

Your Child's Special Needs

Regular medical care is important for all children, but especially for those with congenital heart disease. Your pediatric cardiologist will want your pediatrician or family doctor to check your child regularly.

A child with a heart defect usually gets through common childhood illnesses as quickly and as easily as children with normal hearts. Sometimes parents think that their child with heart disease will need more medicine to get through an illness but this is usually not true. Also, your child doesn't need antibiotics to help prevent infections with a few notable exceptions (e.g., children with heterotaxy syndromes like asplenia or in some cases of DiGeorge syndrome). Some parents think that giving their child antibiotics before the child is very sick will prevent the illness from getting worse. This also isn't true and may make the infection more serious and more likely to be resistant to the antibiotic that's given.

It's best to remember that preventing infection starts with good hygiene, good nutrition and common sense. Frequent hand washing (or using water-free hand washes) especially during the cold and flu season and avoiding ill contacts is a good way to prevent illness. Try to avoid crowded settings like shopping malls if your child's doctor is concerned that your child wouldn't tolerate an infection. You may want to discuss with your child's doctor or nurse if it's appropriate to have your child in daycare.

Your child should have routine care and the standard immunizations that your doctor recommends for all children. Your child may also need additional immunizations, such as the influenza vaccine. If your child has certain heart defects, a special monthly immunization for a cold virus (RSV) may be recommended during the winter months.

Checkups With Your Pediatric Cardiologist

Most children with heart defects need periodic heart checkups. Usually, they're scheduled more often (days, weeks, months) just after the diagnosis or surgery and less often later. For minor conditions checkups may only be needed every one to five years. Depending on your child's problem, periodic testing may be needed (see preceding section for descriptions of tests). These tests may include:

- Standard electrocardiogram
- 24-hour ambulatory electrocardiogram (Holter scan)
- Chest X-ray
- Routine (transthoracic) echocardiogram

- Transesophageal echocardiography
- MRI or CT scanning of the heart
- Exercise stress testing
- Cardiac catheterization and angiography

Preventing Infective (Bacterial) Endocarditis

Infective endocarditis (IE — also called bacterial endocarditis [BE]) is an infection caused by bacteria that enter the bloodstream and settle in the heart lining, a heart valve or a blood vessel.

Although IE is uncommon, children with some heart defects have a greater risk of developing it. The American Heart Association recently updated guidelines for preventing endocarditis. In the past, children or adults with nearly every type of congenital heart defect needed to receive antibiotics one hour before dental procedures or operations on the mouth, throat, gastrointestinal genital, or urinary tract.

This recommendation has changed and is much simpler. Now antibiotics are only recommended for people with:

1. an artificial heart valve or who have had a heart valve repaired with artificial material,
2. people who have previously had endocarditis,
3. heart transplant patients who develop abnormal heart valve function, or
4. people with certain congenital heart defects including:
 - Cyanotic congenital heart disease (birth defects with oxygen levels lower than normal), that has not been fully repaired, including children who have had a surgical shunts and conduits;
 - A congenital heart defect that's been completely repaired with prosthetic (artificial) material or a device (either placed by surgery or by catheter intervention) for the first six months after the repair procedure;
 - Repaired congenital heart disease with residual defects (persisting leaks or abnormal flow) at the site or adjacent to the site of a prosthetic patch or prosthetic device.

Your pediatric cardiologist will give you more information about preventing endocarditis. If you have questions, ask the pediatric cardiologist or nurse. Good dental hygiene is the best way to prevent heart infection from a tooth or gum infection. For years your child may have been taking antibiotics before dental or other surgical procedures at the recommendation of your pediatric cardiologist. These new simpler recommendations were made after years of study and review by physicians, dentists and scientists around the world.

If your child still requires antibiotic prophylaxis for dental treatment or oral surgery, your pediatric cardiologist may give you an American Heart Association wallet card. Show this card to your dentist, pediatrician, family doctor or other physician. It advises them to give your child the proper antibiotic and dose. For smaller children, the dose will vary according to your child's weight. Always remind the dentist or doctor if your child is allergic to any antibiotics or other medications.

Finally, operations or procedures on the gastrointestinal, genital, or urinary tract no longer require antibiotics for any children or adults with heart disease.

Physical Activity

Most children with a congenital heart defect can be fully active and don't need restrictions. In fact, pediatric cardiologists encourage children to be physically active to keep their hearts fit and to avoid obesity. Such healthful activities include swimming, bicycling, running, rope jumping and tennis. For a few specific heart conditions, a pediatric cardiologist may advise that your child avoid some strenuous physical activities and junior varsity or varsity competitive sports.

Development and Education

Infants and children with CHD may have delays in development, learning disabilities or special educational needs. Discuss with your primary care physician what testing may be appropriate for your child. Fortunately, almost all children with congenital heart defects can attend regular schools. Most children don't have any physical or mental limitations that prevent them from participating fully in the school program. Most school districts, with the aid of their school nurses, can evaluate these children and make changes to meet their needs.

Financial Support

Diagnosing and treating congenital heart defects with surgery is costly. Your child may need many specialists and several days in the hospital. If hospitalization and care are at a center far from your home, you'll need money for travel, food and lodging. Because the medical expenses of cardiac care are often extremely high, some families — even those with health insurance — need help to pay them. Every state has an agency to help eligible families meet their medical expenses. Your doctor can give more information about the program in your state and help you apply. The amount of financial aid you can get depends on the rules for eligibility in your state, your financial situation and insurance policy, and the cost of cardiac care.

Take a look at your health insurance. Most families are covered under a group plan bought by an employer. Under such a plan, all family members must be covered even though they have preexisting health problems. If you're thinking about changing jobs, find out your child's eligibility for health coverage by the new employer, or if your child can stay covered under your current policy. Don't stop your existing health insurance until you know your child is covered by the new policy.

Future Vocations

There are now hundreds of thousands of adults who are survivors of congenital heart disease. For most people with congenital heart defects, job choices aren't limited. Young adults with heart defects have entered a variety of professions and occupations. A few people may have a limited capacity for exercise or low endurance. People with pacemakers or implantable defibrillators may be limited from jobs involving direct contact with sources of electromagnetic interference (e.g., arc welding, high power lines, transformers). Job counselors can help them choose less risky types of work.

High school and college counselors can help a person select a vocation. Sometimes the state vocational rehabilitation program may be needed for those rare patients whose ability to earn an income has been impaired by a physical handicap due to a heart problem.