

Common Problems



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Sick at School

Josie is 7-year-old girl. Josie was born prematurely and now has developmental delays and stomach problems. When Josie was a baby she often threw up when she was fed. She had a surgery called a Nissen to treat gastro-esophageal reflux (GERD), the cause of her vomiting. Josie does not eat any food by mouth. Josie gets her feedings four times a day through a tube in her stomach called a g-tube. She also takes medicine to control her GERD.

Josie is in second grade. During the school day she has a teacher's aide who helps take care of her. One day while the aide is feeding Josie through her g-tube, she starts retching and gagging. Then she throws up a small amount of formula. Josie is fussy and seems like something is bothering her.

The aide hasn't worked with Josie for very long. She is worried and doesn't know what to do. The aide calls Josie's mom at work to ask if there is a plan for what to do when Josie throws up. Her mom is not sure what to do and does not have a written plan. She wonders if she should call the pediatrician or the specialty doctor.

- How can Josie's mom make a plan for what to do when Josie has problems?
- What can Josie's mom give the school so they know what to do when Josie has a problem like this?



What's It All About

Caring for a child with a life-long health condition involves learning a lot. It usually starts with learning about your child's health condition. With time you learn how it affects daily life and about routine care and treatment.

Learning about common problems is your responsibility. There may be certain problems that are more likely because of your child's health condition. You must know what could happen, what to look for, and what to do. Knowing what is "normal" (your child's baseline) helps you notice problems when they start. Baseline means that your child feels well and can do usual activities like playing or going to school.

Most caregivers feel unsure about when to call doctors for help. Talking with doctors, nurses, and other parents helps you learn. Reading about the health condition may help too. In the beginning you may call your child's doctors and nurses a lot for support and advice. With time and experience you will become an expert on your child and need less help from the team.

Sometimes caregivers get very worried when they hear or read about common problems that their child could have. No one can say for sure which problems your child will have. Every child is different. It is rare for one child to have every possible problem that could happen.

Learning about possible problems and what to do helps you be ready no matter what the problem is. When you are prepared, your child can get the right care as soon as possible.

Steps to Learning About Common Conditions

1. List common problems your child may have.
2. Watch for signs of common problems.
3. Follow the right steps to deal with common problems.

Take Action

Talk with your health care provider.

List common health problems your child could have.

Common problems are health problems that your child :

- Has now.
- Had in the past.
- Has a greater chance of having.

Some ways you can learn what problems are common for your child are:

- Ask doctors, nurses, case managers, and therapists.
- Read about your child's main health condition.
- Talk with caregivers of children who have the same condition.
- Find organizations and resources that help families and patients with your child's health condition.

Use the Common Problem form to make a list of possible problems.

Problems often change over time. Add or take away problems and other information on the form when needed.

Discuss one common problem at a time with health care providers.

- Ask questions during doctor or nurse visits.
- Ask for the medical term. It helps when talking with doctors and others.
- Know the layman's term. It helps when talking with teachers, baby sitters, and family who are not health care providers.
- Know why each problem matters. Ask how the problem could affect your child's health and what could happen if it's not treated.
- Take notes to help you remember.

Questions to ask doctors and nurses

- What common problems could my child have?
- What signs will I see if my child has this problem?
- Are there routine things I can do to help me watch for the problem?
- Are there situations that can cause or trigger this problem, like hot weather or flying on an airplane?
- What should I do if my child has this problem?
- What are the signs that the problem is becoming an emergency?

Take Action

Talk with your health care provider.

Watch for signs of common problems.

Know your child's baseline, the signs when your child is feeling well. For example, know his or her usual blood pressure, energy level, or ability to walk. Knowing the baseline helps you notice any changes and quickly spot problems. Remember that every child is different. What is normal for your child could be a sign of a problem for a different child.

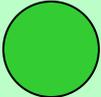
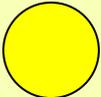
Ask how to watch (monitor) for signs of common problems.

- Ask if there is something you can do to check for each common problem.
- Ask how to check, how often, and any special directions to know.

Write it down.

- Use the Traffic Light Action Plan Form to write notes about watching for common problems.
- You probably won't fill the form out all at once. Learning about common problems takes time.
- Add or change notes as you learn.

Think about a traffic light as you and your child's team make a plan. See the table below. Green is when your child is well. It means to continue what you are doing. Yellow is a warning that your child is not at baseline. Watch closely, and be ready to take action. Red means the situation is urgent. Do what is best to keep your child safe and healthy.

