

Adult care for congenital heart disease patients should begin in adolescence

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Doctors should transition their patients from pediatric to adult medical care for congenital heart disease during early adolescence, experts recommend in a scientific statement published in *Circulation: Journal of the American Heart Association*.

"It's not as simple as getting the name of a new doctor and going to see them when a patient turns 18," said Craig Sable, M.D., co-chair of the statement committee and director of [echocardiography](#) and cardiology fellowship training at Children's National Medical Center in Washington, D.C. "There are multiple steps associated with the transition process that need to be started at a very young age, so that by the time these children become adults the process is well under way."

The transition should be a joint effort between the healthcare provider (usually a pediatric heart specialist), the patient and the patient's family that starts when patients are between 12 to 14 years old, Sable said.

Critical steps include:

- Select an adult care physician to provide and coordinate comprehensive care;
- Offer reproductive/genetic and career counseling;
- Secure health insurance;
- Educate adult care providers in managing congenital [heart disease](#);
- Maintain communication between patients, families and healthcare professionals.

Congenital heart disease occurs before birth and is the most common type of [birth defect](#). These heart

disorders are usually relatively mild and treatable.

Most children born with congenital heart disease today survive into adulthood and live normal lives. In the United States, more than half of those affected are now adults.

However, many patients need specialized and uninterrupted medical treatment. Ideally, the transition process minimizes disruption and stress while maintaining appropriate treatment continuity. But less than one-third of adults with [congenital heart disease](#) receive care from qualified, trained specialists, Sable said.

"The vast majority of the patients we see are not necessarily the most severe, so there's a real concern that some of the patients who really need care are not seeking it," he said. "The bottom line is to ensure that, as patients grow up, they receive the necessary care."

Beginning in 2008, Sable and his team researched transition literature to identify the most effective practices that they presented in the paper.

Provided by American Heart Association

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