American Heart Association®

Adults With Congenital Heart Disease Guide

Navigating life with congenital heart disease can bring unique questions and challenges, especially as young adults begin taking charge of their own health. This guide was created to support that journey. It offers understandable, practical information about congenital heart defects, daily self care and the skills needed to confidently manage health decisions. It also covers important topics such as building independence, preparing for transitions, understanding family planning considerations and knowing when to seek specialized care. Our goal is to help every young adult feel informed, supported, and empowered to live a full and healthy life.

Contents

Section 1 and 2:

About Congenital Heart Disease and Common Types of Heart Defects

Understanding your congenital heart condition is an important part of taking charge of your health. You're likely already familiar with your diagnosis, but this section offers a clear, easy-to-remember overview of many different types of heart defects — including your own. Think of it as a refresher that can help you better understand what's happening in your heart, why certain follow-up care matters and how to talk confidently about your condition as you start becoming an active participant in your care. This knowledge is an empowering step toward managing your care and staying heart healthy for life.

Section 1: About Congenital Heart Disease

Congenital heart disease (CHD) develops when the heart's early formation is disrupted within the first two months of pregnancy. There are many causes for childhood heart problems, including defects from faulty embryo development, genetic causes and heart rhythm disturbances. In many cases, the exact cause can't be identified. These cardiac defects can be diagnosed before birth or early in childhood.

"Congenital" means existing at birth. While "defect" describes a structural difference, many health care professionals and researchers use "disease" to reflect the full range of experiences people may have with CHD. There are several categories of possible childhood heart problems:

- ✔ Septal defects
- ✔ Conotruncal anomalies
- ✔ Right/left outflow tract obstruction
- ✔ Anomalies of the great arteries and veins
- ✔ Single ventricle physiology
- ✔ Coronary anomalies
- ✔ Valve abnormalities
- ✔ Complex cyanotic CHD

Heart defects can range from mild to severe. Some barely affect blood flow and cause no symptoms, while others significantly interfere with how blood circulates through the body.

Depending on the type of CHD, long-term complications can include:

- ✔ Pulmonary hypertension
- ✔ Systemic hypertension
- ✔ Arrhythmias
- ✔ Infective endocarditis
- ✔ Heart failure
- ✔ Kidney and liver disease
- ✔ Valve dysfunction
- ✔ Aortic dilation
- ✔ Thromboembolism
- ✔ Pregnancy-associated risks

CHDs affect nearly 1% of births in the U.S. per year, or about 40,000. Almost all children with simple defects survive into adulthood. Most people with simple heart lesions, such as ventricular septal defects, lead typical lives and can exercise normally despite needing treatment. People with more complex heart lesions, such as single ventricle lesions, may have exercise limitations. Developmental or learning differences are more common in children with complex CHD, especially those who need heart surgery early in life.

Section 2: Common Types of Heart Defects

Congenital heart defects are structural problems arising from abnormal formation of the heart or major blood vessels. There are at least 18 distinct types of congenital heart defects, with many additional anatomic variations. Ongoing progress in diagnosis and treatment (surgery and heart catheterization) makes it possible to treat most defects, even those once thought to be hopeless.

The Outlook

If you or your child is born with a heart defect today, the chances of successful treatment and a fulfilling adult life are better than ever. As diagnosis and treatment continue to advance, treatments for other defects will be developed. You or your child's cardiologist will discuss your or your child's specific heart defect, treatment options and expected results.

The descriptions and illustrations of common heart defects that follow will help you understand the heart problem you or your child are facing. For more detailed information, use the links provided. They offer an in-depth explanation of the science and will also answer questions about treatment options, ongoing care and expected limitations or activity levels.

Congenital Defects – A Simplified Glossary

Healthy Heart Function

A normal heart has valves, arteries and chambers that carry the blood in a circulatory pattern: body → heart → lungs → heart → body. When the heart works as it should, blood goes to the lungs for oxygen and then back out to the body. If valves, chambers, arteries or veins don't develop normally, this blood flow can be disrupted. Congenital heart defects are malformations present at birth. They may or may not affect circulation.

Learn how the healthy heart works.

Aortic Valve Stenosis (AVS)

Aortic valve stenosis is a problem with the valve that carries blood from the heart to the body. The valve does not open fully and may also leak blood. When the blood flow out from the heart is blocked by a stiff valve, pressure builds up inside the heart and causes damage.

More information about aortic valve stenosis.

Atrial Septal Defect (ASD)

An atrial septal defect is a hole in the wall that separates the upper chambers of the heart. This opening allows oxygen-rich blood from the left atrium to flow into the right atrium, where oxygen-poor blood is normally found. As a result, extra blood flows to the right side of the heart and to the lungs.

More information about atrial septal defect.

Coarctation of the Aorta (CoA)

Coarctation of the aorta is a narrowing of the major artery (the aorta) that carries blood to the body. This narrowing reduces blood flow to different parts of the body and can make the heart work harder. CoA can cause high blood pressure or heart damage.