	Green: Everything is going well There is no sign of a problem. Able to do usual daily activities.	Continue to watch (monitor) as you always do. Continue routine care and treatments.
	Yellow: Warning There are changes. May not be able to do normal daily activities. Monitor to watch for signs more often.	May need to change routine care or give "as needed" treatment. Call doctor if your child does not improve.
	Red: Stop, Think, and Act Urgent medical situation.	Your child needs to see a doctor as soon as possible. Call your child's doctor, go to the emergency room, or call 911.

Take Action

Talk with your health care provider.

Follow the right steps to deal with common problems.

Make a plan with your child's health care providers. Discuss:

- What to do first and what to do next.
- What to do if the things you try don't help.
- When to call a doctor.
- When to take your child to an emergency room.
- When to call 911.

Write the steps down.

Continue to use the action plan forms.

- Write the plan so that anyone can understand it.

Know when to call a doctor.

Knowing when to call the doctor can be hard. Caregivers don't want to ignore serious problems. They also don't want to "bother" the doctor about something that's not a problem.

- Call when you have concerns and think something is wrong.
- Call before a problem becomes an emergency.

Know which doctor to call for which problem. For example:

- Call your pediatrician with concerns about an ear ache.
- Call GI doctor or nurse with concerns about reflux (GERD).

Questions to ask doctors:

- For what problems should I call you?
- Who do I call at night or on weekends?

Trust yourself as an expert about your child. Call the doctor if you have a feeling that something is not right. It's okay if you don't have a name for it. You can still explain what you are worried about.

Write it down.

- Use the Provider List Form to keep track of providers' contact information.
- Use the Traffic Light Action Plan Form to keep track of what to look for and what to do for each problem. The next page shows an example of a filled out form.

What doctors need to know when you call

Your name and your child's name.

The problem your child is having.

Whether your child has had this same problem before.

About the problem:

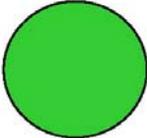
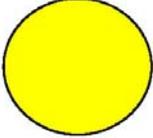
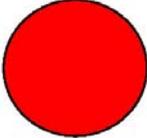
- Your child's baseline.
- Signs that there is a problem.
- When you first noticed the problem.
- What makes it better or worse.
- If the problem is constant or comes and goes.
- If it only happens at certain times. For example, after eating or during the night.
- If you have tried anything to help the problem, and if it helped.

Anything else you think is important.

Take Action

Talk with your health care provider.

Here is an example of a filled out Common Problems Action Plan. Remember that what to look for and what to do are different for every child.

Common Problems Action Plan		
Problem: <u> Gastro-Esophageal Reflux Disease (GERD) </u>		
	What to look for	What to do
All Clear 	<ul style="list-style-type: none"> Occasional vomiting without pain. No pain with eating. Normal weight gain. Eating and drinking normal amounts. No choking, gagging, or trouble swallowing Normal breathing. Sleeping well. 	<ul style="list-style-type: none"> Weigh each month. Give GERD medicine each day even if doing well. Watch for problems with weight, drinking, eating, pain, and breathing. See GI doctor as usual. Call if any questions between visits.
Caution 	<ul style="list-style-type: none"> Vomiting more than 2 times each week. Pain with eating, or when vomiting. Slow weight gain or weight loss. Eating or drinking changes. Choking, gagging, or trouble swallowing when eating Changes in amount of urine each day. Breathing problems. Sleeping problems. Complaining of sore throat or "bad taste" in mouth 	<ul style="list-style-type: none"> Continue to give GERD medicine each day. Give pain medicine if the doctor prescribed it. Weigh each week. Call if losing weight. Keep track of how much and how often vomiting happens, and if it causes pain, breathing, or sleeping problems. Write down what your child eats and drinks. Watch for signs that your child is dry (dehydration). Call doctor or nurse if you have questions or your child is not getting better.
Stop, Think, and Act 	<ul style="list-style-type: none"> Vomits during or after most meals. Vomit is bloody or bright green Constant pain. Choking or breathing problems when eating. Weight loss. Looks and acts very sick Dry (dehydrated): No tears, dry mouth, no urine for 12 hours, sleepy, or weak. Breathing problems are getting worse. Turning blue or becoming limp. Stops breathing. 	<ul style="list-style-type: none"> Call doctor now. Go to emergency room if you can't reach doctor. Start CPR if your child stops breathing. Call 911 if: <ul style="list-style-type: none"> You think your child's life is in danger. You think your child needs help right away. You can't wake your child up Your child is blue and is having a lot of trouble breathing. Your child stops breathing.

Check Yourself

- I listed common problems my child may have.

- I watched for signs of common problems.
 - I know what to check.
 - I know how to check.
 - I know how often to check.
 - I know the signs that a problem may be starting.
 - I know the signs that I need to take action.

