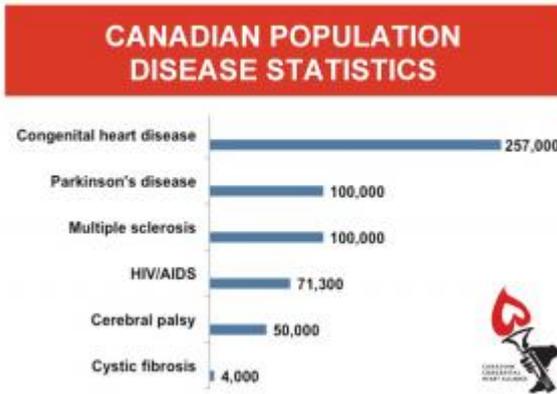




Facts and issues



Source: Canadian Congenital Heart Alliance, Parkinson Society of Canada, Multiple Sclerosis Society of Canada, Public Health Agency of Canada, Adult Living Alliance, Cystic Fibrosis Canada

CHD Facts and Issues

- Congenital heart disease (CHD) is the world's leading birth defect. About 1 in 80-100 Canadian children are born with CHD.1 Sixty years ago only about 20% of children survived to adulthood; that number has since increased to about 90% - resulting in a growing population of young adults who require life-long cardiac care.2
- There are an estimated 257,000 Canadians with Congenital Heart Disease.3
- Of the 257,000 Canadians with CHD, two-thirds are adults. At least half face the prospect of complications, multiple surgeries, and/or premature/sudden death.3
- There are far fewer resources allocated for the care of adult CHD patients than other cardiac patients. As a result, wait times for clinical visits and surgical intervention are much longer than for other cardiac patients - leading to increased anxiety, added risk and even death.
- There are over 40 types of congenital heart defects

SIMPLE CONGENITAL HEART DISEASE		
<p>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.</p>		
<p>Unrepaired Conditions:</p> <ul style="list-style-type: none"> - Isolated small atrial septal defect (ASD) - Isolated small ventricular septal defect (VSD) - Mild pulmonary stenosis - Isolated dextrocardia, no other heart problems 	<p>Repaired Conditions:</p> <ul style="list-style-type: none"> - Patent ductus arteriosus (PDA) - Secundum atrial septal defect (ASD) - Isolated ventricular septal defect (VSD) 	<p>Repaired or Unrepaired Conditions:</p> <ul style="list-style-type: none"> - Isolated aortic valve disease - Isolated mitral valve disease - Isolated patent foramen ovale (PFO)
MODERATELY COMPLEX CONGENITAL HEART DISEASE		
<p>These patients should be seen every two years or more frequently at an adult congenital heart program.</p>		
<p>Repaired or unrepaired conditions:</p> <ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - Coarctation of the aorta - Ebstein anomaly - Infraductal right ventricular outflow obstruction (moderate or severe) - Pulmonary valve regurgitation (moderate or severe) - Pulmonic valve stenosis (moderate or severe) 	<ul style="list-style-type: none"> - Sinus of Valvesia 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		
<p>These patients should be seen every year or more frequently at an adult congenital heart program.</p>		
<p>Repaired or unrepaired conditions:</p> <ul style="list-style-type: none"> - Completely 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, HRS, common primitive ventricle) - Transposition of the great arteries (d-TGA) - Tricuspid atresia - Tricuspid arterioles/ hemitricuspid - Other abnormalities of AV connections (i.e., cross heart, anomalous, heterotaxy syndromes) 	<p>All patients who have undergone any of the following procedures</p> <ul style="list-style-type: none"> - Arterial switch procedure - Any conduit, valved or nonvalved - Double-switch procedure - Fontan procedure - Mustard procedure - Norwood procedure - Rastelli procedure - Senning procedure <p>All patients with Eisenmenger syndrome</p> <p>All patients who are cyanotic ("blue")</p>	

Here are some specific Canadian statistics regarding services for adults with CHD:

- There are 15 dedicated centres across Canada to treat adults with CHD (Click [HERE](#) to find a centre).
- In 2012 of approximately 96,000 adult CHD patients in Canada, only 21,879 (23%) are being followed in one of the 15 centres. The other 77% are considered "lost to follow-up".⁴ Recent studies and improvements to Transition programs across Canada indicate this number is now averaging about 50% successful transition.⁵
- There are approximately 20 CHD surgeons who operate on CHD adults, and of these 12 are pediatric cardiac surgeons.⁴
- Of the 80 adult and pediatric cardiologists affiliated to an adult clinic, only 27% had received formal training in adult CHD.⁴
- 3.6% of all Canadian adult cardiologists, 36% of all Canadian pediatric cardiologists, and 11% of all Canadian cardiac surgeons were affiliated with an adult CHD centre.⁴
- 1.8% of all Canadian adult cardiologists had formal adult CHD training.⁴
- Four of the 15 centres had no dedicated nursing time. Two centres had full-time equivalents, and 9 centres had no institutional clerical support.⁴
- There is currently no coordinated plan to transfer the medical records of CHD patients transitioning from pediatric to specialized adult care. Less than half of patients with complex congenital heart defects transition successfully; as a result, many do not receive the care they need.
- Research in the area of adult CHD has not reached the level of sophistication observed in other areas of heart disease research - even though CHD-related research has the potential for greater impact. At the same time, peer review committees for research funds rarely include adult CHD specialists and frequently mistake the lack of research sophistication for a lack of quality or relevance.

1. Health Canada Report 2002 - Congenital Anomalies in Canada.

2. Moons P, et al. Temporal Trends in Survival to Adulthood Among Patients Born With Congenital Heart Disease From 1970 to 1992 in Belgium. *Circulation* 2010;122:2264-2272.

3. Marelli AJ, et al. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. *Circulation* 2014 doi: 10.1161.

4. Beauchesne LM. Structure and process measures of quality of care in adult congenital heart disease patients: A pan-Canadian study. *Int J Cardiol* 2012;157:70-74.

5. Suliman A, et al. The Critical Transfer from Paediatrics to Adult Care in Patients with Congenital Heart Disease: Predictors of Transfer and Retention of Care. *CJC Pediatric and Congenital Heart Disease* 2022;129-135.