More information about coarctation of the aorta (CoA).

Complete Atrioventricular Canal Defect (CAVC)

A CAVC defect is a large opening in the center of the heart that affects all four chambers. Because the walls and valves that normally separate the upper and lower chambers are not fully formed, oxygen-rich and oxygen-poor blood can mix. This makes the heart work harder and prevents blood from being routed properly to the lungs and the rest of the body.

More information about complete atrioventricular canal defect (CAVC).

d-Transposition of the Great Arteries

In d-transposition of the great arteries, the two major arteries are connected to the wrong heart chambers. The aorta, which should carry oxygen-rich blood to the body, instead arises from the right ventricle. The pulmonary artery, which should carry oxygen-poor blood to the lungs, arises from the left ventricle. Because of this reversal, the blood flows in two separate loops instead of one continuous cycle:

- Body → heart → body (without going to the lungs for oxygen) or
- Lungs→ heart → lungs (without delivering oxygen to the body)

To survive, a baby needs at least one natural "mixing" site — such as an atrial septal defect, a ventricular septal defect or a patent ductus arteriosus — so some oxygen-rich blood can reach the body. Doctors may create or enlarge a connection between the upper chambers of the heart using a balloon atrial septostomy to improve mixing.

Corrective surgery is usually required soon after birth to restore normal circulation.

More information about
d-transposition of the great arteries.

Ebstein's Anomaly

Ebstein's anomaly is a rare heart defect in which the tricuspid valve — the valve between the right atrium (upper chamber) and right ventricle (lower chamber) — is abnormally formed and positioned. Because the valve doesn't close properly, blood can leak backward from the right ventricle to the right atrium. Many people with Ebstein's anomaly also have an atrial septal defect (ASD), which allows blood to flow between the two upper chambers (atria) of the heart.

More information about Ebstein's anomaly.

l-Transposition of the Great Arteries

In l-transposition of the great arteries, the heart's lower chambers (the ventricles) and the two main arteries are switched. The right and left ventricles are reversed in position, and the aorta and pulmonary artery arise from the "wrong" ventricles.

Because both the ventricles and the arteries are switched, the blood still follows through a normal pathway:

- Oxygen-poor blood eventually reaches the lungs, and
- Oxygen-rich blood is still sent out to the body

This is why l-TGA is often called a "double reversal" and is usually less immediately dangerous than d-TGA.

However, the ventricle that is normally designed to pump blood to the lungs must instead pump to the body over many years, which can lead to heart-function problems or valve issues later in life.

More information about
l-transposition of the great arteries.

Patent Ductus Arteriosis (PDA)

Patent ductus arteriosus is a congenital heart condition in which a temporary blood vessel (the ductus arteriosus) that normally closes shortly after birth remains open.

Before a baby is born, the fetus's blood does not need to go to the lungs to get oxygenated. The ductus arteriosis is a hole that allows the blood to skip the circulation to the lungs. However, when the baby is born, the blood must receive oxygen in the lungs and this hole is supposed to close. If the ductus arteriosis is still open (or patent) the blood may skip this necessary step of circulation.

More information about
patent ductus arteriosis (PDA).

Pulmonary Valve Stenosis

Pulmonary valve stenosis occurs when the pulmonary valve is thickened or fused, preventing it from opening fully. This makes it harder for blood to flow from the right ventricle (lower chamber) into the pulmonary artery and on to the lungs. The heart must work harder to push blood through the narrowed valve.

More information about
pulmonary valve stenosis.

Single Ventricle Defects

Single ventricle defects are rare heart lesions in which one of the heart's lower chambers (ventricles) is underdeveloped or cannot function normally. The affected ventricle may be too small, poorly formed or missing a working valve. As a result, the heart cannot pump blood effectively.

Hypoplastic Left Heart Syndrome (HLHS) — In HLHS, the structures on the left side of the heart, including the left ventricle, aorta and aortic valve, are severely underdeveloped. Openings in the heart and major vessels that normally close after birth may remain open so that blood can continue to flow to the body and lungs. HLHS requires urgent treatment soon after birth.

Pulmonary Atresia/Intact Ventricular Septum — In this defect, the connection from the right ventricle to the pulmonary artery does not form. Because the pulmonary valve and the opening beneath it are completely closed, blood cannot leave the right ventricle to reach the lungs. Instead, the body depends on other temporary pathways, such as the ductus arteriosus, which normally closes after birth to deliver blood to the lungs for oxygen.

Tricuspid Atresia — Tricuspid atresia occurs when the tricuspid valve and the opening from the right atrium to the right ventricle do not form. Blood from the body cannot flow normally into the right ventricle. Instead, it passes from the right atrium to the left atrium through an atrial septal defect, then to the left ventricle and out to the body — without being oxygenated. To receive oxygen, blood must find another pathway to reach the lungs, such as a ventricular septal defect (VSD) or a patent ductus arteriosus (PDA).

More information about
single ventricle defects.

