

Family Living

Caring for a child with heart disease, either congenital or acquired, can be both challenging and rewarding. Yet, careful consideration of these tips for family living can greatly reduce the challenges you may face.

Bacterial Endocarditis

Bacterial Endocarditis, also known as SBE (Subacute Bacterial Endocarditis), is a serious bacterial infection of the inner lining of heart structures, most often the heart valves. Children and adults with certain congenital or acquired heart defects are sensitive to this infection, although it is extremely rare in people with normal hearts. Symptoms include unexplained persistent low-grade fever, paleness, night sweats, weight loss and a general feeling of illness. When SBE occurs, it often requires a lengthy, expensive, and painful hospital stay, and can make any existing valve damage worse. Thus all efforts should be directed toward prevention.

Anyplace where there is turbulent blood flow, such as a hole in the heart or an abnormal heart valve, bacteria may grow with SBE.

The bacteria may settle, multiply, and damage tissue, sending infection into the blood stream (sepsis). Foreign material, such as patches, valves, and tubes, which may be inserted during heart surgery, may also be sources of infection. Dental procedures, especially when oral health is poor (inflamed or infected gums) may also introduce germs into the bloodstream. Children and adults with heart problems should be very careful to maintain good oral hygiene and have frequent dental check-ups.

In order to prevent SBE, the American Heart Association recommends the use of antibiotics prior to any surgery that may cause bleeding. This is especially true of dental, oral, or upper airway procedures, such as removal of tonsils or adenoids, because of their proximity to the heart. With a high level of antibiotic (germ killing medication) in the bloodstream at the time of the procedure, the likelihood of infection is very small. The American Heart Association and the American Dental Association recommend the antibiotic Amoxicillin (a prescription medication) by

mouth one hour before a dental procedure with no follow-up dose necessary. The administration of antibiotic before a surgical or dental procedure is called SBE prophylaxis.

For procedures within the digestive tract, the esophagus (swallowing tube), and genitourinary tract (bladder, genitals), a combination of intravenous Ampicillin and Gentamycin is recommended one hour before the procedure begins.

For the normal vaginal delivery of a baby, antibiotics are not recommended.

Some people may be allergic or oversensitive to these drugs, or are supposed to be fasting, or are considered to be a higher than usual risk because of a previous episode of SBE or foreign material in the heart). In that case, other antibiotics may be preferred to be given intravenously. Consult with the cardiologist or dentist to determine the best way to deal with this problem, especially since these recommendations may change from time to time.

At present, loss of loose baby teeth (even with bleeding), skin wounds and other superficial injuries do not require SBE prophylaxis, unless they become badly infected and the physician recommends it. In general, call your cardiologist or cardiac nurse if you are unsure of what to do.



Dental Care Issues

Because of the risk of bacterial endocarditis, children with heart defects need meticulous dental care: cleaning teeth three times a day, flossing, and visiting the dentist regularly. Taking the prescribed regimen of antibiotics prior to any dental procedure is important. Children do not need antibiotic protection when they lose a primary tooth unless there is a special problem.

Like all children, those with heart conditions may need orthodontic treatment. These children's special needs should be discussed with the orthodontist because antibiotic treatment will probably be needed when dental appliances are installed. It is critical to properly clean such appliances to avoid infection over time. Appliances can

cause tissue injury during vigorous activities such as contact sports, so these children should wear mouth guards to protect their teeth and prevent damage.

Mouth injuries, abscessed teeth, recurrent canker sores, and accidental tooth loss are all situations that should be discussed immediately with the dentist, who may recommend antibiotics.

A pediatric dentist may be helpful as they often have had direct experience dealing with children who have heart defects and are familiar with the antibiotic regimen. A child who has been through numerous medical procedures may also have some fear of medical personnel. A pediatric dentist may be better able to respond to such a situation.



CPR Training and Renewal

It is recommended that all parents take a course in CPR (cardiopulmonary resuscitation), but it is especially important for parents of a child with heart disease. Follow up with an annual refresher course in CPR is advisable. Many local colleges, park districts, or fire departments offer such classes periodically. Your local hospital or fire department should be able to direct you to programs in your area. The American Heart Association publishes the Textbook of Pediatric Basic Life Support, which includes basic instructions on CPR. Written materials, however, should not be used as a replacement for a hands-on course in CPR. They are available to supplement your CPR knowledge.



Fire Department Notification

It is a good idea to notify the local fire department about a child's heart defect if the child is still at all symptomatic or has episodes of arrhythmia, etc. Many parents keep a full description of their child's defect, including a diagram of the child's heart, on file at the local fire department. In this way, paramedics can be alerted to the child's condition as they are en route to the home should there ever be an emergency requiring immediate medical attention.



Preparing for Daycare, School, Camp, etc.

As more children have complete repair of heart defects in infancy or early childhood, fewer of them enter school still needing major cardiac treatment. It is unlikely that any restrictions will be placed on the child's physical activity; most children who have had surgery in infancy can run and play actively. Some children, however, will have some restrictions placed on them by their pediatric cardiologists.

In any event, it is essential for the school to know that surgery has been performed and whether or not full activity is possible. Without specific knowledge, a teacher may be overly anxious and restrict the child's activity needlessly.

For children who enter school with a major health problem, their activity will likely be limited, and close coordination between family, school, and cardiologist is critical. When restrictions on physical activity are necessary, alternative ways for the child to participate should be found in order to allow the child to feel as included as possible.

Prior to entering school, there will no doubt be health forms to be completed, and any heart problem or surgery should be described. It is recommended that in addition to this paperwork, a face-to-face meeting with the primary teacher, gym teacher, school nurse, and possibly the principal, be arranged to make sure that they are fully apprised of the child's health and heart history. If the child's physical activity is restricted, ongoing discussions regarding the level of physical activity are most important. It is important for all involved to recognize the subtle differences between challenging, coddling, and embarrassing the child by asking him or her to exceed physical capabilities.

Often the cardiologist will say that a child with a cardiac defect will voluntarily limit himself physically. These children have an exertion point beyond which their bodies will not go; they will be forced to rest. The teacher who is aware of this can make it possible for the child to rest unobtrusively.