of ‘stairway two’ and I will tell you what to do next.”

If communicating may be a problem, consider carrying preprinted messages with you, for example:

I cannot speak, but I do hear and understand. I use a communication device. I can point to simple pictures or key words. You will find a communication sheet in my wallet.

Advice from Users

- **Bob Mauro, WEBSITE: <http://www.geocities.com/ram9872002>
Author of *SUCKING AIR, DOING WHEELIES* available on amazon.com**

I have my resuscitator bag with me at ALL TIMES, in case my vent fails. I have drills to see how long it takes to deploy it and use it. I can pump it myself for at least 15 minutes with my foot. I have a long hose on it that gives me time to call 911 if I am out. I do drive and use paratransit. I also save my old wheelchair batteries because even though they no longer work for my wheelchair. They will run my plv-100 vent for about ten hours each. I have 4 batteries I keep on trickle charge (trickle charger is a small charger you can get from the vent company or most electronic stores, like radio shack. It charges the battery at a slow rate so you can leave it connected to the battery for long periods, unlike a normal car battery charger). I also have one on my wheelchair and one on my bed vent. All 6 batteries are on charge at least daily. During the big northeast blackout, I was without power for 22 hours. I went thru one battery and was on the second battery when power came back on. I have the batteries on a cart I can easily drag anywhere in the house.



On Support Teams:

My mom and dad used to help me, but now they have mild Alzheimer's and I help them. I do have a personal assistant /attendant 5 days a week 4 hours a day. I depend on 911 in big emergencies, but in 33 years living here, I have not had to use them more than once.

I joined the Automobile Association of America so I can get help in my van if I get a flat tire, etc. They helped me get going again several times. They are great.

Here's the story on using 911. The day after this Christmas, I had a bad cough from bronchitis. It scared me. Mom and dad can't drive and my brother was nowhere to be found when I called his home. So I called 911.

They were here in 4 minutes, 2 cars and an ambulance. I did not want to leave without my wheelchair. They could not, and would not get it in the ambulance. Those ambulances should be wheelchair accessible! The paramedics offered to put me on a stretcher and use a resuscitation bag to breathe for me. I said no. Then they offered to drive my van with me in it to hospital. Their bosses said no.

So I drove to ER with a police escort and the paramedics following in the parade. We drove with sirens and lights flashing. We drove thru red lights. It was fun and funny! When I got to the hospital, the cops said I drive great. I asked if they were going to give me a ticket for going thru all the red lights. They laughed.

It turned out I was fine. No pneumonia or temperature. But I did spend 6 hours in ER and then drove home. It was an experience. The next day, I timed how long the internal battery in my vent would last disconnected from my big vent battery on my wheelchair. The vent's internal battery lasted 90 minutes before the vent died. So if I need to go to ER in ambulance, they can just take my vent and leave my wheelchair home, since the vent's internal battery will run my vent for 90 minutes.

Riding Out Ike on a Vent **by Margaret A. Nosek, Ph.D.**

Margaret A. Nosek, PhD, is Executive Director of the Center for Research on Women with Disabilities and Professor in the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine. She can be reached at mnosek@bcm.edu or www.bcm.edu/crowd

What on earth was I thinking?! Throwing caution to the wind (sorry), I made the decision that my family, my helpers, and I, my power wheelchair, and my ventilator could withstand a direct hit by a category two hurricane with a gasoline powered generator, plenty of canned food, water, and batteries, and a good supply of chocolate. We rode out the storm here, completely prepared and dutifully following instructions to shelter in place. It was mighty terrifying but luckily we had no damage to the house, only lots of fallen limbs. Here are some of the lessons I learned:

