# Ready, Set, Go!

Making a Smooth Transition From Pediatric to Adult Cardiac Care



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# Considerations

- 1. Transition and Life-Long Care
- 2. Check-in Questions Where are we at?
- 3. Resources
  - MyHealth Passport
  - 3-Sentence Summary
  - ON TRAC Use your phone

Q & A

# 1. Transition and Lifelong Care

# Definitions

## **Transition**

 "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (Blum et al. J Adolesc Health, 2004)

## Transition is a *process*, not an *event*

## **Transfer:** is an event

when the adolescent is sent to adult care





# Life-Long Cardiac Care

"A lapse in specialized care for people living with CHD likely includes a lack of education about their condition," said **Amy Verstappen**, **president and CEO of the ACHA**. "It remains very difficult for us to reach out to people who have been lost to care, so we place a great importance on educating parents and families to ensure more children with CHD grow up receiving the **lifelong treatment** they need."



### Transition & Lifelong Care

Although our name contains the word 'Children', we support research and advocate for all Congenital Heart Disease (CHD) patients regardless of age. We are extremely proud to serve patients and families from before birth through childhood, adolescence, teenage years, adulthood and the elderly population. As the 'first' generation of open-heart surgery survivors age, we are keenly aware of many new significant dynamics in the CHD population.

- CHD population has more adults than children
- CHD is a chronic disorder requiring lifelong ongoing congenital heart care
  - Long-term outcomes unknown
  - Risk of additional problems is high

### Transition & Lifelong Care Goals

- Every CHD survivor should be equipped to independently negotiate lifelong cardiac care
- Every CHD survivor needing life-long congenital heart care should be transitioned to appropriate Adult Congenital Heart Disease care

### Transition & Lifelong Care Strategies

- Educate on cardiac health surveillance benefits
- Encourage awareness of care guidelines
- · Encourage education for transition from Pediatric to Adult Congenital Heart Cardiologists
- Educate patient/families on how to choose adult congenital heart care www.achaheart.org/for\_members/clinicdirectory/index.php



## Taking Responsibility for Your Health

Are You Ready?



The CHAPTER Program
Congenital Heart Adolescents:
Program of Transition
Evaluation Research

### What is Transition?

Congenital heart disease requires ongoing, lifelong specialized care.

<u>Transition</u> is a process that occurs as a child or adolescent matures into early adulthood. During this time, the young person gradually takes increasing responsibility for personal health care, health maintenance and decision-making.

The transfer of a teen's medical care to an adult health care provider is a single event in the transition process. The health education and skills needed to negotiate the adult health care system make up the majority of medical transition Many teens may programming. benefit from guidance specific to their unique situation regarding maintenance. health career development, and relationships, among other subjects.

Adolescents living with chronic conditions such as congenital heart disease are encouraged to become <a href="mailto:independent">independent</a> when it comes to health maintenance. Transition represents the time during which this happens.

Transition & Lifelong Congenital Heart Care



### When do I Transition?

Transition is a continuous process throughout the teenage years. However, transfer of medical care to the adult clinic is a specific event that for most teenagers happens around 17-18 years of age.

### Where is the Adult Clinic?

The Northern Alberta Adult Congenital Heart (NAACH) Clinic is located right next to the Stollery Children's Hospital at the Mazankwoski Alberta Heart Institute.

The NAACH clinic has four cardiologists: Drs. Dylan Taylor, Isabelle Vonder Muhll, Jonathan Windram, and Yashu Coe. The clinic has two electrophysiology experts, Drs. Michael Kantoch and Joseph Atallah, who see patients with heart rhythm problems.

Pam Heggie and Deb Jandura are the Adult Cardiology Nurses for the clinic. Bonda Toppin is the clinic administrator.