Tetralogy of Fallot

Tetralogy of Fallot is a heart defect that includes four related problems:

1. **Ventricular septal defect (VSD):** A hole between the lower chambers (ventricles) of the heart.
2. **Pulmonary stenosis:** An obstruction that makes it harder for blood to flow from the right ventricle to the lungs.
3. **Overriding aorta:** The aorta, which carries blood to the body, is positioned over the hole between the ventricles instead of over the left ventricle.
4. **Right ventricular hypertrophy:** The muscle of the right ventricle becomes thickened because it must work harder to push blood through the obstruction to the lungs.

   These four problems together reduce blood flow to the lungs and allow oxygen-poor blood to flow out to the body. This can cause cyanosis ("blue baby" appearance) if not treated.

More information about
tetralogy of Fallot.

Total Anomalous Pulmonary Venous Connection (TAPVC)

TAPVC is a heart defect in which the veins carrying oxygen-rich blood from the lungs do not connect to the left atrium as they should. Instead, these veins connect to other veins or to the right side of the heart.

Because of this abnormal connection, oxygen-rich blood mixes with oxygen-poor blood and does not flow normally from the lungs to the heart and out to the body. A hole between the upper chambers of the heart is needed so oxygenated blood can reach the body.

More information about total anomalous pulmonary venous connection (TAPVC).

Truncus Arteriosus

Truncus arteriosus is a heart defect in which one large blood vessel comes out of the heart instead of two separate vessels — one to the lungs and one to the body. Because of this, oxygen-rich and oxygen-poor blood mix together before leaving the heart. The body does not get enough oxygen-rich blood.

More information about truncus arteriosus.

Ventricular Septal Defect (VSD)

A VSD is a hole in the wall (septum) that separates the heart's two lower chambers, called the ventricles. Normally, this wall closes before birth, so oxygen-rich and oxygen-poor blood stay separate. When the opening remains, blood can flow between the ventricles, which may cause the heart to work harder, increase pressure in the heart and lungs or reduce the amount of oxygen delivered to the body.

More information about ventricular septal defect (VSD).

Section 3: Family Planning

Genetic Counseling for Congenital Heart Disease

When a child is born with a congenital heart defect, two common questions are "Why did this occur?" and "Will it happen again in our family?" These same questions come up when a person with congenital heart disease considers having children. Genetic counseling can help answer these questions and address your concerns about starting a family.

What happens in genetic counseling?

The goal of genetic counseling for adults with congenital heart disease is to determine the likelihood that their children will also have a heart defect. The chance for a heart defect to happen again in a family depends on its cause.

During your genetics evaluation, the counselor and geneticist will try to determine the cause of your heart defect by looking at your medical and family history and doing a physical exam. Genetic testing on a sample of your blood may also help determine the cause. Sometimes it's helpful to obtain blood samples for genetic testing from other members of your family, especially if they also have a heart condition.

Who should have genetic counseling?

Genetic counseling can help anyone with a heart defect who wants to understand its cause or the chances their children will have one. It is relevant for both men and women with congenital heart disease. The chance of children having a heart defect rises if either parent has one.

Genetic counseling is particularly important if other family members have heart defects, or if you or someone in your family have features that might suggest a genetic syndrome, such as multiple birth defects, developmental delays or certain inherited medical conditions.

When is the best time to have genetic counseling?

The best time to have genetic counseling is before a pregnancy. You may also learn about any special testing needed during the pregnancy. Genetic testing may help identify the cause of a defect, although in many cases no specific genetic explanation is found.

During the pregnancy

If a genetic cause is found for your heart defect, you may be able to do genetic testing during the pregnancy to see whether the baby inherited that genetic condition. In most cases, it is recommended to have a fetal echocardiogram done by a pediatric cardiologist who is an expert in imaging congenital heart disease.

American Heart Association.

Congenital Heart Disease and Family Planning

Congenital heart disease (CHD) is the most common birth defect in the United States. About 40,000 babies are born with heart disease each year. People with a family history of CHD may be more likely to pass it on if they choose to have children. Still, advancements in research and technology are providing adults with CHD with more opportunities to safely have families of their own.

Both male and female adults with congenital heart disease (ACHD) should talk with their ACHD cardiologist to understand the best and safest options when planning a family. These include:

- **Birth control options**
- **Genetic testing**
- **How pregnancy could affect their heart health**
- **Safe birthing options**

Adults with CHD may benefit from seeing a multidisciplinary team of several medical specialists who work together on treatment decisions. OB-GYNs and maternal-fetal medicine specialists should work with ACHD cardiologists and specialists for ACHD patients.

Pregnancy and congenital heart disease

With proper risk assessment and monitoring, most pregnant ACHD patients can give birth vaginally.

Doctors can detect CHD in babies in utero with a screening known as early fetal echocardiography. This is done around 11-12 weeks gestation. Standard heart screenings are done around 18-20 weeks gestation. This allows AHCD pregnant patients and their care team to plan for how to treat their baby's heart once the child is born.

Support for mental health

Mental health support is an important part of overall care. CHD survivors are more likely to have mental health challenges. Health care professionals should regularly check for signs of depression, anxiety and PTSD before, during and after pregnancy and refer patients to treatment when needed.

