

# Adult Congenital Heart Fact Sheet

## What is a congenital heart defect?

- A congenital heart defect is a problem with the heart's structure that is present at birth.
- Common problems include holes in the heart and misplaced, malformed, and/or missing valves, vessels, and heart chambers. Heart defects often involve a combination of problems.

## How common are congenital heart defects?

- Heart defects are the most common birth defect. About one in 120 babies are born with some kind of heart defect.
- Heart defects are about three times more common than muscular dystrophy and childhood cancer and about 40 times more common than cystic fibrosis.
- There are about one million adults and 800,000 children living with congenital heart defects in the United States. Thanks to increases in survival, the number of adults rises by 5% a year.
- At least 10% of all congenital heart defects are first found in adulthood.

## What is the long-term outcome for adults with heart defects?

- Due to medical breakthroughs, over 90% of children born with heart defects are now expected to live to adulthood and beyond.

- All those born with heart defects have an increased risk of developing additional heart problems.
- The 50% of heart defect patients born with more complex problems face a high risk of developing new heart problems as they age.
- Common long-term problems include rhythm problems, valve problems, heart failure, heart infection, and stroke.
- Many adults with heart defects require additional heart surgeries.
- All adults born with more complex defects should be seen regularly by congenital heart defect specialists.
- Most adults with heart defects have few or no on-going physical limitations or symptoms.
- The United States has a severe shortage of cardiac centers fully equipped to care for adults living with more complex heart defects.
- With appropriate medical care, adults with all kinds of heart defects can now live longer, fuller lives than ever before.

For more information, visit [www.achaheart.org](http://www.achaheart.org).

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