



## Transition Timeline Recommendations

The purpose of these transition recommendations is to support families understand the stages of Transition and support discussions with your CHD healthcare team. Transition should be personalized for each individual, in accordance with their chronological age, developmental stage and abilities. Active engagement in the transition process is vital for teens and young adults and families to prepare for a healthy life as an adult with CHD

### Life Stages

#### Introduction to Health: Age 2-7 years old

##### Goal - Understanding their body

Transition preparation begins when your child is a toddler; coach them to be able to:

- Describe how they feel (their symptoms)
- Say how it makes them feel (emotions about their symptoms)
- Show what hurts or is uncomfortable

Direct questions from your healthcare towards your child, allow them time to answer and support their answer with your observations of how they are doing. Allowing children to describe their feelings empowers them and provides a foundation for learning.

#### Introduction to Transition: Age 8-11 years old

##### Goal - Awareness of CHD

- Support learning about their cardiac condition through pictures and simple language
- Support learning about symptoms that warrant immediate medical attention
- Support developing knowledge about the names and scheduling of medications
- Request your healthcare provider speak directly to your child. Support your child to answer questions about symptoms and encourage them to ask questions of their health care providers. Providing some responsibilities for your child is important as children welcome impressing their parents and physicians at this stage of development.

#### Early Transition: Age 12-14 years old

##### Goal - Knowledge of CHD

- Support them to be able to explain their medical condition(s) and health history to others
- Support them to explain the signs and symptoms of a worsening health condition
- Support them to verbalize name, purpose, and amount of each medication they are taking
- Support them to explain the medical devices they require (i.e. pacemaker, wheelchair, vent, etc)
- Support their understanding for tests and procedures

#### Middle Transition: Age 15-17 years old

##### Goal - Independently manage CHD

- Support increasing confidence in asking questions and talking to their healthcare team
- Support awareness of the adult health care system and culture
- Support independence in refilling medications
- Support an understanding of their healthcare team and health services available to them (social worker, dietician, psychologist and family doctor)
- Support them to arrange appointments with increasing levels of independence
- Arrange for a ride or take bus to appointments
- Reinforce awareness of transfer to an adult cardiology team once turns 18

Adolescence is associated with exploration of social roles and identity formation; which can involve an increase in risk-taking behaviours. Teens themselves are experiencing transition in a much broader context. Examples include changes and decision making with respect to friendships, romantic relationships, living situations, and academic and career decisions.

##### Engagement in Health Behaviours

- Understand the importance of taking their medications. Understand the risks of medication non-adherence
- Understand how to cope with stress, anxiety or depression. Know how to get mental health care if needed
- Understand the importance of balancing social life with school and healthcare management
- Understand the impact and risks of cannabis, vaping, smoking, alcohol and drugs on with their CHD

- Understand how CHD and/or treatment may impact sexual health and/or pregnancy

### **Late Transition: Age 18-21 years old**

#### **Goal - Assume responsibility for own health - with support**

- Develops knowledge about health insurance
- Has an awareness of medication interactions and effect on cardiac condition
- Understand their legal rights as a patient
- Develops confidence in consent and release of information Develops support system - someone/people they can ask for help when needed
- Attached to an adult care provider for all their health care needs
- Develops confidence to inform healthcare providers their understanding of discussion about their health condition
- Develops comfort requesting information about tests, treatment options, and risks/benefits.

#### **Engagement in Health Behaviours**

- Planning for school and career considering health insurance conditions
- Navigates securing resources and accommodations for school or work
- Independently manage own healthcare (medications, immunizations, healthcare appointments, refill prescriptions and contacting healthcare providers, etc.)
- Knowledgeable about accessing student health services and mental health services as needed

For youth with a chronic health condition, the transition to adult care can be a challenge. They experience changes that impact their health care including: insurance, transitioning from paediatric to an adult care, and once reaching the age of 18 - the responsibility of health care decision making. These life changes can be confusing and overwhelming, youth and parents may question how best to navigate.

The experience of healthcare professionals and multiple research studies support the use of technology in educating and supporting youths and their families. Apps, websites (see our [Tools and Resources](#) section) and online support groups (follow CCHA on social media) that are inclusive of all age groups living with CHD or other chronic conditions are known to increase youth engagement.

Visit our [Tools and Resources](#) page for helpful websites, toolkits and apps to assist youth, parents and families and facilitate the transition to adult CHD care.

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

References 1.Mackie et al: Transition and Transfer From Pediatric to Adult Congenital Heart Disease Care in Canada: Call for Strategic Implementation. Canadian Journal of Cardiology 35 (2019) | 2. Lui, G et al.: Management of Cardiovascular Risk Factors in Adults with Congenital Heart Disease. JAMA v3(6) (2014) | [www.childrens.com](http://www.childrens.com) | [jamanetwork.com](http://jamanetwork.com) | [www.healthychildren.org](http://www.healthychildren.org) | [health.usnews.com](http://health.usnews.com) | [patientengagementhit.com](http://patientengagementhit.com) | [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov) | [pediatrics.aappublications.org](http://pediatrics.aappublications.org) | [www.the-hospitalist.org](http://www.the-hospitalist.org) | [www.cheo.on.ca](http://www.cheo.on.ca) | [www.childrenshealthcarecanada.ca](http://www.childrenshealthcarecanada.ca) | [www.bcchildrens.ca](http://www.bcchildrens.ca) | [www.sickkids.ca](http://www.sickkids.ca)

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