Heart.org/CHD

Scan to
Read More

A Survivor's Story - Victoria Rodriguez

Victoria Rodriguez was 6 years old when she found out she had been born with heart disease. She had open-heart surgery to correct a hole in the upper chamber of her heart and a pulmonary vein that backed up blood into her lungs instead of sending it to the left side of her heart. As an adult, Victoria gave birth naturally to two daughters. Her second child was born with a small hole in her heart. Doctors expect it will close on its own.

Section 4: Transitioning to Adulthood

Helping Teens with CHD Transition to Adulthood

The transition from pediatric to adult CHD care is a critical period, typically beginning with planning between ages 12 and 16 and transferring to adult providers between ages 18 and 21. Preparing for this shift helps ensure better health outcomes by building your confidence in understanding your specific heart condition, navigating the health care system, managing medications and handling insurance needs. Mental health support is also an essential part of this process, as CHD survivors are more likely to have mental health challenges. Regular screening and timely referrals can help you receive the care you need to support both your physical and emotional well-being throughout adulthood.

American Heart Association.

Helping Teens with Congenital Heart Disease Transition to Adulthood

In the U.S., about 1 million children are living with congenital heart disease. Many will require specialized follow-up as they grow, especially during the shift from teenage years to adulthood.

Lifelong specialized care results in better outcomes
It's important to help teens with CHD transition from pediatric cardiovascular care to adult CHD treatment centers. Planning this transition usually begins around ages 12-16. The transfer of care is often done between ages 18 and 21. To help shift to a new health care team, it's helpful for young adults with CHD to:

- **Understand their specific heart condition**. This includes knowing the kind of heart defect(s) they have, which surgeries they have had and how their heart is working, and any medications they are on, including how much, how often and why they are taken.
- **Understand how to navigate the health care system.** The American Heart Association can help guide adults with CHD. Contact us at 1-800-AHA-USA-1 or 1-800-242-8721 to get started. Patients can also find information on how to make appointments and communicate with their care team online.
- **Know how to refill prescriptions.** Adults with CHD should know which medications they take and how often they need refills. They should find a pharmacy nearby that can refill their prescriptions. Some online pharmacies can fill multiple months of their supply.
- **Know how health insurance works.** This includes knowing the cost of preventive care to help avoid serious illness that could affect their heart, regular care for ongoing heart conditions and treatment for new health issues, such as chronic disease or injury.

Support for mental health
Mental health support is an important part of overall care. CHD survivors are more likely to have mental health challenges and teenagers can have unique stressors. Health care professionals should regularly check for signs of depression, anxiety, PTSD and thinking or memory problems and refer patients to treatments when needed.