1. **The decision about whether or not to evacuate should be made out of consideration for those people who are my life support, not just me.** I was completely confident we would be all right and my house would hold up. My attendants, Perla and Amalia, however, were terrified. The wind started getting very bad at around seven o'clock in the evening and the electricity went out around 10:30. I finally went to bed at two o'clock in the morning; I was tired but not afraid. My two friends didn't sleep the whole night; they just huddled in the next bedroom with Perla's three kids. They even came to my bedroom around four o'clock to move my bed away from the window. The wind was howling and there was a constant rumble like a freight train, with trees swirling as if they were lassos and limbs snapping all over. By the morning we all agreed -- never again!
2. **Generators smell really bad!** And may affect your breathing, especially if you have a breathing problems. Fumes may surround the house depending on weather conditions. As soon as we got up, four of our neighbors came over to check on me and help set up the generator. Everything worked okay and we plugged in the refrigerator and battery chargers for my ventilator and wheelchair. It was still raining and the wind was still blowing pretty hard, making all the fumes from the generator surround the whole house. The combination of fumes, heat, and humidity really started getting to me by the afternoon and I was having a lot of trouble breathing. This was the main reason, that I made the quick decision that we had to leave.
3. **Sprint cell phones don't work in a crisis.** Apparently they don't build their towers as robust as Verizon. Thanks to Amalia's Verizon cell phone I was able to connect with my nephew in Atlanta. He searched the net and found me what was probably the last available hotel room in Austin.

4. **When electricity goes out you don't just lose your lights.** In my naïveté about how the world works, I never realized that without electricity gasoline pumps won't work, air pumps won't work, and water purification plants shut down. Generators only run about 10 hours before you have to put in more gas. No gasoline stations were open or functioning. The fact that our water was contaminated was the final straw, propelling us down the road to Austin. After visiting two abandoned gasoline stations we finally figured out why the air pumps weren't working so we fill up our tires using an old-fashioned hand pump my neighbor had in her garage. We finally got to the hotel in Austin by midnight. It was really eerie driving the first hour through a totally dark city. Only the car dealerships were lit up.

5. **Neighbors and family really are lifelines.** Once I was able to get a cell phone signal I kept in constant touch with my nephew and my neighbors. We had a sinfully wonderful time in Austin. We took in some sights and caught up with lots of old friends. I even got to teach two classes at the University of Texas, one in rehabilitation counseling and one in nursing, when some faculty friends found out I was available and not particularly busy. It was glorious fun! Man, I love that city. My neighbors called me late Wednesday evening to say that electricity was back on my side of the street. Thus ended our unexpected adventure. After lunch at Threadgill's and a little more playing around, we came home Thursday evening.

6. **The aftermath is so much worse for low income areas.** Driving around town over the past week has deeply saddened me, not just for all the lost trees and damaged houses or the utter devastation in Galveston and Bolívar Peninsula. It's the disproportionate effect of the event on people who lack the resources to bounce back. FEMA, some churches, and others are helping get some folks through the crisis, but I'm really concerned about those who won't have the resources to repair or rebuild. The effect on them is so much worse than for those of us who could escape and regroup.

7. **Regulations are good.** Whatever happened to the rule that says utility companies have to trim trees around power lines? I think deregulated public service industries have failed us miserably. Maybe enough middle- and upper-class people have been severely inconvenienced by this event that they will vote Democrat in November and get us back to a society that protects its people.

Now that I have survived, it's time to rekindle the fire in my belly and get back to work!

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International Ventilator Users Network - Ventilator Backup: Are You Prepared? Advice From Users: http://www.post-polio.org/whatwks_b.html#vent

- **PAUL KAHN** (cairokahn@aol.com) is editor of *Disability Issues*, a quarterly publication of the Community Information Network for Individuals with Disabilities, Boston, Massachusetts. Paul is a ventilator user due to centronuclear myopathy.

"I have two PLV-100 ventilators that my home care company provides. I keep one by my bed. It is plugged into the house current. The other sits on a tray on the back of my wheelchair. It is powered by an external battery underneath the chair. My apartment building has an emergency generator that kicks in when the electricity goes out. It supplies current to certain public areas of the building. There is an outlet for the generator down the hall from my apartment. When the electricity goes out, I plug a long extension cord into that outlet and connect it to a power strip. Then I plug my bedside ventilator into the power strip.

