



Transition



Transition

Children pass many milestones growing up, the first day of kindergarten, the liberty of becoming a licensed driver and -going-off-to-college or university, just to name a few. Parents give the necessary “talks” about responsibility, risk and behaviour. These transitions are thought of as rites of passage.

Prepping our youth for entry into adult health care should be no different than transitioning into college, university or into the workforce. At some point, most individuals will assume responsibility for maintaining and managing their own health. There remains work to do to support youth to make successful transitions to adult health care.

Some transitions can be emotionally challenging and stressful for both the youth and families. Youth transitioning from paediatric cardiology to adult CHD care is challenging as they leave cardiology healthcare teams they may have known for their entire life and enter the unfamiliar world of adult health care.

CHD FACT

Research has shown that barriers to successful transition to adult CHD care were emotional attachment to the paediatric cardiologist by parents (87%) and patients (86%). Provider attachment to patients and families was identified as a barrier by 70%.¹

Healthcare transition is a purposeful, planned movement of youth with chronic health conditions from family oriented care (pediatric care) that relies on significant parental involvement in decision making to an adult-oriented health care systems that requires increasingly autonomous and independent decision making and skill of patient to manage their health, sometimes without access to as many interdisciplinary resources.

Healthcare transfer is a single point in time, when youth and their medical records move from paediatric to adult providers, which is mandated to occur at the age of 18 throughout much of Canada. Transition is a lengthy process ideally beginning by the age of about 10 years and continuing through to their mid-20s.

Healthcare transition is important for youth, whether they have a chronic health issue or not -- to optimize their lifelong health.

A Canadian study found 3 factors that are linked to a successful transition¹:

- **Health knowledge.** Youth with CHD who are knowledgeable about their heart condition have increased comfort levels communicating with health care providers. Parental knowledge of their CHD also correlates positively with patient knowledge.
- **Self-management.** Self-management of a health condition refers to a person's ability to manage their health care needs. This would include completing tasks such as arranging medical appointments, filling prescriptions, and communicating and decision making with healthcare providers. For more information visit our [Tools and Resources](#) section
- **Self-advocacy.** Self-advocacy is the ability of an individual to advocate for their needs. For individuals with a congenital heart condition, self-advocacy skills are necessary for communication with health care providers, managing their day to day activities and making effective use of community resources. Developing self-advocacy skills involves preparing youth to assume ownership of their health and supporting parents to facilitate this independence.

It was estimated in 2016 approximately 5200 teens in Canada would transition into the adult CHD system¹, with this number continuing to grow each year. Guidelines recommend that all CHD patients be seen at least once in an ACHD centre to have their diagnosis confirmed by an adult CHD cardiology team. Those with moderate and complex CHD in the classifications will require active surveillance by an ACHD team. In some with simple CHD shared care with a community cardiology team may provide acceptable surveillance.

Transition care is important work for youth, families and health care teams. We must do it, and do it well.

Risk

Youth is associated with exploring social roles and identity formation; which can involve an increase in risky behaviours. Youth experience transition in a much broader context such as changes with respect to friendships, romantic relationships, living situations, and academic and career decisions.

There are differences between adult and paediatric health care models. Paediatric care is family oriented and relies on significant parental involvement in decision making; in contrast adult care supports individual decision making and requires the individual to determine the role of their support systems.

CHD FACT

Adults with moderate or complex CHD are at higher risk of other health issues such as heart attack, stroke, heart failure, diabetes and even premature death. Adults with CHD have higher rates of mental health challenges such as anxiety and depression.²

Risks associated with an unsuccessful transition to adult care include:

- Adults with moderate or complex CHD live at risk of increased cardiac and other health concerns. These risks include heart attack, stroke, heart failure, diabetes and even premature death.
- Pregnancy in women with CHD has increased risks to both the mother and the fetus. Contraception and pregnancy counselling should be discussed with your cardiology team for both women and men.
- Adults with CHD have higher rates of mental health conditions; specifically depression and anxiety -- which are known to have an effect on their health-related quality of life.
- Research has demonstrated that specialized ACHD care can significantly reduce mortality for adults living with CHD.

Youth with CHD frequently have long periods of stability and well being, where physical symptoms and medications may not be part of their daily lives. Absence of symptoms may result in underestimating the severity of their CHD, and they may not recognize the value of specialized ACHD care or the potential for long term complications. Living with CHD, may require invasive and specialized procedures at certain periods across the lifespan – involvement of an ACHD centre will provide monitoring and appropriate intervention as part of the regular surveillance.

Positive experiences of receiving ACHD care include:

- Increased autonomy and responsibility
- Opportunities to discuss adult focused health issues (eg, family planning)

See our [Transition timeline recommendations](#) for more information about the stages of Transition.

For helpful websites, toolkits and apps to assist youth, parents and families and facilitate the transition to adult CHD care at visit our [Tools and Resources](#) 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 | jamanetwork.com | www.healthychildren.org | health.usnews.com | patientengagementhit.com | www.ncbi.nlm.nih.gov | pediatrics.aappublications.org | www.the-hospitalist.org | www.cheo.on.ca | www.childrenshealthcarecanada.ca | www.bcchildrens.ca | www.sickkids.ca

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