



Adult Congenital Heart Fact Sheet

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What is a congenital heart defect?

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

What are common issues associated with heart defects?

- Individuals with CHDs often need additional operation(s) and/or medications as adults. This is true even when they have had a successful repair.
- Common long-term problems of CHDs include developmental delays, difficulty with exercise, heart rhythm problems, heart failure, sudden cardiac arrest, stroke and premature cardiovascular death.
- Many adults with CHDs in the United States report having problems getting insurance and coverage for specialized care.
- Compared to the general population, adults with CHDs have 3-4 times higher rates of emergency room visits, hospitalizations, and intensive care unit stays.
- People with CHDs are now living long enough to develop new problems such as high blood pressure, obesity and acquired heart disease like the rest of the adult population.

How common are congenital heart defects?

- Heart defects are the most common birth defects. Almost one in 100 babies are born with some kind of heart defect.
- There are between 2-3 million adults and children living in the United States with CHDs. It is difficult to give more exact estimates because there is no U.S. system to track CHDs beyond early childhood.

What are the long-term outcomes for adults with heart defects?

- Overall, one in 10 children born with CHDs won't survive to adulthood.
- People born with more complex CHDs face a higher risk of death before age 18.
- Adults with CHDs continue to face a high risk of early death and disability.
- Fewer than 10% of adults with CHDs in the United States who need care from specialty adult CHD centers are receiving this recommended care.
- Thanks to advances in medicine, it is now believed that the number of adults living with CHDs is at least equal to, if not greater than, the number of children living with CHDs.

Most Important

- All adults born with more complex defects should be seen regularly by adult congenital heart defect specialists.