

**4 Can my child just stay with a pediatric heart team their whole life?**

No, though some young adults do continue to get outpatient care from a pediatric cardiologist for a while. If your child chooses to go away to school or move for work, they will need to start with a new heart care team. As your child gets older, she may have new adult health issues, such as pregnancy. There are also heart problems that older adults with heart defects get that teens and young adults do not. Adult congenital heart programs treat congenital heart patients who “outgrow” pediatric care. Also, in most parts of Canada, adults cannot be treated in pediatric hospitals, so transition to an adult congenital heart specialist is always part of the plan.

Your child’s heart care team are the experts on your child’s heart. Ask them to tell you more about your child’s long-term care needs. The chart inside lists recommendations for adults with congenital heart disease. Learn more about lifelong care for congenital heart patients at [www.cchaforlife.org](http://www.cchaforlife.org).



**Have more questions?**

Your child’s heart care team can help you learn more about his or her lifelong heart needs. We encourage you to talk to them now. The more questions you ask, the better you can plan for your child’s future

The **Canadian Congenital Heart Alliance (CCHA)** is a national non-profit organization organization committed to improving and prolonging the lives of Canadians with congenital heart disease.

CCHA offers resources to help heart kids thrive to adults. Visit us at [www.cchaforlife.org](http://www.cchaforlife.org).

The information in this brochure was based on the ACC/AHA 2008 Guidelines for the Management of Adults with Congenital Heart Disease and the Canadian Cardiovascular Society 2009 Consensus Conference on the management of adults with congenital heart disease. To access these documents, please go to [www.cchaforlife.org/managing-congenital-heart-defects.html](http://www.cchaforlife.org/managing-congenital-heart-defects.html).

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# When your Child has a Heart Defect

## Planning Ahead for Lifelong Heart Health



## Was your child born with a Heart Defect?

The good news is that children born with heart problems live longer than ever before. But getting the right kind of heart care will help will help your child's special heart stay as healthy as possible. When your child is an adult, he will still need to get his heart checked regularly; this is true even if he had successful surgery or other treatment. Children with congenital heart disease (CHD) need lifelong care from congenital heart experts. This brochure lists congenital heart defects considered simple, moderately complex, and highly complex. How can you lay the foundation to help your child thrive as a teen and adult with CHD? Your child's heart team can guide you through what you and your child need to know. Ask them what you can do now to plan for the future. You and your child can learn together. Here are some questions and answers to get you started:

### 1 Should I tell my child about her heart defect?

**Yes.** You and your child should learn the name of the congenital heart defect before the teen years. At your child's next visit ask your heart care team to write it down here:

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Practice saying this at home. Sometimes it is easy to forget. Don't be afraid to ask to review it at every heart check. Your child's heart care team can also give you tips on how to talk with your child about their heart.

### 2 Will my child always need to see a heart doctor?

**Yes.** Just as your child needs special heart care today, they will always need special heart care – even as a teenager and adult. It's very important that people born with heart defects get regular heart checks. Heart problems can start with no symptoms. Finding and treating the problems early can prevent big problems later on.

### 3 Will my child need a special kind of heart doctor when they grow up?

**Yes.** Most adult cardiologists do not have the special training needed to take care of complex heart defect patients. Your child will always need to look for a doctor with special training in congenital heart disease. Ask your child's heart care team what they recommend. The Canadian Congenital Heart Alliance (CCHA) ([www.cchaforlife.org](http://www.cchaforlife.org)) has an online listing of adult congenital heart programs throughout the country.

## SIMPLE CONGENITAL HEART DISEASE

Periodic heart checks should occur. General cardiologists can usually oversee care. One visit to an adult CHD program to verify diagnosis and health status is recommended. Adult CHD care is usually not needed unless new problems arise.

### Unrepaired Conditions:

- Isolated small atrial septal defect (ASD)
- Isolated small ventricular septal defect (VSD)
- Mild pulmonic stenosis
- Isolated dextrocardia, no other heart problems

### Repaired Conditions:

- Patent ductus arteriosus (PDA)
- Secundum atrial septal defect (ASD)
- Isolated ventricular septal defect (VSD)

### Repaired or Unrepaired Conditions:

- Isolated aortic valve disease
- Isolated mitral valve disease
- Isolated patent foramen ovale (PFO)

## MODERATELY COMPLEX CONGENITAL HEART DISEASE

These patients should be seen every two years or more frequently at an adult congenital heart program.

### Repaired or unrepaired conditions:

- Anomalous left coronary artery from pulmonary artery (ALCAPA)
- Anomalous pulmonary venous drainage (partial or total)
- Atrioventricular (AV) canal/septal defects (partial or complete)
- Ostium primum or sinus venosus ASD
- Coarctation of the aorta
- Ebstein anomaly
- Inundibular right ventricular outflow obstruction (moderate or severe)
- Pulmonary valve regurgitation (moderate or severe)
- Pulmonic valve stenosis (moderate or severe)
- Sinus of Valsalva fistula/aneurysm
- Subvalvar or supra-valvar aortic stenosis
- Tetralogy of Fallot
- Ventricular septal defect (VSD) with any valve problems and/or obstructions

## HIGHLY COMPLEX CONGENITAL HEART DISEASE

These patients should be seen every year or more frequently at an adult congenital heart program.

### Repaired or unrepaired conditions:

- Congenitally corrected transposition of the great arteries (ccTGA or L-TGA)
- Double outlet ventricle
- Mitral atresia
- Pulmonary atresia (all forms)
- Pulmonary arterial hypertension
- Shone syndrome
- Single ventricle - all forms (i.e. double-inlet ventricle, HLHS, HRHS, common/primitive ventricle)
- Transposition of the great arteries (d-TGA)
- Tricuspid atresia
- Truncus arteriosus/ hemitruncus
- Other abnormalities of AV connections (i.e., criss-cross heart, isomerism, heterotaxy syndromes)

### All patients who have undergone any of the following procedures

- Arterial switch procedure
- Any conduit(s), valved or nonvalved
- Double-switch procedure
- Fontan procedure
- Mustard procedure
- Norwood procedure
- Rastelli procedure
- Senning procedure

### All patients with Eisenmenger syndrome

### All patients who are cyanotic ("blue")

Not sure what you have? You should visit an ACHD program to help you figure it out.

To find an ACHD program in Canada, go to [www.cchaforlife.org](http://www.cchaforlife.org).