- I followed the right steps to deal with common problems.
 - I can describe the steps to take for each common problem.
 - I have written down the steps.
 - I gave copies to anyone caring for my child.



More Information and Resources

Keep health information online, on a flash drive, or on your personal computer. One place to keep health information for free is **Children’s Hospital of Wisconsin Family Portal:**

<https://familyportal.chw.org/>

“**When to Call 911**” is a video for parents and caregivers about calling 911. Scroll down to the bottom of the website page. Click on “A Minute for Kids Audio Files.”

<http://www.aap.org/healthtopics/emergencycare.cfm>

Resource Centers: Many hospitals and community centers have resource centers with information about special health care needs. Ask health care providers, teachers, and your local library about resource centers near your home.

Medline List of Organizations: Agencies that help patients and families often have information about special health care needs.
http://www.nlm.nih.gov/medlineplus/organizations/orgbytopic_a.html

Medline Plus: Information about health conditions, tests, treatments, drugs, and resources. Click on *dictionary* to look up medical terms.

<http://medlineplus.gov/>

KidsHealth: Information about kids’ health, behavior, and development. It has a parent, teen, and child section.

<http://kidshealth.org/>

Medline: Tips for finding good health information on the Internet

<http://www.nlm.nih.gov/medlineplus/webeval/webeval.html>

Children’s Hospital of Wisconsin – Caring for My Child: Find information about your child’s condition.

<http://www.chw.org>

Common Problems Forms

Form Name	How it can be used
Dealing With Common Problems	Use this form to list the common problems your child is most likely to have. <ul style="list-style-type: none"> • Only write the most important information. • Use it when you want to give others a quick picture of all possible problems.
Common Problems Action Plan	Use this form to help you learn about and treat common problems. <ul style="list-style-type: none"> • Use a separate page for each common problem. • List problems your child is likely to have and how to check for them. • Explain how to tell there is a problem and what to do. • Write what to do so that anyone can follow the steps. • Use it as a guide when you teach others about common problems.
About Health Condition	Use this form to help you learn about your child's health condition. Use the form to help you explain your child's condition to others. Give it to people caring for your child.
Resources for My Child's Health Condition	Use this form to help you keep track of helpful resources about your child's health condition.
Provider Contact List	Use this form to keep track of how to contact providers.
Emergency Information Form (EIF)	Write the emergency plan on the EIF. Give the EIF to first responders and people caring for your child before an emergency. Give it to first responders, Emergency Room (ER) doctors, and others during an emergency.
Family Emergency Contact List	Write phone numbers of the people you may need to call in an emergency. Show the form to anyone who can use a phone in your home. Keep the form where it's easy to see. For example, by the main phone or on your refrigerator.

Name: _____

Date updated: _____

Dealing With Common Problems

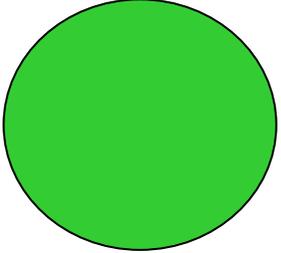
Problem	Things to look for	Actions to take	Reasons to call for help	Who to call

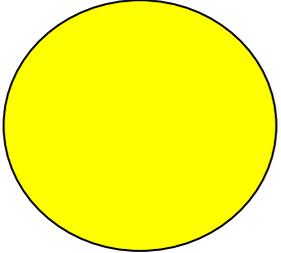
Common Problems Action Plan

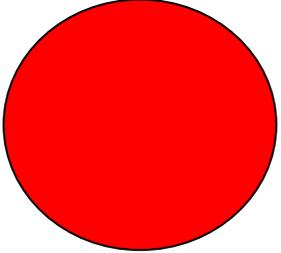
Problem: _____

What to look for

What to do

<p>All Clear</p> 		
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<p>Caution</p> 		
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<p>Stop, Think, and Act</p> 		
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About Health Condition

Main Health Condition <i>Diagnosis</i>		
Describe Health Condition <i>Use your own words.</i>		
Health Problem <i>List problems caused by health condition.</i>	How Problem Affects Daily Life and Activities	How problems are managed <i>List equipment, special diet, medicine, therapy, tests, etc.</i>

About Health Condition

Health Problem <i>List problems caused by health condition.</i>	How Problem Affects My Child <i>Explain how problems affect daily life and activities.</i>	What We Do <i>Explain how problems are managed. List equipment, special diet, medicine, therapy, tests, etc.</i>

About Health Condition

Optional Information *You might not have information to fill in every section. You can leave some or all of this page blank.*

Cause of Health Condition *Sometimes the cause is not known.*

How Condition Was Diagnosed *Child's age when you found out, doctor who diagnosed it, tests done, etc.*

Other Information *Things you want others to know about the condition and how it affects your child.*

Name _____

Resources About Health Condition

List resources that help you learn about the health condition

Resource <i>Websites, DVDs, libraries, organizations, etc.</i>	How To Find Resource <i>Phone number, website, address, name of contact person, etc.</i>	Notes About the Resource <i>How it can help, services it offers, trainings, group meeting day and time, when to check back, etc.</i>

Provider Contact List

List doctors, therapists, pharmacies, and other health care providers.

