



Transition Tools and Resources

Resources

Health Information Summary

It's important that your teen carry a Health Summary record in some form at all times. It should include

- name of cardiac condition and other medical conditions
- previous cardiac surgeries/interventions and other surgeries
- name of medications
- allergies
- need for endocarditis prophylaxis (Yes/No)
- names and contact details of health providers (CHD and primary care)
- other vital info (i.e. low HR, low O2 sat, no pulse in right arm)

IMPORTANT NOTE

It is important to know what is normal for you and your CHD. Normal ECG rhythm, heart rate, blood pressure, O2 saturation. Other medical issues can arise such as a broken leg or car accident, lack up to date medical information about your CHD could result in delays of treatment or prolonged hospital stays.

There are many options to achieve this.

Medical Alert bracelet - consider getting a Medic-Alert bracelet as they have 24 hour medical emergency contact available (www.medicalert.ca)

MyHealthPassport - a health passport is available from the SickKids website www.sickkids.ca/myhealthpassport

Smartphone apps - most mobile devices have a health app or provide ability to input medical information in case of emergency. Check out these links to learn how to input for your type of mobile device

<https://www.cnet.com/how-to/first-responders-can-help-you-even-when-your-phone-is-locked/>

<https://techguylabs.com/blog/put-emergency-info-your-phones-lock-screen>

<https://www.gotttransition.org/resourceGet.cfm?id=439>

Don't forget to review your Health Information Summary with your CHD healthcare team to make sure you haven't forgotten anything vital in an emergency.

Tools

I Heart Change: helping you make the move to adult care <https://iheartchange.org/>

A website designed mainly for young people with congenital heart disease (CHD). Family and friends might also want to check it out

Alberta Health Services – Peter Loughed Centre – Calgary - [meet the team](#)

Pacific Adult Congenital Heart (PACH) clinic – Vancouver - [meet the team](#)

Toronto General Hospital – Peter Munk Cardiac Centre – Toronto - [meet the team](#)

MyTransition App

Created by CanChild at McMaster University, the MyTransition App is a free tool that can be easily accessed and used by the majority of youth with chronic health conditions, in order to support and improve individual transition of care experiences and health outcomes. The software includes the

MyHealth 3-Sentence Summary, MyHealth Passport, and TRANSITION-Q as well as a key contact person from the youth's treating healthcare team to integrate into one's healthcare. The app provides an easily and readily accessible central location for young adults to track their transition, keep contacts in one place, and improve communication with their healthcare team.

Download free for Apple iOS or Google Android below:

[App Store for iOS](#)

[Google Play Store](#)

Toolkits

These resources are available to all youth living with CHD (not just those at BC Children's hospital)

Transition toolkit for youth: <http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care/youth-toolkit>

Transition toolkit for families: <http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care/family-toolkit>

Below is the Congenital Heart Disease Transition of Care tip sheet, developed in collaboration with Heart & Stroke, I Heart Change, Fondation en Cœur, Braveheart Support Society and Global ARCH

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.¹



Many people with CHD require
lifelong expert medical care,
and struggle with both physical
and mental health challenges.²



There are now more adults
with CHD than children,
thanks to medical and surgical
advancements.³

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?
Simple	<ul style="list-style-type: none"> Mild pulmonary stenosis Repaired ventricular or atrial septal defect 	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.
Moderate	<ul style="list-style-type: none"> Coarctation of the aorta Ebstein anomaly Milder forms of tetralogy of Fallot 	You must be seen by an adult CHD specialist at one of the 15 adult CHD centres.
Complex	<ul style="list-style-type: none"> Any of the single ventricular disorders Transposition of the great arteries with a Mustard type of repair Any type of congenital heart disease that causes cyanosis (blue lips or fingertips because not enough oxygen getting to the body's tissues) Complex tetralogy of Fallot 	

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The Quebec Foundation
for Children with Heart Disease



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/

Know that lots of info about transition and living with CHD is available at
iheartchange.org

Access transition resources and find an adult CHD centre near you
cchaforlife.org/transition

Join Heart & Stroke's Facebook group for online community support
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.^{4,5}



Acknowledgement:

This flyer is co-created by Heart and Stroke Foundation, HeartChange, Canadian Congenital Heart Alliance, Fondation En Coeur, Global ARCH and Braveheart Support Society.
1. Public Health Agency of Canada. A Perinatal Health Surveillance Report. Ottawa, ON: 2013. 2. Page MG, et al. Psychol Health. 2012;27(11):1260-1270. 3. Marek-Areane J, et al. Circulation. 2007;115(2):163-172. 4. Verheugt CJ, et al. Eur Heart J. 2010;31(10):1220-1229. 5. Marek-A. Canadian Journal of Cardiology. 2019;35(12):1609-1619.

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 [Download CHD_Transition of Care tip sheet_EN_2020.pdf](#) (155.92 KB)

Resources from hospitals

BC Children's Hospital: Transitioning Responsibly to Adult Care

[http://www.bcchildrens.ca/our-services/support-services/transition-to-adult...](http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care)

Children's Hospital of Eastern Ontario (CHEO)

<https://www.cheo.on.ca/en/resources-and-support/transition-to-adult-care.aspx>

Sick Kids Hospital

<https://www.sickkids.ca/en/patients-visitors/transition-adult-care/>

IWK

<http://www.iwk.nshealth.ca/transitions>

Got Transition

<https://www.gotttransition.org/index.cfm>

For more information about Transition, visit our [Transition and Risk](#) page.

To better understand the life stages of transition, read the [Transition timeline recommendations](#)

Tags:

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