

Geisinger

A Guide for Families of Children with Special Needs

Introduction

While we can't foresee or predict all emergencies, you can take steps to help your child with special needs be as prepared as possible if an emergency occurs. This toolkit is intended to guide you through important considerations when preparing for unexpected events.

Making the plan

In your folder, you'll find a sample information sheet as well as a blank information sheet for you to complete. Some of the information you'll fill out could be used for more than just an emergency plan. For example, sharing this document may provide helpful information for other caregivers such as babysitters or new teachers.

Your child

Each child's information sheet should be tailored to fit their unique needs. When filling out the information sheet, try to think about how you would describe your child to a new teacher or caregiver. For example, it will be very important to let others know how your child prefers to communicate. Also consider your child's receptive language skills. Will they respond to their name or obey a simple command, such as "stop"?



Types of emergencies

Fire: According to the U.S. Fire Administration, most residential house fires are caused by cooking. Never place anything flammable near the stove, even when it's off.

Weather: Pennsylvania is impacted by a variety of natural disasters, including severe winter weather, severe thunderstorms, flooding and tornados. There are multiple scenarios to be prepared for when weather hits, including loss of power, need to shelter in place and need to evacuate.

- Loss of Power: Power loss can occur sporadically, even outside of a major weather incident. Alert your local power company if your child uses medical equipment that requires electricity.
- Shelter in Place: Some weather emergencies, such as snowstorms, may require you to stay in your home for extended periods of time. Consider making it part of your normal routine to get medications refilled as soon as allowable.
- Evacuation: Keep an evacuation bag in your house that includes a first aid kit, a few changes of clothes, medications, toys, spare batteries/chargers and other important items. It may be helpful to practice an evacuation scenario so it's more familiar to your child. Designating a family meeting place is important in case the family loses track of each other and cell phones are not in service. Take attendance at the family meeting place.

Medical Trauma/Accident: An emergency kit should be kept in all cars that your child may ride in. This would include vehicles used by all primary caregivers including parents, care-taking relatives, siblings who drive and babysitters. The kit could include your information sheet, flashlight, basic first aid supplies, car reflectors, blankets and bottled water.

Sharing the plan

Once you have a formal plan, it's time to share it with those who work with your son or daughter. Even though family members or caregivers may know many things about your child, it's helpful to have this sheet readily available. Not all emergencies are serious medical crises. Other unexpected situations may require a less-familiar caregiver to step in and assist. Keep the sheet somewhere readily accessible and let all caregivers know where to find it.

If your child attends school, share the information sheet with the lead teacher/case worker and ask that it be distributed to all members of the school team. School staff should also keep one copy at a central location and identify someone who will be responsible for implementing the plan at appropriate times. If your child attends before or after school childcare at a different setting, provide them with a copy, too.

Take the time to identify local police, fire companies and urgent care centers. Call and ask them if you could bring

your child and introduce them. Letting your child meet emergency responders in a nonthreatening situation can help them in the future. You can also offer to share the plan with them. Some police departments have a procedure for registering your child. If the staff is agreeable, ask to take some pictures of the facility with your child. These photos could be used in many ways, such as a photo book or in a story about emergencies. See your folder for an example.

Teaching children about emergencies and the emergency plan

When an emergency strikes, we often realize that we could've done more to be more prepared. This applies to family members, pets, property and possessions. Having the information sheet prepared and readily available will be of great value if an emergency occurs. Be sure to review and update the information sheet annually.

Most children learn safety rules such as "don't touch the hot stove" or "don't talk to strangers" at an early age. These rules are difficult to teach children with special needs, who may have limited understanding and do not learn simply by being told what to do. People with a range of special needs may require more intensive instruction or support to respond appropriately in emergencies. Many resources that are typically prepared for children with autism spectrum disorder (ASD) are appropriate for children with other special needs.

Some evidence-based tools that have been successfully used in educational and therapeutic settings include:

- Visual supports
- Role play
- Rehearsal
- Video modeling
- Written social stories

These strategies are easily tailored to the child's level of understanding and allow for various manners of presentation. And since they're proactive tools, they often reduce anxiety related to uncertainty and unfamiliarity.

Many children and adults with special needs are familiar with medical staff, such as doctors and nurses at their pediatrician's office. You may already have developed successful strategies around routine medical visits that are familiar and predictable.

You may want to plan a non-emergency visit to your local urgent care center or hospital emergency room. At that time, you could take pictures of the entrance area, waiting room, building and an ambulance if one is in the parking lot. Consider including your child in the photographs. If your local hospital has Child Life Specialist team, they may be able to help arrange a non-emergency meeting.

National Fire Prevention Week is celebrated in early October. Some schools host visits from local firefighters or field trips to a local fire station. This may be a good time to get photos of your child with a firefighter and the fire engine and equipment.

