

5 Report new symptoms

Tell your ACHD care team if you have fainting and/or dizziness, a racing or skipping heart beat, shortness of breath, swelling in your ankles or abdomen, or excessive tiredness. They can determine whether or not these symptoms are related to your heart condition. They can also give you prompt treatment if new heart problems arise.

6 Protect yourself from heart infection

Heart infection (endocarditis) is when bacteria grow in the heart. It is serious and needs prompt treatment. Tell your ACHD care team if you have unexplained fever for five days or more. Ask your ACHD care team for instructions on if/when to use antibiotic protection.

7 Be kind to your heart

Heart healthy habits will help protect your heart. Maintain a healthy weight. Eat a healthy diet. Discuss with your ACHD care team an exercise routine that is right for you. Don't smoke, abuse drugs, or drink to excess. Talk to your heart care providers about your specific risks for acquired heart disease.

8 Keep your medical records

All your health care providers should know as much as possible about your heart's unique anatomy and history. Health records can get lost over time. Your health records belong to you. Ask for copies of key information, like test reports and surgical records.

9 Learn about your heart

Heart defects and surgeries can be hard to understand. But the more you learn, the more you can take charge of your heart health. Learn your complete diagnosis and how to draw your defect on a heart diagram. Ask questions of your ACHD care team until you understand your condition and special health concerns.



Would you like to learn more?

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

CCHA is dedicated to connecting congenital heart survivors with the peer support, information, and resources they need to thrive. For more information and to join CCHA, go to 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.

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Adults Born with Heart Defects

Tips for Lifelong Heart Health



**Were you born with a heart defect?
Told as a child you had a heart problem?
Did you have a childhood heart surgery?**

The good news is that most people who have childhood heart surgery grow up to be healthy adults. But it is important that you get the heart care you need to keep well. Experts suggest that you have your heart checked at least once at a special adult congenital heart disease (ACHD) program. The ACHD specialists can make sure that your diagnosis is accurate and that any repair you had is still working well. This brochure lists heart defects considered simple, moderately complex, and highly complex. If your defect is listed as complex, you should get lifelong care from experts in congenital heart disease (CHD). This is true even if you had successful childhood surgery. Here are some more tips to help you take charge of your heart health

1 Get regular heart check ups

Repaired hearts sometimes develop new problems over time. These include leaks, valve problems, heart muscle problems, and problems with heart rhythm. Your heart should be checked regularly to make sure that nothing has changed. Get checked even when you feel well. Heart problems can start without any symptoms. Early detection and treatment can protect your heart.

2 See the right kind of heart doctor

If you were born with CHD (see list next page) experts recommend you get care at a special ACHD program. Congenital heart problems are very different from “regular” adult heart problems. Your heart care team should have special training in taking care of adults born with complex heart defects. This will ensure that you get testing and treatments that are right for you.

3 Find the right ACHD care team for you

You can find a listing of Canadian ACHD programs at www.cchaforlife.org > Resources. If you do not live near an ACHD program, you should travel to one for a consult.

4 Tell all your providers about your heart

Treatment for other parts of your body can affect your heart. Certain medications and treatments may be risky. Whenever a new treatment is recommended, ask about any special risks for you due to your special heart.

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