Tips to Help Your Child Live Well With Congenital Heart Disease

Many children born with heart problems face challenges, including other health problems that need to be managed. Here are some tips to help you and your child along the way.

1. Find a heart team with expertise in managing congenital heart disease.
   In most cases, your child will need lifelong monitoring and care, even if he or she feels well. Your daughter will, at some stage, need to understand the risks of pregnancy and the need for careful planning.

2. Understand your child’s heart defect and ask lots of questions. Find out what the defect means for your child’s health now and in the future. Learn about what your child should do to stay healthy and prevent complications.

3. Stay organized. Keep a complete summary of these items:
   - Type of heart defect and when it was diagnosed
   - Every test, procedure and surgery performed, along with dates and the name of the ordering doctor and facility
   - Medicine your child took before and takes now, and the purpose of each
   - Results from cardiac imaging or blood tests
   - Other conditions, such as allergies
   - Dates of follow-up health visits, echocardiogram or other tests

4. Don’t skip health checkups or tests. Even if your child seems to be doing well, follow-up visits are key to staying ahead of any problems.

5. Lifelong congenital cardiac care is essential. It will be important for your child to find the right team at each stage of life and to feel confident in the team’s understanding of the specific defect and how to manage it.
   This includes readying your child to transition to an adult congenital heart specialist when the time is right.

For more information about congenital heart disease, visit CardioSmart.org/CHD.
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6. **Teach your child to stay in tune with his or her body.** Children with heart defects need to feel comfortable sharing any changes in how they feel with their heart team and other health care professionals.
   As a parent, it’s important to keep an eye on your child’s physical abilities; for example, how well they keep up with other kids or if you notice a change in what they can do.

7. **Help your child adopt heart-healthy habits early on.** This includes eating well, getting appropriate exercise, not smoking, and managing and reducing stress.

8. **Learn how to manage the anxiety that often comes with having a heart defect.** Anxiety and feelings of uncertainty are very common among people with congenital heart disease. It affects families, too. Developing coping strategies early in life is important.

9. **Find emotional support.** Living with a chronic disease, especially from birth, can be stressful. Make sure to tap into support groups or find families who have a child with a similar condition to talk to and share experiences.

10. **Stay positive and keep an open mind.** More adults are living with congenital heart disease than ever before, thanks to significant medical advances. Technologies and treatments are continually improving. For many, the future is bright.