

# Congenital heart disease transition of care tip sheet

Congenital heart disease (CHD) is any defects in the heart valves, great vessels, heart walls or chambers of the heart that are present at birth.

## Do you know...



**CHD is the most common** birth defect among newborns.<sup>1</sup>



**Many people with CHD require lifelong expert medical care,** and struggle with both physical and mental health challenges.<sup>2</sup>



**There are now more adults with CHD than children,** thanks to medical and surgical advancements.<sup>3</sup>

## Making the transition to adult congenital heart disease care

Transition is a process that begins in the early teenager years and continues through early adulthood. The transfer from a pediatric care provider to an adult congenital cardiologist will likely happen at around age 18. As part of the transition, you will learn to be more responsible for your own health and health decisions.

## Where will I be transferred to?

Degree	Examples	Who should you see about your heart?
<b>Simple</b>	<ul style="list-style-type: none"> <li>Mild pulmonary stenosis</li> <li>Repaired ventricular or atrial septal defect</li> </ul>	Even simple CHD can have complications. The adult cardiologist will decide who should be following your care. They might refer you to a general cardiologist or community cardiologist who are doctors who work outside of hospitals.
<b>Moderate</b>	<ul style="list-style-type: none"> <li>Coarctation of the aorta</li> <li>Ebstein anomaly</li> <li>Milder forms of tetralogy of Fallot</li> </ul>	You must be seen by an adult CHD specialist at one of the 15 adult CHD centres.
<b>Complex</b>	<ul style="list-style-type: none"> <li>Any of the single ventricular disorders</li> <li>Transposition of the great arteries with a Mustard type of repair</li> <li>Any type of congenital heart disease that causes cyanosis (blue lips or fingertips because not enough oxygen getting to the body's tissues)</li> <li>Complex tetralogy of Fallot</li> </ul>	

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## Steps to take for a successful transition

- Talk to your healthcare team about transitioning to adult care and next steps.
- If you need to choose a different primary healthcare provider, ask your cardiologist if they can recommend a provider who has other CHD patients.
- Keep a health passport with you. This is a summary of record of your own medical information including the name and phone number of your cardiologist, your diagnosis and surgical history, and medications.
- Ask questions. Learn about your condition.
- Know that moving to adult care can seem stressful for some people. It's a good idea to talk about your concerns and feelings with people you trust, including your healthcare team.

## Other actions you can take :

**Learn** about your heart condition and steps to make a successful transition  
[heartandstroke.ca/heart/conditions/congenital-heart-disease/](http://heartandstroke.ca/heart/conditions/congenital-heart-disease/)

**Know** that lots of info about transition and living with CHD is available at  
[iheartchange.org](http://iheartchange.org)

**Access** transition resources and find an adult CHD centre near you  
[cchaforlife.org/transition](http://cchaforlife.org/transition)

**Join** Heart & Stroke's Facebook group for online community support  
[heartandstroke.ca/heart/recovery-and-support/the-power-of-community](http://heartandstroke.ca/heart/recovery-and-support/the-power-of-community)

**Find** a parent support group such as **Braveheart Support Society** or **Fondation En Coeur** on Facebook

**Share** your stories on social media using **#CHDAwarenessWeek** or **#CHDAwareness**

**“Seeing your CHD cardiology team regularly through life is very important even if you feel 100% fine. Adults with CHD who are followed regularly are less likely to develop urgent medical problems.”**

– Pam Heggie, RN, BN

## Do you know...

**Adult CHD patients are at higher risk for a variety of health issues, including heart rhythm problems, heart failure, coronary artery disease, stroke, and others.**<sup>4,5</sup>



### Acknowledgement:

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1. Public Health Agency of Canada. A Perinatal Health Surveillance Report. Ottawa, ON; 2013. 2. Pagé MG, et al. Psychol Health. 2012;27(11):1260-1270. 3. Marelli Ariane J, et al. Circulation. 2007;115(2):163-172. 4. Verheugt CL, et al. Eur Heart J. 2010;31(10):1220-1229. 5. Marelli A. Canadian Journal of Cardiology. 2019;35(12):1609-1619.

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