

Division of Specialized Care for Children



Emergency Preparedness

Emergencies like power outages and weather events affect everyone. They can be especially dangerous for individuals with underlying medical conditions. Emergency knowledge and disaster planning can make all the difference.

Type of Disaster to Prepare For:

- Power outage
- Weather event (flooding, blizzard, extreme cold/heat)
- Natural disasters (blizzard, tornado, earthquake)
- Fires
- Hazardous material spills

Considerations:

If...	Then...
Battery backups run out	Unable to operate powered devices for transport
Power outage	Unable to run medical equipment (ventilator/continuous positive airway pressure (CPAP), nebulizers, chest physiotherapy (CPT) vests, oxygen, suctioning, feeding pumps)
Lack of water/refrigeration	Food/medicine safety issues
Loss of air conditioning or heat	Hypothermia, heat stroke, seizure risk
Unable to travel/slowed deliveries	Supply/medication shortages

Shelter in Place

Travel conditions, blocked roads or structural damage may force you to stay in your home or a certain area of your home.

- Prioritize medical technology needs. For example, ventilators and oxygen are crucial to survival, but you can give tube feedings slowly as boluses to conserve power.
- Keep specialized supplies and equipment stocked, especially when severe weather is in the forecast.
- Keep survival essentials (water, nonperishable food, batteries, flashlights, blankets/clothing to layer) on hand. Prepare for four to five days without power and/or water.
- Consider other ways to transfer/transport your participant without power equipment.

- Consider getting a backup generator, particularly if you live in a rural area.
- Think of nearby friends, family and neighbors who may be able to help you.
- Backup batteries are critical.
 - Keep them on hand and charged.
 - Know how long they should last.
 - Test them regularly to make sure they hold a charge.
 - Check with your equipment provider for backup charge options (converter outlet that plugs into your vehicle lighter/accessory outlet or jumper cables to pull power from a car's battery).
 - Allow yourself time to evacuate. Leave before your battery is almost out.

Planning for Evacuation

- Do not wait until the last minute to seek help. Downed trees and power lines or unsafe travel conditions may delay you.
- If you cannot make it to a relative/friend's house, connect with first responders through 911 or the American Red Cross.
- In large-scale events, 911/emergency responder phone lines might be down or overwhelmed. Have a backup plan to get to your local shelter or fire station.
- If using a powered mobility device/wheelchair, ensure that a manual chair is available for back up.
- Keep a list (both a physical and digital copy) of special health considerations. This list should include medications/dosages, providers with contact information, equipment directions/durable medical equipment (DME), location of backup batteries, communication and behavioral needs, mobility needs and so on.)

Who to Contact for Help

- 911/police department
- Your Division of Specialized Care for Children (DSCC) care coordination team
- Primary/managing physician
- Nursing agency
- Equipment company (can help you troubleshoot issues that come up)

Your DSCC Care Coordinator can help you contact other members of the team as well as your utility providers. ***If you cannot reach your Care Coordinator, ask to speak to their manager. Our staff will return after-hours messages as soon as possible.***

Available Benefits

The Home and Community-Based Services Waiver for the Medically Fragile Technology Dependent (MFTD waiver) may be able to pay for power generators for Home Care participants who are eligible for waiver services.

More information is available in our [*Home Generator Information for Families tip sheet*](#). (The tip sheet is also ***available in Spanish.***)

Resource Toolbox

DSCC's mission includes connecting families with resources. Below is a list of resources with expert advice on emergency and disaster planning. This list includes specific resources for pediatric, disability and/or advanced healthcare needs.

Resources	Where to Find
CDC: Children and Youth with Special Healthcare Needs in Emergencies	https://www.cdc.gov/children-and-school-preparedness/special-healthcare-needs/index.html
American Red Cross: Disaster Relief and Emergency Planning Information for People with Disabilities	www.redcross.org/get-help/how-to-prepare-for-emergencies/inclusive-preparedness-resources.html
CDC: Severe Weather Recommendations	https://www.cdc.gov/natural-disasters/?CDC_AAref_Val
CDC: Emergency Preparedness for People with Disabilities	https://www.cdc.gov/disability-emergency-preparedness/people-with-disabilities/index.html
Ready.gov: Diverse information on Emergency and Disaster Preparedness	www.ready.gov/ www.ready.gov/disability
Complex Child.org: Emergency Preparedness Information for Children with Medical Complexity from Families	https://complexchild.org/articles/2017-articles/november/emergency-one-page/
The September 26th Project: Annual Emergency Preparedness Checkup for Autism and Special Needs Families	www.september26.org/
Family Voices: Emergency Preparation Tips for Families	https://familyvoices.org/wp-content/uploads/2018/06/EmergencyDisasterPlanning_FamilyHandout.pdf
DSCC Carbon Monoxide and Fire Safety Handout	https://dsc.uic.edu/dsc_resource/carbon-monoxide-and-fire-safety-handout/

Creating Your Emergency Plan

We recognize that you as the family/participant are the expert on your specific needs. This knowledge is the best resource for creating an emergency plan to keep you and your family safe and prepared. You can create your own plan, use the [DSCC Emergency Plan Template](#) or find another template online.

Putting Your Plan in Place

- Once you develop a plan, keep a printed and digital copy. Have the plan readily available, such as posted on your refrigerator.
- Share your plan with three to five emergency contacts who can serve as allies during an event. Include specifics about your participant's treatments, health needs, behavioral considerations, medications, supplies and equipment.
- Have more than one way to access your emergency contacts and plan. (For example, technology may not be available or printed copies may not be accessible.) Keep emergency contact information with you, such as in your wallet.
- Set a reminder to review your plan regularly (at least annually). Verify that all information, especially emergency contacts, is accurate.

Home Care Program

Since Home Care participants depend on technology, our DSCC team takes extra steps to help you plan for emergencies. Your nursing agency also must partner with you to develop an emergency plan (a template is provided but optional).

Our team sends priority notification letters to Home Care participants' utility and local emergency service providers. These letters:

- Notify utility companies and first responders a medically fragile individual lives at your address. The letter asks them to prioritize your home in the event of a power outage, weather event or other type of emergency.
- Should place the participant on the existing "priority reconnection service list" if the needs are for life-support devices (ventilators, dialysis, etc.).

Letter limitations

- Updated letters are only sent if you update DSCC when you change addresses. We can only send letters with a signed authorization to the providers.
- Utility providers vary throughout the state in their response. They are not obligated to prioritize DSCC participants.
- Large-scale or long-term outages may affect families for several days despite efforts to prioritize.

Please note that some counties require notice about a medically fragile individual through the Smart911 Portal rather than printed priority notification letters.

Your DSCC Care Coordinator can help you set up a Smart911 account if you need help.

Contact us at **(800) 322-3722** for questions or
or more information!

Visit our website at **dsc.uic.edu**.