Role play and rehearsal can be used with favorite stuffed animals, toy kits, etc. Siblings or classmates can make this more fun. Be prepared to guide the language and the activities. If you record or photograph the activities, they can be used as a fun refresher in the future.

You can also create simple photo books that describe common emergencies and periodically review them. If you live in an area that frequently floods or loses power in storms, you could create a photo book about what happens and how to respond. If there was a prior instance when you had to evacuate or you lost power, this book should contain photos of you and your family being safe and having fun at an evacuation location (e.g., a relative's house). While the topic of emergencies is serious, try to focus more on proactive safety strategies rather than the emergencies themselves. The goal is to help your child understand and be less fearful.

During the emergency

During an emergency, use your information sheet to help your child successfully weather the situation.

Stick to the plan: You've used this guide to prepare an information sheet and emergency bag. Use these resources and the strategies that typically work best for your child. If your child understands best using visuals, don't forget about low-tech strategies that may be just as effective as visuals on an iPad (line drawings, bulleted lists).

Be consistent: When things are unknown, your child may ask questions that you don't know the answer to, such as, "When can I go back to school?" Give your child a consistent answer that provides as much information as you have at their developmental level. Be on the same page with other caregivers to provide consistent feedback.

Make a routine: Try to resume your normal routine as soon as possible. Some children may notice if their caregiver's routine changes, even if theirs does not. And some emergencies may prevent you from being able to return to normal. For example, you may not be able to return home after a house fire. If a normal routine can't be resumed, try to institute a new routine for the family to follow, or create a new routine daily that's reviewed with the child each morning. Even a small amount of structure can provide comfort during unpredictable times. Visual schedules are a powerful tool to provide structure and make days more predictable.

Keep It fresh: You may need more powerful reinforcers to help a child during an emergency. Have the most motivating toys and activities available if you didn't include them in your emergency bag.

Add structure: If you're unable to leave your house due to an emergency, designate areas of the house for different activities to help clarify expectations. For example, one area of your home can have a table and chairs set up for school activities while another area may be more play-focused. Try to include a variety of activities in your child's day, including physical activities.

Focus on life skills: If your child has to miss school due to an emergency, use this time to focus on daily living activities such as laundry, meal preparation and hygiene. Look at your child's Individualized Education Plan (IEP) for ideas on goals to target. Think about new ways to target challenging skills, such as using siblings as peer models.

Ask for support: Caregiver health and well-being is critical to supporting a child with special needs. Think about who else may be able to help you and your child during this difficult time. This can include family, neighbors and the medical community. Try not to neglect your own needs. If others are also assisting with caregiving responsibilities, be there for each other. Just like we schedule breaks for our kids throughout the day, schedule breaks for yourself. If one of the caregivers needs a break, communicate to the child at their level who is available for their help or questions.

After the emergency

While the best way to handle emergencies is preparedness, caregivers should also provide appropriate support to children after the event. All children, including those with developmental disabilities, may experience long-term impact from witnessing or experiencing an emergency. There is no "typical" response, and it may be difficult to predict how a child will react. Some common responses include physical complaints (stomach aches, headaches), irritability, increased anxiety or depression and changes in sleep or appetite. You know your child best. Focus on changes in your child's typical behavior to recognize when you need to act.

Debrief: Review your emergency plan to identify additional steps that could've been taken to be more prepared in the future. Consider including the current emergency as an example in your photo book.

Talk: Allow your child to talk to you about their thoughts and feelings about the emergency. Caregivers should let children know that how they are feeling is normal and that they are there for support.

Seek help: Ask professionals for help if you feel your child's reaction is extreme or beyond what you would expect. A mental health professional such as a psychologist, counselor or social worker may be able to help. And if you're also experiencing unmanaged emotions related to the emergency, seek treatment for yourself. It's difficult to support others when your own needs aren't being met.

Additional resources

FEMA emergency preparedness: fema.gov/disaster/4339/emergency-preparedness

Ready Kids: ready.gov/kids

Sesame Street: sesamestreet.org/toolkits/ready

FEMA: fema.gov/media-library/assets/documents/34411

Ready Wrigley- CDC: cdc.gov/cpr/readywrigley/

Health and Human Services: acf.hhs.gov/ohsepr/children-and-families

CDC overview: cdc.gov/cpr/whatwedo/children.htm

CDC site for children with autism: blogs.cdc.gov/publichealthmatters/2017/05/autism-and-preparedness/

First responder toolkit: nationalautismassociation.org/store/#!/NAAs-Be-REDy-Booklet-for-First-

Responders/p/57932218/category=2416355

Big Red Safety Toolkit: nationalautismassociation.org/docs/BigRedSafetyToolkit.pdf

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