

Cardiac conditions: Care at home

What is a congenital heart defect?

A congenital heart defect is a heart problem that happens before birth. The name of your child's heart condition is

How can I care for my child?

Talk to the doctor or nurse about guidelines for feeding your child.

Crying is the most active state for a baby. Some crying is normal and cannot be avoided. But prolonged crying can be stressful for your baby. Help your baby conserve energy by attending to the crying and keeping your baby comfortable. Avoid having your baby wait for feedings.

You may find your child gets tired more easily with normal play. Extra naps and quiet play are good ways to help your child regain needed energy. Talk with the doctor about your child's activity level.

What should I tell the school?

Tell the school nurse and teacher about any medicines your child takes and any activity limits. Encourage school personnel to treat your child as normally as possible. If needed, a letter can be sent to the school listing any restrictions. Please talk with your child's cardiologist about this.

What do I need to know about my child's medicines?

Learn the names of all medicines your child is taking, what they do, side effects, and any precautions that need to be taken.

Have a schedule and give medicines on time (within 1 hour). Do not put medicines in food or liquids because if your child does not finish the food you will not know how much medicine your child received. Keep medicines out of children's reach and sight. See the education sheet, "Medicine Safety".

When should my child see the doctors?

The cardiologist will tell you when your child needs to be seen. You should also continue to see the primary doctor to check your child's physical and emotional growth and development.

What else do I need to know?

Children with heart problems may be more likely to get endocarditis (heart infection) after routine dental care or some types of surgery. This can occur when bacteria that are normally found in the mouth enter the bloodstream and travel to the heart. See the education sheet, "Subacute bacterial endocarditis: Prophylaxis."

The risk of endocarditis is reduced with good dental care. Brush the teeth at least twice a day. Clean an infant's teeth with a washcloth wrapped around your finger.

Your child should begin seeing a dentist for regular check ups by the first birthday. Tell the dentist about your child's heart condition.

For dental procedures and some surgeries, an antibiotic may be needed **before and after** the appointment. Check with the cardiologist if you have questions about the need for antibiotics.

Your child may be moody or irritable after major surgery or hospital stays, often within the first few days at home. This may last for several weeks. If you become concerned, call the doctor.

Toddlers and preschoolers may go back to earlier behaviors in areas such as toilet training and independence, and may have more separation anxiety for a while. They should regain these skills after some time.

Toddlers and preschoolers may have nightmares for a short time. Reassure and comfort them to help them go back to sleep. If siblings also have nightmares, they may need extra reassurance and comforting too.

When should I call the cardiologist?

- breathing faster or harder
- pale color
- eating poorly or sweating while eating
- sleeping more than usual
- very irritable and cannot be comforted
- less interested in play
- cool with mottled (blotchy) arms or legs
- more blueness of the hands, feet, fingernails, lips, or gums
- vomiting or diarrhea for more than 24 hours
- temperature higher than 101°F (38.3° C) for more than 24 hours
- marked changes in activity or eating
- vomiting medicines

For some of these problems, the cardiologist may ask you to contact the primary doctor.

What resources are available?

Children's Specialty Care Center
2530 Chicago Avenue South
Suite 500
www.childrensheartclinic.org

Children's also has a **support group**, "Parents for Heart", for parents of children with heart problems. Ask the nurse or cardiologist for information, call (612) 813-6645, or visit www.parentsforheart.org

The **American Heart Association** has information about congenital heart disease. The phone number is (612) 835-3300.

Meld Special is a free Twin Cities program that offers information and support for parents of children with chronic conditions. This program focuses on the "ordinary" tasks of raising a child as well as the impact of a chronic condition on raising children. The phone number is (612) 332-7563.

PACER Center, Inc. (612) 827-2966, is a resource for parents of children with disabilities.

Your child may qualify for **financial help** because of his or her heart condition. Children's social work staff can help you find out what financial resources are available. The nurse can help you contact them at your request.

Questions?

This sheet is not specific to your child but provides general information. If you have any questions, please call the cardiologist.