### Web Sites

#### Transition Sites

- ON TRAC Transitioning Responsibly to Adult Care http://ontracbc.ca/
- Good 2 Go Transition Program including MyHealth Passport http://www.sickkids.ca/good2go/
- 2) Health Care Transitions http://hctransitions.ichp.ufl.edu/

### Adult Congenital Heart Disease

- Canadian Adult Congenital Heart (CACH) Network
   http://www.cachnet.org/index.cgi
- The Adult Congenital Heart Association (ACHA)
   <a href="http://www.achaheart.org/">http://www.achaheart.org/</a>
- Canadian Congenital Heart Alliance (CCHA)
   http://www.cchaforlife.org/

#### General Health

- 1) Young and Healthy http://www.youngandhealthy.ca/caah/
- 2) Healthy Alberta http://www.healthyalberta.com/
- Medic Alert
   <a href="http://www.medicalert.ca/en/index.asp">http://www.medicalert.ca/en/index.asp</a>

### Planning Ahead

One important change that will happen over the next few years is that your heart care will take place in a clinic for adults rather than for kids. At the same time there will be an expectation that you will become responsible for taking care of your own health rather than relying on your parent(s) to do so. This process is called health care transition.

Health care transition is important because it supports the activities that you want to do in life such as living on your own, maybe going to college, and having a job. In practical terms, health care transition not only means getting medical care from health care providers trained to treat adults, but also becoming means knowledgeable about your heart condition, being responsible for carrying out your health tasks, and making good health and health care decisions.

Transition education sessions with a clinic nurse are designed to help you prepare for adult health care by:

- better understanding your heart condition, and
- obtaining information that will make the transition easier.

### Contact Information

Pediatric Cardiac Sciences Program Stollery Children's Hospital 4C2 Phone 780-407-3952 Fax 780-407-3310



Northern Alberta Adult Congenital Heart (NAACH) Clinic Mazankowski Alberta Heart Institute 2A7 Phone 780-407-6552

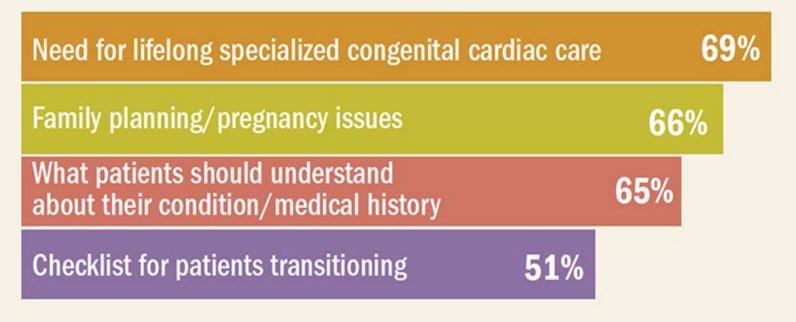


8440 – 112th Street Edmonton, AB T6G 2B7





# **Most Valuable Tools To Support CHD Patients**



Q: Which of the following would you find most valuable to support CHD patients? (n=248)

Gurvitz M, Valente A, Broberg C, et al. Prevalence and Predictors of Gaps in Care Among Adult Congenital Heart Disease Patients: HEART-ACHD (The Health, Education, and Access Research Trial). *J Am Coll Cardiol.* 2013;61(21):2180–2184.

# 2. Check-in Questions Where are we at?



Transitioning Responsibly to Adult Care



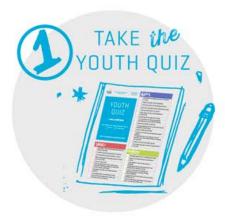
ON TRAC is a province-wide, multifaceted Transition Initiative to support comprehensive, continuous, accessible, sustainable and developmentally-appropriate care to youth and young adults (ages 12-24 years) with chronic health conditions and/or disabilities (CHC/Ds) as they plan, prepare and transfer from pediatric to adult health care services.

http://ontracbc.ca/





This Toolbox is for Youth, 12 -24 years of age, filled with tools, materials, activities and websites to help you make a continuous, safe and smooth transition into adult health care.



