Knowing what to do

Prepare for an emergency. Know what to do if an emergency arises. It is like planning for a house fire or earthquake—you hope one will never happen, but being prepared will improve the outcome.

Your plan should include: ■ learning the signs to watch for, such as symptoms or drug reactions, ■ including family members and other caregivers in the plan, ■ knowing what information to provide to paramedics or emergency department staff ■ knowing how and where to get emergency help.

**Monitoring your child’s health: signs and symptoms**

It is important for each of us to listen to our bodies. As children with CHD grow and develop they learn to recognize small changes in their health. Parents of infants or younger children often are the first ones to notice changes in their child’s health.

Symptoms are the body’s way of telling us something is wrong with us. Just as a cough and a stuffy nose are the body’s way of telling us we have a cold, there are symptoms we can learn that tell us how our hearts are working.

Each child growing up with heart disease has a unique heart, and therefore a unique set of indicators that there is a problem. It is important that you ask your child’s cardiologist at each follow up appointment what symptoms you should be watching for or paying attention to as your child grows and develops.

Different symptoms will have different degrees of significance depending on your child’s unique heart condition and medical history. Discuss with your cardiologist the level of urgency for your child and the plan of action should your child develop any of the following symptoms:

■ gradual increased effort of breathing

■ decrease in exercise performance or tolerance

■ increasing pallor (pale skin) or cyanosis at rest

■ increasing tiredness or lethargy

■ decrease in appetite or food intake

■ significant weight gain or weight loss over a short period of time

■ severe nausea or vomiting

■ change in bowel patterns (diarrhea, constipation)

■ dizziness or faintness with exertion or at rest

■ anxiety or restlessness

■ chest pains, particularly with exercise or activity (this is often normal and related to muscles and bones changing and growing, but can also indicate that the heart is needing to work harder).

■ palpitations or pounding in the chest that may indicate an abnormal heart beat (some children use different words such as “butterflies in my chest” or “my heart is racing” to describe the sensation).

Ask your cardiologist if there are any other symptoms that you should watch for and who you should call if you notice them.
How can family members help?

Family members, teachers, babysitters, and other caregivers should recognize if your child is having serious problems.

Encourage everyone to take an infant/child cardiopulmonary resuscitation (CPR) course. Contact the Heart and Stroke Foundation to find courses in your community.

Your family can also help you plan to look after your other responsibilities if you are going to be away from your home for a long time. Some of the things they can help with are children, livestock, pets, and calling your workplace.

What should we do if our child requires urgent medical help?

If your child appears to require urgent medical help, follow these instructions:

- Have your child stop any activities and rest.
- Give any emergency medications as instructed by your doctor.
- Recognize the problem, stay calm, and act at once. Do not delay getting to the hospital by packing a suitcase or notifying family or friends.
- Call 911 or your local emergency number if your child needs urgent medical attention. Unless you are minutes away from the hospital and can get there safely, you are better off calling an ambulance. Although it may seem to take more time than to go to the local hospital yourself, it is important that your child be monitored and given any necessary treatment during transport.
- If an ambulance is not available, drive carefully to your nearest hospital emergency. Any doctor or emergency department can contact the cardiologist on call 24 hours a day, 7 days a week.
WHAT INFORMATION SHOULD WE HAVE AVAILABLE?

It is helpful to have a summary of your child’s medical history on hand. Store copies in your wallet, car, diaper bag, and your child’s backpack, and make sure caregivers know where they are.

Your medical summary should include the following information about your child:

<table>
<thead>
<tr>
<th><strong>Medical Summary</strong></th>
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<tr>
<td><strong>Name</strong></td>
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<td><strong>Weight</strong></td>
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<tr>
<td><strong>Surgeries or treatments</strong> (when and where they were performed)</td>
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<td><strong>Pacemaker</strong></td>
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<td><strong>Allergies or drug reactions</strong></td>
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<td><strong>All medications</strong> (including the exact name, the amount they take, how often it is taken)</td>
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<td><strong>What the child is normally like</strong> (saturation levels, breathing, activity, awareness, etc.)</td>
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<td><strong>Language, religious, and/or cultural considerations that may affect your child’s care</strong></td>
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<tr>
<td><strong>Contact Information</strong></td>
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Date summary last updated
