

Planning for Health Emergencies

a toolkit for families of children with special health needs

August 2019

Any trip to the emergency room is stressful. For parents whose children have special health needs, it can be especially complicated. The right information needs to get to the right people, and quickly. Planning ahead for emergencies can help everyone involved, and give you peace of mind.

This toolkit was developed by parents of children with special health needs in collaboration with emergency medical professionals. The tools will help you be ready if your child has to go to the emergency room.



Questions? Contact us.
We're here to help.
1-855-323-6744
www.oregonfamilytofamily.org



OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs



Family's Emergency Support Team

Someone who will be responsible for keeping my family and friends up to date on our situation

Name _____
Phone # _____

Someone to go with me to the emergency room

Name _____
Phone # _____

Someone who can provide financial support until emergency is over

Name _____
Phone # _____

Someone to be with me at the hospital

Name _____
Phone # _____

Someone who can provide a ride for me or my children

Name _____
Phone # _____

Someone for spiritual support or prayer

Name _____
Phone # _____

Someone to cook a meal, make kids' lunches or [arrange a Meal Train](#)

Name _____
Phone # _____

Someone to run errands

Name _____
Phone # _____

Someone to help my kids with homework if I cannot be there

Name _____
Phone # _____

Someone to take care of pets

Name _____
Phone # _____

Someone to keep in touch with my employer

Name _____
Phone # _____
Name _____
Employer
Phone # _____

Someone to communicate with the school for us, get homework, etc.

Name _____
Phone # _____

Someone to help with laundry or housework

Name _____
Phone # _____

Before an Emergency

a checklist to help you prepare

- Schedule an appointment with your child's doctor(s) to talk about:
 - What constitutes an emergency, and what to do when an emergency happens
 - Transportation to the Emergency Room

- If your child has complicated conditions, ask your child's doctor(s) for an **Emergency Protocol Letter** (see next page) including:
 - Major medical issue/diagnosis
 - High-risk situations and simple key phrases to deal with them, such as "ER staff should (*physician's advice here*) and contact (*names*)."
 - Critical information such as "difficult airway due to (*condition*)" or "has responded well to (*medication/treatment*) in the past."
 - Medication dosage
 - Special equipment needs such as tracheostomy size, g-tube, VNS
 - Date created, physician contact information, and signature

Have several copies of the letter on-hand and easy to find.

- Fill out the **ACEP/AAP Emergency Form** (in this toolkit). Give copies to caregivers, school, church, grandparents, childcare, etc. Have them immediately available at home, in the car, and other easy-to-access locations.

- Decide who is on your **Family's Emergency Support Team** (see facing page). Fill out the worksheet and put it with your other emergency documents.

- Set up a visit to the local fire department
 - Ask if child can look at the emergency vehicles
 - Explain to the staff the reasons the child might need them
 - Show the staff the child's specialized equipment
 - Ask the staff how you should be prepared when you call 911

Emergency Protocol Letters

for children with complicated conditions or histories

An emergency protocol letter from your child's doctor may help emergency health care providers. The letter should be current, personalized to the specific patient, and signed by the physician/specialist most familiar with the child's medical needs.

Suggestions for information to include in the letter:

- An introduction to the child's medical history and specific condition(s)
- A description of the pathophysiology
- Presentation of symptoms
- Assessments needed for correct diagnosis
- Detailed therapeutic strategies and potential side effects
- Description of the patient in recovery

EXAMPLE #1

TO: Emergency Department Personnel
FROM: Provider's name and contact information
RE: Name of patient
DOB: Patient's date of birth
CC: Parents' or guardians' name(s)

(Child's name) is followed by *(provider office name)* at *(address)* for *(condition and related important information about the condition)*.

Because of *(specific issue)*, *(child's name)* may *(describe consequence that requires an ER visit)*.

We have instructed *(child's name)* parents to bring them to the Emergency Room when *(describe)*.

In the Emergency Room, *(name initial steps to take and other key information. This may include unique vital sign or physical exam features to watch for, key steps to diagnosing and managing emergency conditions, managing certain procedures, awareness of past medical trauma, working with family, etc.)*.

For questions, *(process for reaching this provider or another provider with knowledge of the patient)*.

EXAMPLE #2

Primary diagnoses	Seizure disorder
Key home medications	Phenobarbital Keppra
Emergency management	1. Watch for respiratory depression with seizures 2. Lorazepam 0.1mg/kg IV for seizures longer than 5 minutes, repeat once 3. Phenobarbital 10mg/kg IV load if seizures do not stop with 2 doses of lorazepam
Key contacts	OHSU Pediatric Neurology fellow (503-494-xxxx)



Last name:

Emergency Information Form for Children With Special Needs

 American College of
Emergency Physicians®

American Academy
of Pediatrics



Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prostheses/Appliances/Advanced Technology Devices:
5. _____	_____
6. _____	_____

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____
Procedures to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: _____ **Print Name:** _____

Before the Hospital (Fire/Ambulance)

When paramedics arrive, give them the completed [ACEP/AAP Emergency Form](#), and the **Emergency Protocol Letter** if you have one. Tell them:

- **How the child is presenting differently today.** Say what was out of the ordinary that made you call 911. For example: *“He can usually make eye contact and smile, but he isn’t doing that now.”*
- **Medications** given recently (with dosages), *especially if they are different* from what the child usually takes.
- **Preferred position** for the child or the child’s position of comfort.
- **Specialized equipment or supplies** such as g-tubes, suction, etc. Offer specialized equipment to the Emergency Medical Services (EMS) team, and bring what the child needs to the hospital.
- **What is most important right now.** For example, do you want the EMS provider to treat the child at your home, transport the child to the nearest hospital, or something else?
- **Who will ride in the ambulance?** Tell EMS team who you want to ride with the child in the ambulance if possible.
- **Medical Power of Attorney.** Have your forms handy if your child is over 18 or if there are complex custody issues.
- **Hospital Preference.** If the child is having a medical emergency, EMS will often take the child to the nearest facility. If it is not a medical emergency, tell EMS your hospital preference.

At the Emergency Room

- Give the [ACEP/AAP Emergency Form](#) to the attending physician and other key providers, along with the **Emergency Protocol Letter** if you have one.
- Help the emergency room staff by giving them information such as:
 - Medical fears or triggers such as white coats, certain smells, etc.
 - Child’s preferred position, name, etc.
 - Medical power of attorney form if needed
- Before leaving the emergency room, gather any of your child’s personal equipment or supplies you brought from home.

Tips from Parents of Children with Special Health Needs

Taking care of YOURSELF during an emergency

In an emergency, or when traveling to the emergency room, try to:

- Take a moment for yourself
- **BREATHE!**
- Have your own supplies/meds/vitamins etc in one place in case you have to go quickly
- Make a plan for an emergency trip and think about a back-up plan, too
- Stay in the moment
- If you can't be calm, let another responsible person take over for you until you are
- Remember that your child's safety is what matters most
- **BREATHE!**
- Drink water
- Eat nutritious food
- Wash your hands
- Ask all the questions you need
- If something doesn't sit right with you, say so; follow your instincts
- Be nice to yourself; this is hard
- Be ready for a long wait
- Download a funny book to escape worry
- Get up and move around
- Talk to other families in the waiting room
- Keep your heart and mind open so you can be receptive to incoming advice
- Be nice to nurses and others while advocating
- **BREATHE!**
- Tell support people what you need

These tips are offered with love from the Parent Partners of the Oregon Family to Family Health Information Center.

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