"For my wheelchair ventilator, I rely on its internal battery to take over if the external battery fails. The internal battery will power the ventilator for close to two hours. I also have an Ambu[®] bag that I take with me whenever I'm away from home. I also have two suction machines. One is stationary and like my bedside ventilator, can be connected to the house current or the emergency generator. The other is portable and has a battery that I recharge regularly."

- **MARGARET E. DAVIS** (med43@earthlink.net) is a respiratory polio survivor who uses noninvasive nasal ventilation at night and mouth intermittent positive pressure ventilation during the day.

"We live in central Arkansas where tornadoes are common; being without power is a given. We have a large gasoline generator at home. It will power my ventilator and my husband's bilevel unit and a few other appliances for eight hours before we need to refill it. I can easily start it myself by turning a key. Our van has an inverter hardwired to an auxiliary battery with two outlets. I can charge my wheelchair battery and my HT50[®] (Newport Medical Instruments, www.newportnmi.com) at the same time without any problems.

- **BILL MILLER, (MaxNWM@aol.com)
C1/C2 quad, uses tracheostomy positive pressure ventilation and lives in Florida.**



The emergency management services (911 people) know I'm a priority for power. If the power goes out for an extended period, I'm among the first to have it restored. My primary backup is my van which has a converter that runs off the van's battery to produce AC. If the van is running, the alternator keeps the battery strong (just like in regular vehicles) and I can have electricity as long as I have gasoline in the tank. I try to always leave it full or at least above half of a tank. My van would also allow me to drive to another location that had electricity, if there was no power for several days.

I also keep a very long, heavy-duty extension cord with a 3-outlet expander in the back of my van. If I'm out in the van and need electricity, I can use an outlet at a store or restaurant. If I'm at home, I can run the extension cord all the way from the van to my bedroom.

For the van, I purchased a generator that can do two crucial things: it can start a dead vehicle battery with a jumper cable attachment, and it provides plugs for electricity. But it is gas-powered (loud, gives off fumes and needs to be used about once a month to keep it running well) and small, so it's only good in short-term scenarios but ideal for a dead van battery. These generators can be purchased at Home Depot, Lowe's, Sears, etc. for about \$300-500.

For ventilator backup, I have two LP10s ([Puritan Bennett - http://www.puritanbennett.com/](http://www.puritanbennett.com/)) and each has its own internal and external battery. The internal battery lasts about 45 minutes. The external battery lasts 8-10 hours (manufacturer's claim) but on a full charge, I can get about 15 hours. To recharge it, I simply plug it in. For an emergency, it's wise to be plugged in to keep that external battery as full as possible. You never know when you'll need it.

I keep an Ambu[®] bag on my chair at all times, just in case. These resuscitators can be found online at less cost, about \$20, no prescription required (www.buyeremp.com/dept.asp?dept%5Fid=10213). Technically they are disposable, but mine have lasted years by adding a bacteria filter and changing it periodically.

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Spring 2004, Vol. 18, No. 1, http://www.post-polio.org/ivun/val_18-1.html#con Accessed 10.24.09

[Consumer Reports](#) (November 2003) contained an excellent review
“Generators: power in a pinch.”

Sources for More Information

Disaster Resources for People with Disabilities and Emergency Managers
<http://www.jik.com/disaster.html>

EMERGENCY PREPAREDNESS: TAKING RESPONSIBILITY FOR YOUR SAFETY - Tips for People with Activity Limitations and Disabilities
www.espfocus.org

Power-Dependent Equipment
www.redcross.org/services/disaster/beprepared/dissup.html

FDA Offers Tips about Medical Devices
www.fda.gov/cdrh/emergency/hurricane.html#outage

Videos regarding generators:

- Generator Buying Advice - Consumer Reports' tests reveal the pros and cons of portable generators and the advantages of more expensive alternatives. <http://www.consumerreports.org/cro/video-hub/home--garden/tools--power-equipment/generator-buying-advice/17037617001/5030179001/> Accessed 10.24.09
 - Portable Generators - When your power goes out, a portable generator can be a big help. But these generators can also pose hazards. <http://www.consumerreports.org/cro/search.htm?query=generators&isTypeAhead=false> Accessed 10.24.09
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