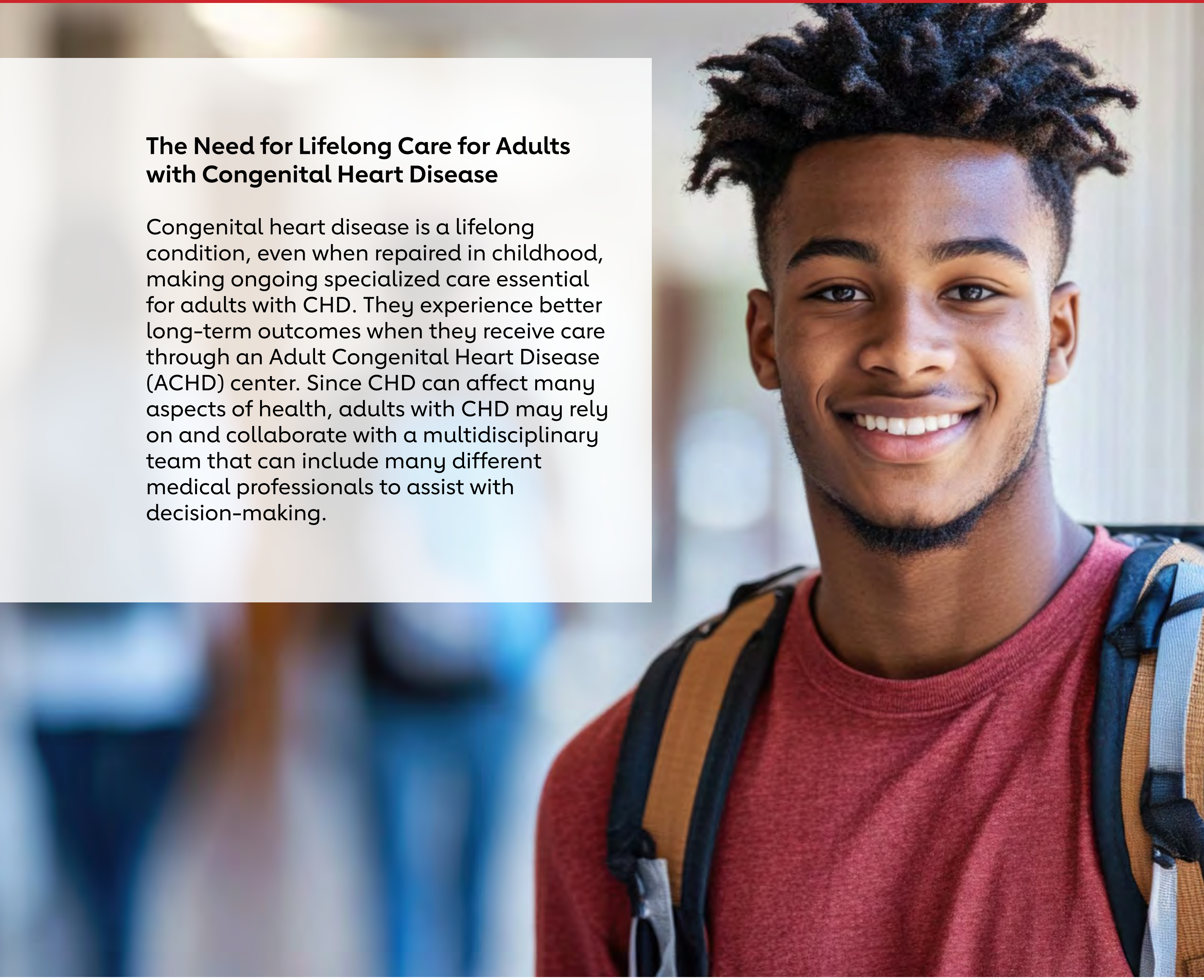
Heart.org/CHD

A Survivor's Story – Hunter Appleton

Hunter Appleton was 18 months old when he was diagnosed with coarctation of the aorta, a congenital heart defect that restricts blood flow. He had a heart catheterization procedure, and as he grew older, he had open-heart surgery and physical therapy. Today, Hunter is a student at Mississippi State University where he is studying to become a pediatric cardiothoracic surgeon.

Scan to Read More

Section 4: Transitioning to Adulthood



The Need for Lifelong Care for Adults with Congenital Heart Disease

Congenital heart disease is a lifelong condition, even when repaired in childhood, making ongoing specialized care essential for adults with CHD. They experience better long-term outcomes when they receive care through an Adult Congenital Heart Disease (ACHD) center. Since CHD can affect many aspects of health, adults with CHD may rely on and collaborate with a multidisciplinary team that can include many different medical professionals to assist with decision-making.

The Need for Lifelong Care for Adults with Congenital Heart Disease

Congenital heart disease (CHD) lasts a lifetime, even if the heart was repaired in childhood. Adults with congenital heart disease (ACHD) have better health outcomes when they receive care at an **ACHD center**. If accessing an ACHD center is difficult, patients should talk with their cardiologist to help get this type of health care.

Working with a multidisciplinary care team

Adults with CHD may need to work with a multidisciplinary team of medical specialists to help with complex decision-making. This team may include:

- **Adult congenital cardiologists** care for adults with CHD and assume care when patients shift from pediatric to adult cardiology services.
- **Congenital cardiac surgeons** repair heart defects and abnormalities of the major blood vessels connected to the heart in people with CHD.
- **Electrophysiologists** diagnose and treat irregular heart rhythms (arrhythmias).
- **Interventional cardiologist**s treat heart problems using catheters and minimally invasive procedures to avoid open-heart surgery.
- **OB-GYNs and maternal-fetal medicine specialists** help with pregnancy care and reproductive health for women.
- **Genetic counselors** help people understand how certain health conditions can be passed down to their children.
- **Heart failure and transplant cardiologists** treat patients with heart failure and help those who may need a heart transplant.
- **Pulmonologists** treat lung and respiratory conditions, which can impact heart health.
- **Hepatologists** diagnose and manage diseases of the liver, which may complicate heart disease.
- Other clinical care team members can include **advanced practice providers**, **nurses** and **social workers**.

Support during noncardiac surgeries and procedures

Adults with CHD should check with their ACHD cardiologist before any type of procedure or surgery. Their cardiologist can help identify risks and offer guidance on procedures, anesthesia and postprocedural management to help inform the best care plan.

Support for mental health

Mental health support is an important part of overall care. CHD survivors are more likely to have mental health challenges. Health care professionals should regularly check for signs of depression, anxiety and PTSD and refer patients to treatment when needed.

Heart.org/CHD

Scan to Read More

A Survivor's Story – Chris Kidwell

In 1986, at 6 days old, Chris Kidwell had surgery to switch his aorta and his pulmonary artery into the correct positions. With lifelong specialized care, he is now a father in his 30s and an avid jiu-jitsu practitioner and teacher, a passion he shares with his son Carter, who was also born with heart disease.

Section 5: Mental Health in Adults with CHD

Supporting Good Mental Health in Adults With CHD

Adults with congenital heart disease (CHD) experience high rates of mental health conditions — such as depression, anxiety, and PTSD — affecting up to half of this population. These challenges can make daily life harder, increase health risks and worsen overall outcomes. Regular screening and timely referrals to mental health care, including individual or group therapy, can greatly improve well-being and support heart health. Many adults with CHD may also have memory, attention or thinking difficulties linked to lifelong CHD or early surgeries, with more than one-third of adults over 40 showing signs of weakness or cognitive decline.

