

Adult Congenital Heart Disease

Managing Your Condition Can Protect Your Life and Lifestyle

If you were born with congenital heart disease – even if you had surgery as a child and feel fine today – the chances are very good that you need lifelong monitoring by a doctor who specializes in adult congenital heart disease (ACHD). Ongoing care throughout adulthood can help maintain your lifestyle and even save your life.

There are many different types of congenital heart disease, and all but a few can cause serious long-term problems (or worse) if not evaluated in adulthood and monitored and treated as needed. Not managing your condition as an adult creates a gap in care that can lead to arrhythmia, valve abnormalities, endocarditis, heart failure, stroke, and even sudden death.

Unfortunately, more than 60% of those with congenital heart disease do not receive the care they need in their adult years. The good news is that congenital heart disease is highly treatable in both children and adults, and most with ACHD are able to lead active and productive lives, getting married and having children of their own. Thanks to significant medical advances, surviving into adulthood is now the norm rather than the exception, and today more than 95% of the people treated for congenital heart disease live well beyond the age of 18.

A few of the most common types of congenital heart disease include:

- Ventricular and atrial septal defects
- Coarctation of the aorta
- Tetralogy of Fallot
- Truncus arteriosus
- Bicuspid aortic valve
- Atrioventricular canal defect
- Transposition of the great arteries
- Single ventricle defects

The American Heart Association and the American College of Cardiology recommend that people with ACHD receive regular follow-up care from a physician specializing in your condition. ACHD specialists have unique experience and knowledge that most doctors do not have. UAB Medicine is the only health care facility in Alabama with the full range of expertise necessary to manage and treat ACHD.

Just in the last decade, the number of adults living with congenital heart disease began exceeding the number of children living with congenital heart disease, as treatments have improved. More than 1.3 million Americans have ACHD, and that number grows by 20,000 each year. In Alabama alone, an estimated 9,000 people are living with ACHD.

Depending on their specific condition and its severity, babies born with congenital heart disease may undergo surgery or other treatment within the first few years of their lives, while others may not need treatment until years later, if at all. Some assume that the surgery they had as a child fixed their problem forever, though additional procedures, surgeries, or medications may be needed in adulthood.

Those who avoid follow-up care do so for a variety of reasons, such as losing the health insurance coverage they had under their parents' policy, financial troubles, or distance from the nearest qualified medical center. By not seeking care for ACHD, you potentially threaten your health and run the risk of a small, manageable problem becoming a much more serious condition.

Modern treatments are very effective, so ACHD specialists are able to focus on helping you more safely enjoy the positive aspects of your life, such as recreation, exercise, and reproduction.

Don't put it off any longer; call UAB HealthFinder at 1-800-822-8816 to make an appointment to see an ACHD specialist.