### **Take The Quiz**

A quiz to help you understand the skills and knowledge you need to plan and prepare for adult health care.

**Download The Quiz** 





I ask health care providers questions about my health

- 1. Got it!
- 2. Needs work







I meet with health care providers on my own

- 1. Got it!
- 2. Needs work





I AM #ONTRAC



I can describe my health conditions to others

- 1. Got it!
- 2. Needs work





- 1. Got it!
- 2. Needs work



I AM #ONTRAC



I know the names of my medications and what each is for

- 1. Got it!
- 2. Needs work





- 1. Got it!
- 2. Needs work



connections

I connect with others who have the same health conditions as me

- 1. Got it!
- 2. Needs work



I AM #ONTRAC



I know how and why to register for College/ University special accommodation

- 1. Got it!
- 2. Needs work



I AM #ONTRAC



I understand why I might need genetic counselling

- 1. Got it!
- 2. Needs work



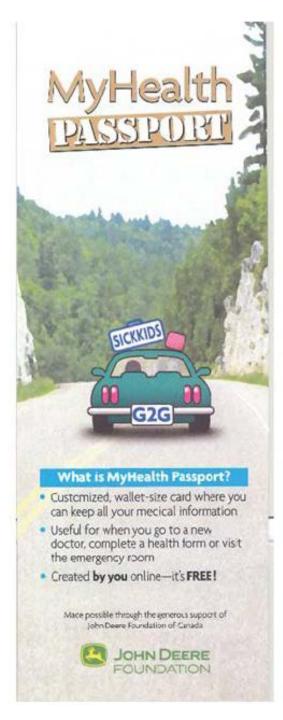


- 1. Got it!
- 2. Needs work

# 3. Resources

MyHealth Passport

3-Sentence Summary
OnTrac – Use Your Phone



## **SickKids**

### How do I get one?

- Go to www.sickkids.ca/myhealthpassport
- Choose your condition from the dropdown menu or choose 'generic'
- Fill in your medical and contact information – takes about 10 minutes
- You can ask your health-care provider to help

## What information will I need to complete a MyHealth Passport?

- Names of your conditions
- Names of your medications
- Names and cates of any major procedures or operations
- Immunization history
- Any special health-care needs, allergies, mobility aids
- Names and phone numbers of your health-care providers and emergency contacts







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# MyHealth Passport

- Name of specific cardiac condition
- Previous cardiac interventions
- Name and purpose of medications
- Need for SBE prophylaxis
- Contact names and location of CHD cardiologist