Supporting Good Mental Health in Adults with Congenital Heart Disease

Up to half of adults living with congenital heart disease (CHD) experience mental health conditions, such as depression, anxiety and post-traumatic stress disorder (PTSD). By comparison, these conditions affect about 30% of adults in the general population. Depression in adults with CHD may be associated with:

- **Being unable to complete daily tasks**
- **An increased risk for heart failure**
- **More poor health outcomes that can lead to a greater need for health care services**
- **A higher risk for PTSD due to uncertainty about their illness and outcomes**

Referring ACHD patients for mental health support

Adults with CHD should be regularly checked for and mental health conditions by a healthcare professional and referred to treatment when needed. Adults with CHD can have fewer symptoms of distress and depression when they receive timely, targeted mental health support, including group or one-on-one therapy. Identifying high-risk ACHD patients and referring them to treatment may help their psychological symptoms, quality of life and heart health.

Neurocognitive differences in adults with congenital heart disease

There is limited evidence on thinking, memory and attention problems in patients with CHD. Yet it is likely that the impact of CHD and surgery in childhood continues to affect these functions in adulthood. More than 33% of adults with CHD ages 40 and older have pre-frailty, frailty or cognitive decline.

Adults with CHD may want to ask for neuropsychological testing. These results can guide therapies to help with academic, behavioral, psychosocial and adaptive functioning. Diagnosis, treatment and rehabilitation may help improve cognitive function and quality of life for adults with CHD.

Heart.org/CHD

Scan to
Read More

A Survivor's Story – Dianne Ruiz

Dianne Ruiz was born with pulmonary stenosis and suffered from panic attacks as a young adult. She learned to practice self-care, including listening to podcasts while taking long walks to support her mental health. Today, Dianne promotes the benefits of a healthy lifestyle in her community.

Section 5: Mental Health in Adults With CHD

People With Congenital Heart Disease Face Challenges That Evolve Over Time

People living with congenital heart disease (CHD) often face challenges beyond their medical needs, including higher rates of psychological and social difficulties. Anxiety and mood disorders are more common among people with CHD, yet mental health support is not always fully integrated into their care. Access to specialized CHD services can also be limited by social drivers of health, especially for those in rural or under-resourced communities. As children with CHD grow, many may struggle to stay connected to regular care during the transition to adulthood, which can lead to worsening health and preventable complications. Addressing mental health needs, reducing access barriers and improving support during transitions are essential to ensuring long-term health and quality of life for people with CHD.

People with **congenital heart defects** face challenges that evolve over time.

Recognizing special needs beyond medical care is important for children and adults living with congenital heart defects (CHD), according to the American Heart Association.

Psychological Care

People born with heart defects may experience psychological and social challenges from infancy through adulthood.

- Children with more complex CHDs are five times more likely to get an anxiety diagnosis in their lifetime compared to children without CHD.
- For adults with CHD, the rate of experiencing a mood or anxiety disorder is about 50%, compared to about 30% for adults in the general population.
- The AHA advocates for mental health assessments and support to be part of comprehensive care for all people with CHD, not just in some circumstances.

Social Determinants of Health

Disparities driven by social determinants of health limit access to the lifelong specialty care needed by people living with CHDs.

- Specialty care services are concentrated in urban areas, making access difficult for survivors in rural or smaller communities and those without transportation or flexible work schedules.
- Certain communities may have limited programs for home monitoring and visitation as well as nutrition, growth and cognitive development (such as school-based outreach).
- Fewer than 500 board-certified specialists in adult congenital heart disease support the growing number of adults with CHD in the U.S., and they are primarily located in urban areas.

Transitioning to Adulthood

Children with CHDs need special attention to successfully transition to adult-oriented health care.

- Young people living with CHDs may not seek care as they become adults until they are facing a health crisis.
- Extended time without routine care can have a significant impact on long-term health and quality of life.
- A better understanding of transition needs and barriers is needed to minimize worsening health disparities for people with low socioeconomic status and those from historically underresourced communities.

The Children's Heart Foundation and the American Heart Association are proud to join forces to raise awareness and advance lifesaving research for congenital heart defects.

