



Congenital Heart Disease Parent FAQ

About Congenital Heart Disease

What is congenital heart disease?

Congenital heart disease, also called congenital heart defect (CHD), is a heart problem that a baby is born with. When the heart forms in the womb, it develops incorrectly and does not work properly, which changes how the blood flows through the heart.

What causes congenital heart defects?

In most cases, there is no clear cause. It can be linked to something out of the ordinary happening during gestation, including a viral infection or exposure to environmental factors. Or, it may be linked to a **single gene defect** or **chromosome abnormalities**.

How common is CHD in the United States among children?

Congenital heart defects are the most common birth defects in children in the United States. Approximately 1 in 100 babies are born with a heart defect.

What are the most common types of congenital heart defects in children?

In general, CHDs disrupt the flow of blood in the heart as it passes to the lungs or to the body. **The most common congenital heart defects** are abnormalities in the heart valves or a hole between the chambers of the heart (ventricles). Examples include **ventricular septal defect (VSD)**, **atrial septal defect (ASD)**, and **bicuspid aortic valve**. At the **Betty Irene Moore Children's Heart Center** at Stanford Children's Health, we are known across the nation and world for treating some of the most complex congenital heart defects with outstanding **outcomes**.

Is CHD preventable?

In some cases, it could be preventable. For example, if a woman has diabetes and she keeps her blood glucose under good control, she can decrease her chances of having a baby with CHD. Also, certain medications should be avoided, such as antiseizure medicines. Finally, it's important to get a rubella vaccination before becoming pregnant. Discuss with your [obstetrician](#) or [maternal-fetal medicine specialist](#) if you would like to learn more.

What are the risk factors for having a baby with CHD?

A family history of CHD triples the risk of certain heart defects. Particular diseases also increase the risk of CHD, including [phenylketonuria \(PKU\)](#), insulin-dependent [diabetes](#), [lupus](#), [connective tissue disorder](#), and a pregnancy resulting from assisted reproductive technology (ART).

Are acquired heart conditions the same thing as congenital heart defects?

There are two main types of heart disease: congenital (present at birth) or acquired (occurring after birth). Acquired heart disease can be caused by infection or other illness, and while it is much more common in adults than in children, it occurs in children as well.

Symptoms and diagnosis of congenital heart disease

What are the symptoms of congenital heart disease?

Babies with congenital heart disease (CHD) may experience abnormal heart rhythms, shortness of breath, a blue tint to the skin, lack of normal physical development, an inability or disinterest in feeding, and swelling in the body. Symptoms of CHD in children and teenagers can include heart palpitations, shortness of breath, chest pain, heavy sweating, or passing out during exercise.

How is CHD diagnosed in unborn babies? Children? Teens? Adults?

The most serious heart defects are identified before birth or within 24 hours of birth. **Fetal heart specialists** at **large, multidisciplinary heart centers** like the **Moore Children's Heart Center** can diagnose heart defects with advanced **cardiac imaging** before a baby is born. **Pediatricians** and **pediatric cardiologists** can catch CHD in the first days of life through simple screening tests. Sometimes certain heart defects, such as **atrial septal defects**, go undetected until later in childhood or adulthood.

Treatment options and expected outcomes for CHD

What are some potential treatments for my child with CHD?

Depending on severity, your child may need **cardiothoracic surgery** to repair the heart defect. People with CHD need lifelong care from specially trained heart doctors to manage their disease and watch for heart conditions that can develop later in life. At our **Adult Congenital Heart Program (ACHD)**—a joint program between **Lucile Packard Children's Hospital Stanford** and **Stanford Hospital**—we offer patients of all ages comprehensive diagnostics, lifestyle counseling, medical management, and **interventional** and **surgical treatments** for the full spectrum of conditions related to congenital heart disease.

Will my child need heart surgery for their CHD?

Statistically speaking, many congenital heart defects are simple and fairly easy to treat, or they can occasionally resolve on their own. About 25% of heart defects are critical, requiring surgery before a child's first birthday. When surgery is needed, it's vital to select a **cardiothoracic surgeon** who is highly specialized in repairing congenital heart defects and a heart center that performs a high volume of heart surgeries—a good indicator of their expertise along with their published survival rates. At Packard Children's Hospital, our heart surgeons perform **more than 700 heart surgeries each year with exceptional outcomes.**

What can my family do to better cope with CHD?

