

Guide to Your Child's Future Care

Congenital Heart Disease (CHD) is lifelong, and patients born with CHD need lifelong care based on the recommended guidelines. However, nearly 50% of patients stop getting care after age 13, and more than 60% after age 18. It is important to know what care your child needs now and what care they will need in the future, even if they are feeling well. These 10 steps will help you understand your child's needs as they age, so that you can help get them ready to take control of their care as they become adults.

1. CHD is Lifelong and Requires Lifelong Care

Remember, your child needs to remain in care, even if they are feeling well. If you are unsure how often your child needs to see their cardiologist or other specialists, contact their care team. Make sure your child understands how often they need to be seen. Teach your child how to schedule their own appointments. Help them make a plan on how to get to those appointments when away at school or as they become young adults.

Each adult with CHD should be seen at least once by an ACHD Cardiologist who will recommend how often your child should follow up based on the specific details of their CHD. Encourage your child to keep appointments. Regular visits help your child's care team maintain your child's health, track any changes, and be proactive should changes occur.

2. Maintain Records

Keep copies of your child's records, including their CHD diagnosis and any co-existing diagnoses, as well as a list of procedures including location, date, and outcomes. It is a good idea to request your child's records from their cardiologist or primary hospital yearly. If you need those records, contact the hospital where your child received care. Often, hospitals allow you to request records online. Ask your team if you need assistance. Make sure your child knows how to access their records as they become more independent. Talk to your child about how important it is to keep track of their health and know where they can find records of their previous care.

3. Understand Your Child's CHD, Ask Questions

Make sure your child understands their CHD as they grow. Can your child name their CHD or describe it to others? If not, have them ask their cardiologist to help with this. Encourage your child to participate in their doctor visits. Empower them to ask questions. You can use our Guided Questions Tool as a starting point.

4. Know Your Child's Medications

Maintain a list of all medications your child currently takes, including the dosage. It is also helpful to keep a list of medications they took in the past and why they were stopped. Make sure you and your child understand why they are taking their current medications and know what they look like. If you have questions, ask your child's care team or pharmacist before they take any medications. Ask if there are any medications your child should avoid. If you think your child needs to stop taking any medication for any reason, discuss it with their care team first.

5. Follow Precautions

Make sure your child knows to follow the precautions recommended by their care team. Does your child need to take antibiotics prior to dental visits, piercings, or tattoos? Do they have a pacemaker, if so, how often does it need to be checked, and did it come with a wallet card? Your child should understand what level of exercise or activity is recommended for their specific CHD, as well as any possible restrictions.

6. Mental Health is Important for You and for Your Child

Ask your center about their mental health services. Both patients and parents need to address the stress caused by CHD. ACHD patients are at a higher risk for mood disorders and anxiety than the general population. It is important your child talks about their feelings and knows there is someone to speak to for help with any concerns. Your child's heart center may also be able to connect you with other resources to address the needs you or your child may have.

7. Know How Your Child's CHD May Impact Their Future

Your child's CHD may affect what kind of job is right for them. By talking with your child and their care team, you both can learn the pros and cons of certain education or job paths. It is also important that your child, as they become teens and young adults, know the risk of sexual activity, pregnancy, and birth control options. Consider discussing this with your child and their care team, too.

8. Maintain Health Insurance

Often, in order for your child to have access to the care they need, they need to have insurance. There are many options for coverage, and it can be a hard topic to understand. Up to a certain age, your child may be able to get coverage through your insurance. Your child's hospital may also have someone dedicated to helping patients and families understand insurance options.

9. Know How to Find a Doctor or Specialist that is Right for Your Child

While your child may still be a long way from grown up, it is important to prepare yourself as well as your child for the future, as it arrives quicker than we expect! Since Congenital Heart Disease is lifelong, it is important that your child has access to a doctor and program that meet their needs for lifelong follow up, based on the recommended guidelines for

patients with ACHD. Your child's current heart center may fit this description.

Ask your child's care team if they offer ACHD services, and ask them to explain them to you. If your center does not offer the appropriate services, you can get help finding one that does on our website - conqueringchd.org.

10. Know When to Seek Help

As caregivers, you may have already talked with your child's care team about visible symptoms that require medical attention. As your child grows, they should be able to tell you or other adults when they are feeling symptoms as well. Talk with your child and their care team about the symptoms that need attention before the next scheduled appointment. Ask your child's care team what the best way is to reach them at any time of day – by phone, text, email, or something else. Ask them how to know when to go to the emergency room and what to do when you get there.

According to the 2018 ACC/AHA Guidelines, adults with congenital heart disease should be seen in an ACHD Program based on their specific CHD. See a brief summary of the guidelines below.

Category	Adult Congenital Heart Disease (ACHD) care needed
Simple Defects Small unrepaired ASD/VSD Mild pulmonic stenosis Repaired PDA – No associated problems Repaired ASD/VSD – No associated problems	Single visit to ACHD center to confirm stable status, or more frequently based on the individual
Moderately Complex Unrepaired Moderate or Large ASD/PDA Repaired ASD/VSD/PDA – Associated problems Repaired or unrepaired: AVSD Coarctation of the Aorta Tetralogy of Fallot Moderate to severe congenital valve disease -all forms Anomalous arterial/venous connections – all forms Congenital fistulas – all forms	ACHD follow-up visit every 3 years, or more frequently based on the individual All cardiac procedures done at ACHD center <ul style="list-style-type: none"> • Surgery • Catheterization • Ablation ACHD check before pregnancy to assess <ul style="list-style-type: none"> • Functional status • Genetic risk ACHD consultation <ul style="list-style-type: none"> • During pregnancy • Before anesthesia • Before surgical procedures • For on-going cardiac management
Highly Complex Double-outlet Ventricle Single Ventricle – all forms Atresia – all forms Fontan – all forms Transposition disorders– all forms Interrupted aortic arch Truncus Arteriosus Other abnormalities of ventricular/arterial connection All forms CHD with associated Cyanosis Hypoxia Pulmonary Hypertension Eisenmenger Syndrome Uncontrolled arrhythmia Heart failure CHD-related liver or kidney dysfunction	ACHD follow-up visit once a year, or more frequently based on the individual All cardiac procedures done at ACHD center <ul style="list-style-type: none"> • Surgery • Catheterization • Ablation • Cardiac imaging ACHD-specific birth control counselling available ACHD check before pregnancy to assess <ul style="list-style-type: none"> • Functional status • Genetic risk ACHD co-management of <ul style="list-style-type: none"> • Pregnancy and delivery • All surgical procedures • All anesthesia • All routine cardiac care