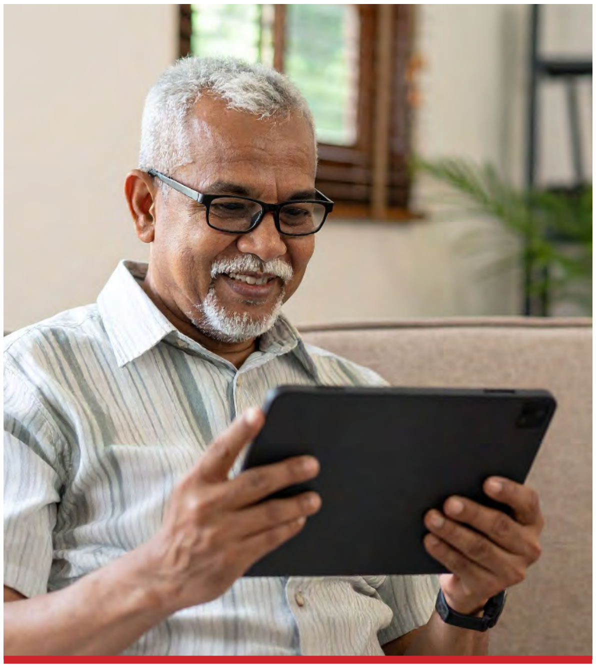
Sources:

- As people born with congenital heart defects now live longer, challenges evolve over time (https://bit.ly/3EcFhmt)
- Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association (https://www.ahajournals.org/doi/10.1161/JAHA.122.025278)
- Addressing Social Determinants of Health and Mitigating Health Disparities Across the Lifespan in Congenital Heart Disease: A Scientific Statement From the American Heart Association https://www.ahajournals.org/doi/10.1161/JAHA.122.025358)
- Advances in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: A Practical Approach to Transition Program Design: A Scientific Statement From the American Heart Association (https://www.ahajournals.org/doi/10.1161/JAHA.122.025278)

heart.org/chd

American Heart Association®
Support Network

THE SUPPORT NETWORK



Support Network: Be a part of a free, online community of heart and stroke patients, survivors and caregivers who come together to connect, share, and listen. Every story matters and wherever you are in your journey, the Support Network is here for you.

heart.org/SupportNetwork

TOPIC FORUMS

Members can participate in discussion boards surrounding heart and stroke topics where they can connect around specific health conditions or interests, ask questions, and share experiences in a supportive environment.

ONLINE SUPPORT GROUPS

Members can join online groups that provide emotional support and peer-to-peer connection, helping individuals feel less isolated while navigating health challenges. Many of the groups facilitate monthly virtual meetings via Zoom.

FIRST-PERSON BLOGS

Members share their personal stories to provide an honest look into their experiences, offering both encouragement and practical guidance. They may describe early warning signs, what occurred during a medical event, what it was like to navigate a doctor's visit or hospital stay, and how they felt at the time as well as how they're feeling now.

RESOURCES

Members can view and download curated materials, tools, and guides designed to inform and empower them with reliable information to manage their health and well-being.

Section 6: Congenital Heart Disease and Physical Activity

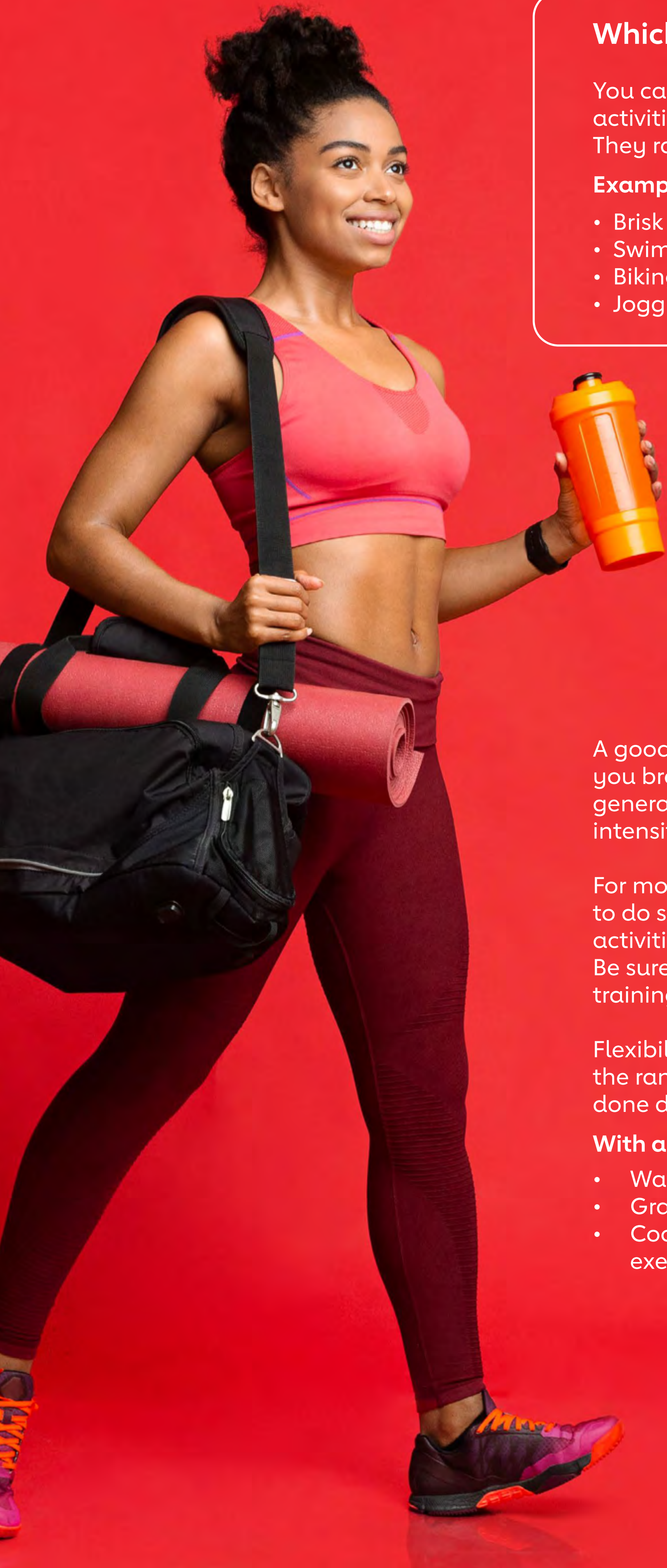
Physical activity has many benefits and should be a regular part of life for nearly everyone. This includes most people with congenital heart disease. Research has shown that routine, moderate exercise is safe and can be beneficial for people with CHD and complex CHD.