Having a child with congenital heart disease can be stressful and overwhelming, and receiving care from trusted experts can bring peace of mind. It's important to choose a multidisciplinary **heart center**, like the Moore Children's Heart Center at Stanford Children's Health, that has **deep expertise in treating CHD** and robust support services and teams, including **social workers, psychologists**, and peer mentors, to help you and your child cope with stress, identify the resources you need easily, and understand your child's condition.

What should I take into account when evaluating a heart center for my child's heart care?

Most important, look for a multidisciplinary, comprehensive heart center known for treating CHD, ideally an accredited ACHA (Adult Congenital Heart Association) **ACHD Comprehensive Care Center**, like ours at Stanford Children's Health. If heart surgery is required, find a center that does a high volume of heart surgeries and interventions, which indicates a high level of expertise in congenital heart disease. Review the provider's **heart surgery outcomes**. Our heart surgery survival rates at Packard Children's Hospital, the center of the **Stanford Children's Health** network, are 97.5% despite taking on the most complex cases. And because the Moore Children's Heart Center is located within Packard Children's Hospital, we have access to top pediatric experts with multiple specialties, should your child need care beyond heart care.

Long-term prognosis and lifelong care needs

What is the life expectancy for someone with CHD?

Advances in care have ensured that most children born with congenital heart disease will grow up, become adults, and live full lives. [According to research studies](#), children with CHD have a survival rate of greater than 97%, depending on severity and the success of surgeries and treatments. However, while congenital heart defects can be repaired through medical interventions that allow your child to live a quality life, CHD cannot be fully cured. Survival rates in adulthood vary widely, depending on the type of congenital heart disease.

Can a person with CHD have a quality of life like that of individuals with a healthy heart?

CHD is a lifelong disease that doesn't go away. However, with excellent, consistent care, children, teenagers, and adults can live an active, quality life. People with CHD may also have non-cardiac conditions, such as diabetes, so healthy lifestyle habits and medical management are highly recommended.

What limitations might a child with CHD face in his or her life?

When a child, teen, or adult receives holistic care from a comprehensive heart center, he or she will likely be able to engage in most activities that life offers. [Stanford Children's Health's Adult Congenital Heart Program](#) team includes [nutritionists](#) and [exercise experts](#) who can provide lifestyle counseling. While it's generally safe to participate in non-contact, light sports and mildly physical work, any recommendations regarding sports or employment need to be tailored to the individual, and formulated in partnership with a cardiologist who is specialized in treating individuals with CHD.

What does lifelong care for CHD consist of?

Moderate to severe CHD likely requires heart surgery and possibly follow-up heart surgery and/or catheter intervention later in life. Children and adults must be followed throughout their lifetimes to monitor for arrhythmias, residual valvular lesions or holes, and/or weakened function of the heart.

CHD care specific to adults

Will my child with CHD need special CHD care when he/she becomes an adult? Additional specialists?

As people age, it becomes even more important to receive care from **board-certified adult congenital heart disease specialists**—doctors who have received extra training in caring for teenagers and adults with CHD. Seeing children with CHD grow into adults is fairly new, and general cardiologists are not trained to treat CHD in this population group. Additionally, people with CHD may also have non-cardiac conditions such as pulmonary hypertension and/or liver disease that require consultations with other specialists, so it is most beneficial for these patients to receive expert, multidisciplinary care in a comprehensive heart center.

How do adults with CHD connect with other adult heart patients?

The **Adult Congenital Heart Association (ACHA)** connects patients and family members with trained peers in their **Heart to Heart Peer Mentors program**. They also have **online forums** where adults with CHD can connect virtually and receive support and answers. Hospital social workers help introduce adults with CHD to local resources.

Can adults with CHD conceive healthy babies?

Pre-conception counseling and follow-up care in a **multidisciplinary ACHD care center** where **heart experts** collaborate with **high-risk obstetricians** and **maternal fetal medicine specialists**, like those available at the **Johnson Center for Pregnancy and Newborn Services** at **Stanford Children's Health**, can help most women with CHD have a healthy pregnancy and delivery.

To learn more about the comprehensive, lifelong care we provide for CHD patients, visit achd.stanfordchildrens.org and achd.stanfordhealthcare.org.