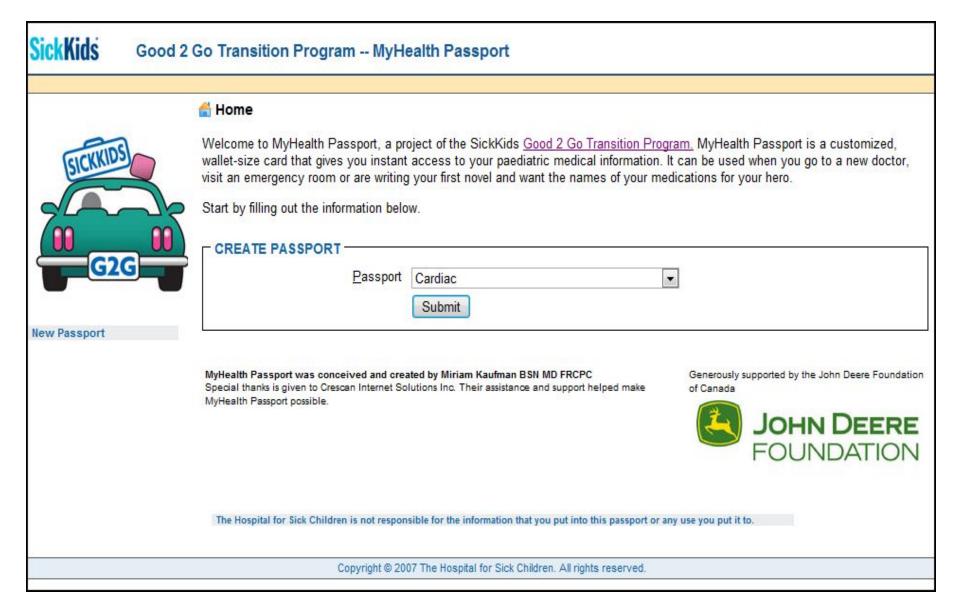




# Check-in Question



- 1. I have an up-to-date MyHealth Passport with me today
- 2. I have an not so up-to-date MyHealth Passport with me today
- 3. I have done a MyHealth Passport in the past that is not with me
- 4. I have never done a MyHealth Passport



## p. 1 https://www.sickkids.ca/myhealthpassport/



### Good 2 Go Transition Program -- MyHealth Passport



**New Passport** 

### Home 🔒

We would like a bit of information from you for our statistics. We will not be saving the rest of the passport, so this information will not be linked to whatever information you put in your passport.

-DEMOGRAPHICS-	
DEMOGRAPHICS	
<u>Ag</u> e	15
Reason for using MyHealth Passport	Creating health passport for myself ▼
<u>G</u> ender	Female ▼
Do you wear a Medic-Alert Bracelet?	○ Yes ● No
Hospital / Institution	Stollery Children's Hospital
<u>C</u> ountry	Canada
Have you done Health Passport before?	○ Yes ● No
	Continue

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**New Passport** 

#### **Cardiac**

This is where you put in your health information. Much of it you will know and the rest is available to the health care provider you are completing this with. If something doesn't apply to you, skip to the next section. There is no need to enter "none" or n/a, unless you want the section to print on the final version. An example of this would be if you want your card to say "Drug Allergies: None". At the end, there is a place you can put in anything that you would want an adult health care provider to know about you.

<u>N</u> ame			
Date of birth			
<u>D</u> iagnosis			
Other current medical problems			
Date(s) and result(s) of diagnostic cardi	ac catheterizations		
Cardiac cath with balloo	n, date and results		
<u>C</u> ardiac cath with stent insertio	n, date and results		
!mplanted Devices		 	 
	acemaker insertion		
	e(s) of ICD insertion		
<u>D</u> ate(s) Mechanical Ad			
200 1708			
<u>D</u> ate(s) Mechanical Pulmor			
<u>D</u> ate(s) Mechanical M			
<u>D</u> ate(s) Loo <sub>l</sub>	p recorder insertion		
$\underline{W}$ hat operations have you had? When were they?			

<u>N</u> ame	
Date of birth	
<u>D</u> iagnosis	
Other current medical problems	
<u>D</u> ate(s) and result(s) of diagnost cathet	tic cardiac terizations
<u>C</u> ardiac cath with balloon, date a	and results
Cardiac cath with stent insertion, date a	and results
Implanted Devices	······································
<u>D</u> ate(s) of pacemake	er insertion
Date(s) of ICE	) insertion
<u>D</u> ate(s) Mechanical Aortic Valve	e insertion
Date(s) Mechanical Pulmonary Valve	e insertion
<u>D</u> ate(s) Mechanical Mitral Valve	e insertion
<u>D</u> ate(s) Loop recorde	er insertion
<u>W</u> hat operations have you had? When were they?	

Do you require IE Prophylaxis?	☐ Yes
What medications are you on? Consider including contraceptive pills, patches, IUCDs. If not comfortable with this, write "Ask me about my other medications".	
<u>D</u> rug allergies	
Other allergies	
<u>I</u> mmunizations	□ DPTP □ MMR □ HIB □ varicella
	meningitis Pneumovax Prevnar
	☐ HPV ☐ Hepatitis A ☐ Hepatitis B