Check with a health care professional experienced in CHD before beginning an exercise routine about how to get started safely. Some people with CHD need more cautious or personalized exercise recommendations. Your health care team can guide you to the safest activities for your health. They may advise an exercise test to help determine your safe exercise limits and the types and levels of activities that are right for you.

Most children with relatively simple congenital heart defects who have had successful catheter-based or surgical repair can do many, and in some cases all, types of physical activities. Other children may have heart conditions that require some activity restrictions. People with pacemakers or implantable cardioverter defibrillators may need to avoid activities that increase the risk of direct impact to the device or leads.

People who are taking anticoagulants (medications that reduce blood clotting) should also use caution. They should check with their cardiologist about physical activity and sports participation, especially with contact or high-impact sports.

Adults with CHD can participate in competitive sports, after a full evaluation by their care team, shared decision-making and assessment of the risks and benefits.



Which exercises are OK?

You can support your heart health with aerobic activities, also called endurance or cardio activities. They raise your heart rate and breathing.

Examples include:

- Brisk walking
- Swimming
- Biking
- Jogging
- Cross-country skiing
- Hiking
- Dancing

A good rule to follow is to increase your activity so you breathe hard and fast but can still talk. This is generally moderate-level exercise. With vigorous intensity, you usually are working too hard to talk.

For more health benefits, adults who are cleared to do so should also do muscle-strengthening activities that involve all major muscle groups. Be sure to discuss your best options for strength training with your health care professional.

Flexibility exercises are recommended to improve the range of motion in your joints. These can be done during your warm-up and cool-down.

With any exercise, be sure to:

- Warm up first
- Gradually increase activity
- Cool down as you approach the end of the exercise period

Section 7: Heart Health Recommendations for Those With CHD

When you have congenital heart disease, it's vital for you to follow healthy-heart recommendations for diet and activity. No matter what type of heart disease you have, better overall physical fitness will help you do your normal daily activities more easily. Also, you face a higher risk than other people in your age group when it comes to developing other cardiovascular conditions, such as coronary artery disease or high blood pressure.

Follow these guidelines to keep your heart healthy:

- ✔ Eat a healthy diet.
- ✔ Maintain a reasonable body weight.
- ✔ Stay physically active according to the specific recommendations of your cardiologist, as exercise requirements (or limitations) vary depending on the type and severity of your heart condition.
- ✔ Check your cholesterol level regularly, especially if your family has a history of heart disease.
- ✔ Avoid smoking, recreational drug use (especially intravenous drugs), and other substances that can significantly increase cardiovascular risk and complications.
- ✔ Get regular medical care from your primary care physician. Even though you have a cardiologist, you still need a primary care physician to oversee all your medical care.
- ✔ Take care of your dental health. Regular dental care helps reduce the risk of infective endocarditis, a serious infection of the heart lining or valves.

Following the recommendations of your cardiologist is important for keeping your heart healthy. These recommendations include:

- ✔ Keep your follow-up appointments with your cardiologist.
- ✔ Take your medications as prescribed.
- ✔ Make sure you have the necessary tests done when your doctor orders them.
- ✔ Follow any physical activity recommendations and restrictions.
- ✔ Talk with your cardiologist if you think that a treatment or follow-up is making your feel worse or is unnecessary. Don’t make any changes to your plan without consulting your doctor.
- ✔ Check on possible side effects of over-the-counter medications, vitamins, herbal preparations or prescription medications before taking them. Discuss any potential cardiac side effects or drug interactions with your primary care professional, cardiologist or pharmacist.
- ✔ Discuss your heart disease with your health care team before having a surgical procedure. Sometimes the surgery or anesthesia can affect your heart.
- ✔ Learn as much about your heart disease as you can. This includes knowing the kind of heart defect you have, which surgeries were done and how your heart is working. Always carry a list of your medications, including how much, how often and why you take them. Don’t rely on your parents, children, family members, primary care provider or anyone else to do this for you!