Provider Name			Type of Provider		
Address					
Phone		Fax		Email	
Notes <i>Who to talk to, best time to call, etc.</i>					
Provider Name			Type of Provider		
Address					
Phone		Fax		Email	
Notes <i>Who to talk to, best time to call, etc.</i>					
Provider Name			Type of Provider		
Address					
Phone		Fax		Email	
Notes <i>Who to talk to, best time to call, etc.</i>					
Provider Name			Type of Provider		
Address					
Phone		Fax		Email	
Notes <i>Who to talk to, best time to call, etc.</i>					

EMERGENCY INFORMATION FORM

Complete this form with a health care provider and share with emergency responders

Name		Birth Date		Primary Language	
Home Address					
PRIMARY PHYSICIAN Name		1st number to call	2nd number to call	3rd number to call	3rd number to call
EMERGENCY CONTACTS		1st number to call	2nd number to call	3rd number to call	3rd number to call
1					
2					
3					
EMERGENCY CARE INFORMATION and CODE STATUS					
Preferred Hospital for emergency care					
Emergency Supply Location		<small>At home</small> <input type="checkbox"/> <small>Other location</small> <input type="checkbox"/>			
Code Status		<input type="checkbox"/> Full <input type="checkbox"/> DNR Do not resuscitate <input type="checkbox"/> Altered (explain)			
Other Information					
HEALTH CONDITIONS See clinical summary or medical records for full history.					
Primary Diagnosis					
Most Important Secondary Diagnoses					
MOST IMPORTANT MEDICATIONS <input type="checkbox"/> Check if complete medication list attached <input type="checkbox"/> Check if no medications					
1	2	3	4	5	6
4					
TECHNOLOGY <input type="checkbox"/> Check if no technology					
1	2	3	4	5	6
3					
Weight	Kg	Date measured	Height	cm	Date measured
MAIN ALLERGIES See record for complete list WHAT HAPPENS? <input type="checkbox"/> check if no allergies					
1.					
2.					
3.					
PRECAUTIONS AND THINGS TO AVOID Latex Precautions: <input type="checkbox"/> Yes <input type="checkbox"/> No					
1.					
2.					
3.					
4.					
5.					
BASELINE (vital signs, sensory, mobility, level of consciousness)					
Heart Rate	Respiratory Rate	Blood Pressure	Temperature	Oxygen Saturation	
Other					

EMERGENCY INFORMATION FORM

POSSIBLE PROBLEMS <i>(Possible Reasons for Needing Emergency Help)</i>	SUGGESTED INTERVENTIONS AND TREATMENTS
We have discussed and agreed on this plan together	
Physician Signature _____	Date _____
Patient or Parent/Guardian Signature _____	Date _____

Family Emergency Contact List

Keep this list where it's easy to see, for example, by your main phone or on your refrigerator.

Family Information			
People Living in Home			
Home Address	Street Address	City	State Zip code Phone
People to Call in an Emergency		Relationship	Phone or Pager Numbers
1			
2			
3			
4			
Emergency Services			
Police	Fire	Poison Control	1-800-222-1222 (TTY: 414-266-2542)
Emergency Medical <i>(First Responders)</i>			
Closest Hospital	Name	Address	city Phone
Preferred Hospital	Name	Address	city Phone
Healthcare Providers		Phone or Pager Numbers	
Primary Doctor <i>For children in home</i>			
Primary Doctor <i>For adults in home.</i>			
Dentist			
Pharmacy			
Other Healthcare Provider			
Other Healthcare Provider			
School and Child Care Providers		Phone Number	
School / Child Care	Name	Address	City
School / Child Care	Name	Address	City
Bus Company / School Transportation	Name	Address	City
People Who Can Help During an Emergency		What Person Can Help With	
Name	Relationship		
Name	Relationship		
Name	Relationship		
Utility Phone Numbers		Where to Find Emergency Shut Off in Home	
Gas	Electricity	Gas Shutoff	Water Shutoff
Water	Phone	Fuse Box	Electricity Main Switch