Date and result last DEXA (bone mineral density)	
<u>D</u> ate and result last EKG	
Date and result last echocardiogram	
Date and result last angiogram	
Date and result last bicycle exercise test	
<u>L</u> ast blood pressure reading	
Date of last GFR and result	
Date of last cholesterol measurement and result	
Date of last LDL measurement and result	
Date of last HDL measurement and result	
Date of last triglyceride measurement and result	
Date of last pulmonary function test and results	
Date of last eye exam and result	

People have different ways of paying for their health care or medications. Some examples are OHIP, Trillium, NHS, ODB, Kaiser, Blue Cross, Medicare, Medicaid. How do you pay for medications and health care?	
Cardiologist name & phone number	
Who do you get most of your health care from? name & phone number	
$\underline{\text{N}}$ ame and number of usual pharmacy (drugstore, chemist)	
Please list any physical activities you aren't supposed to do (eg swimming, weight lifting, bungee jumping)	
Other information  Who should be called in case of emergency? Enter name and phone number	<i>//</i>

		home
SickKids Good 2 G	So Transition Program MyHealth Passport	
	dardiac Cardiac	
- Inc	Your passport is ready.	
SICKKIDS	VIEW AND PRINT PASSPORT	1
	Click here to View and Print Passport	
G2G	When you leave the system, the health passport will not be saved. If you would like to have an electronic copy, you can e-mail it to yourself by filling in your e-mail address below.	-
New Passport	E-MAIL MYHEALTH PASSPORT	1
100000000000000000000000000000000000000	e-mail address	
	e-mail Passpor Proceed to next page	
		20
	Copyright © 2007 The Hospital for Sick Children. All rights reserved.	





Please review the information you entered in the passport and continue if all entries are correct.



**New Passport** 

#### PREVIEW-

Operations

Tarvn Main Name DOB June 23, 1995

Diagnosis TGA (Transposition of the Great Arteries), VSD (Ventricular Septal Defect), None

Diagnostic cardiac cath: Last one: Apr 2014 Mild aortic regurgitation Caths

June 30, 1995 Arterial switch operation and VSD repair

I require IE prophylaxis. If you are unsure of current guidelines, please contact my IE Proph

cardiac program.

Meds None

Drug allergies ?Morphine Other allergies None

EKG: Apr 2015 normal sinus rhythm ,Echo: Apr 2015 mild AR ,Bicycle exercise test: Tests

Mar 2014 ,latest BP: Apr 2015 118/72 right arm

Blue Cross through my dad's work Coverage Dr. Isabel Vondermuhll 780-407-6552 Cardiologist

1° provider Dr. Morton GP 780-435 8877 Pharmacy Shoprper's Drug Mart Leduc Restrictions

No activity restrictions

ICE John Main Dad Cell 780 567 7766 Angela Main Mon Cell 780 576 2245

5/21/2015 www.sickkids.ca/myhealthpassport Date Created

Edit Passport

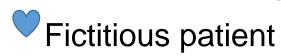
Continue



Please, cut passport and fold it to wallet size.

Name	Taryn Main
DOB	June 23, 1995
Diagnosis	TGA (Transposition of the Great Arteries), VSD (Ventricular Septal Defect), None
Caths	Diagnostic cardiac cath: Last one: Apr 2014 Mild aortic regurgitation
Operations	June 30, 1995 Arterial switch operation and VSD repair
IE Proph	I require IE prophylaxis. If you are unsure of current guidelines, please contact my cardiac program.
Meds	None
Drug allergies	?Morphine
Other allergies	None
Tests	EKG: Apr 2015 normal sinus rhythm ,Echo: Apr 2015 mild AR ,Bicycle exercise test: Mar 2014 ,latest BP: Apr 2015 118/72 right arm
Coverage	Blue Cross through my dad's work
Cardiologist	Dr. Isabel Vondermuhll 780-407-6552
1° provider	Dr. Morton GP 780-435 8877
Pharmacy	Shoprper's Drug Mart Leduc
Restrictions	No activity restrictions
ICE	John Main Dad Cell 780 567 7766 Angela Main Mon Cell 780 576 2245
Date Created	5/21/2015 www.sickkids.ca/myhealthpassport

Please close this window after printing to return to MyHealth Passport.



