Guide to Your ACHD 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 you need now and what care you will need in the future, even if you are feeling well. These 10 steps will help you understand your needs and help you take control of your own care. This guide can also be used by caregivers of ACHD patients, who may still need assistance.

1. CHD is Lifelong and Requires Lifelong Care

Remember, that you need to remain in care, even if you are feeling well. If you are unsure how often you need to see your cardiologist or other specialists, contact your care team. Do you know how to schedule and get to your appointments on your own, or do you have a plan to get help?

Each adult with CHD should be seen at least once by an ACHD Cardiologist, who will recommend how often you should follow up based on the specific details of your CHD. Don't skip appointments. Regular visits help you and your care team maintain your health, track any changes, and be proactive should changes occur.

2. Maintain Records

Keep copies of your records including a full CHD diagnosis and any co-existing diagnoses, as well as a list of procedures and surgeries including location, date, outcomes, or complications. It is also a good idea to request your records from your cardiologist or primary hospital each year. If you do not have your childhood records, contact the Health Information Management department at the hospital where you received your care. Often, hospitals allow you to request records online, such as through the MyChart system. You can request digital copies such as secure emails or DVDs, as well as paper copies. Ask your team if you need assistance. It is helpful to keep all your records in one handy place, either in a MyChart account or on a USB drive, so you can access them when needed.

3. Understand Your CHD, Ask Questions

Make sure you understand your own CHD, independently of your parents. Can you name your CHD or describe it to others? If not, talk to your cardiologist, and they will help you. Participate in your doctor visits, and don't be afraid to ask questions. You can use our Guided Questions Tool as a starting point.

4. Know Your Medications

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

5. Follow Precautions

Make sure you are following the precautions recommended by your care team. Do you need to take antibiotics prior to dental visits, piercings, or tattoos? Do you have a pacemaker? If so, how often does it need to be checked and did it come with a wallet card? Understand what level of exercise or activity is recommended for your specific CHD, as well as any possible restrictions.

6. Mental Health is Important

Ask your center about their mental health services. ACHD patients are at a higher risk for mood disorders and anxiety than the general population. It is important to know that there is someone for you to speak to for help with any mental health concerns you may be experiencing. Your heart center may also be able to connect you with other resources to address other needs you may have.

7. Know How CHD May Impact Your Future

Know how your CHD may affect the kind of job that is right for you. Talk to your care team about the pros and cons of education or job paths that interest you. Also, ask your care team about whether or not it is possible and/or safe for you to get pregnant, have children, and what birth control options are safe for you.

8. Maintain Your Health Insurance

Often, in order for you to have access to the care you need, you need to have insurance. There are many options for coverage, and it can be a hard topic to understand. Talk to your parents or employer about the availability of insurance plans. Your care team may also have someone dedicated to helping patients and families understand insurance options. You can find more information on insurance and work related issues on our website.

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

Congenital Heart Disease is lifelong, so it is important that you have a doctor and program that meet your needs for lifelong follow-up based on the recommended guidelines for patients with ACHD (find a brief summary below).

Your current heart center may fit this description. Ask your 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 in the directory on our website - ***conqueringchd.org***

10. Know When to Seek Help

Talk with your care team about the symptoms that need attention before your next scheduled appointment.
Ask your care team about the best way to reach them at any time of day– by phone, text, email, or something else. Talk to your team about how to know when to go to the emergency room and what to do should you have to go 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 • Surgery • Catheterization • Ablation ACHD check before pregnancy to assess • Functional status • Genetic risk ACHD consultation • 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 • Surgery • Catheterization • Ablation • Cardiac imaging ACHD-specific birth control counselling available ACHD check before pregnancy to assess • Functional status • Genetic risk ACHD co-management of • Pregnancy and delivery • All surgical procedures • All anesthesia • All routine cardiac care