## What are the facts? MyHealth Passport

#### What do the facts mean?

- Learn basics of your cardiac anatomy
- Understand 3-4 potential future cardiac complications
- Understand need for ongoing lifelong congenital heart care

# Heart Diagrams & Potential Complications

American Heart Association

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects UCM 001217 Article.jsp

Cove Point Foundation

http://www.pted.org/

Education session with a clinic nurse

# What do the facts really mean? AKA "Drugs, sex and rock n roll"

- Alcohol
- Smoking & street drugs
- Piercing & tattoos
- Sexuality, contraception, & inheritability of CHD

Corience – European site

http://www.corience.org/living-with-a-heart-defect/adults/body-soul/drugs/

#### 3. Resources

MyHealth Passport

3-Sentence Summary

ON TRAC – Just TRAC it

## MyHealth 3-Sentence Summary

- Learn how to summarize your health history and speak to health-care providers in a concise way – to get across your needs and concerns in every healthcare experience.
- The MyHealth 3-Sentence Summary provides some tips on how to summarize your health and current needs in about three sentences.
- This skill is really important when you meet your new adult health-care providers or when you don't get to spend too much time with a health-care provider.

## MyHealth 3-Sentence Summary

- Being able to summarize your history briefly, sends the message that you are knowledgeable about your health and that you know how to focus on what is important.
- After you give your summary, your provider will typically have questions. This doesn't mean that you've forgotten important information, it just means that you've given enough information that they can now focus on what's important to you during the appointment.

### MyHealth 3-Sentence Summary

Sentence 1: My age, diagnosis and brief medical history

Sentence 2: My treatment plan

Sentence 3: My question/concern to talk about during this

visit

#### **Example**

• Hi, my name is Taryn Main.



**Sentence 1**: I am 20 and had an Arterial Switch operation for Transposition of the Great Arteries and VSD closure when I was one week old. I see a congenital heart specialist annually.

**Sentence 2**: I have regular tests to monitor my aortic valve and I am not on any medications except for antibiotics when I go to the dentist.

**Sentence 3:** I am here today because I have had a fever for a couple of days with no other symptoms.

#### 3. Resources

MyHealth Passport 3-Sentence Summary

ON TRAC – Just TRAC it

## Check-in Question



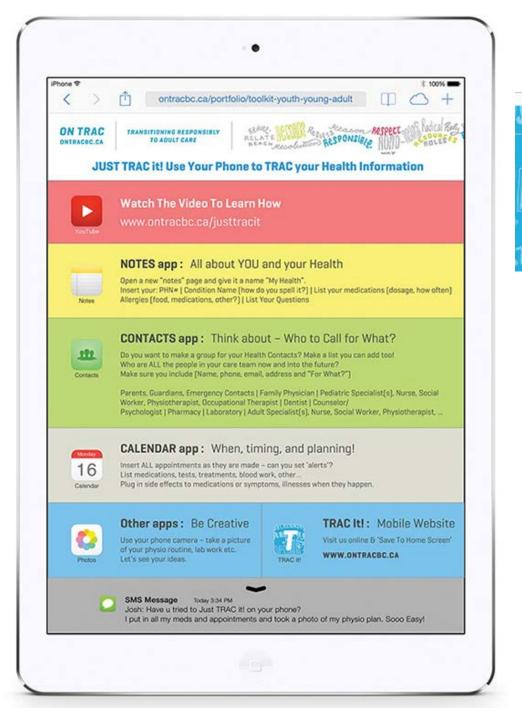
#### Do you have a cell phone?

- 1. Yes, of course I do and it's always with me.
- 2. Yes, but I do not always know where it is.
- 3. No, I do not have a cell phone.





http://ontracbc.ca/justtracit/





#### http://dontforgetthebubbles.com/

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