

Info about transition for mothers, fathers and other important adults!

Congratulations! Your “child” (teen or young adult) is graduating from pediatric cardiology care and moving (or might have already moved) to the world of adult congenital heart disease (ACHD) care! We know that you have probably played a very important role in managing their health care.

For some teens and young adults, the transition to ACHD care can be a confusing time. They might have a bunch of questions and concerns. We understand that this also means changes for their parents and other important adults in their lives. Moving from the familiarity of people and places in the pediatric hospital to a new ACHD team can bring a mix of emotions, including excitement, fear, relief and sadness.

Why is it so important to help young people gradually take increased responsibility for their health care?

Your child’s brain is still developing – this probably doesn’t surprise you! Our brains don’t fully develop until at least our mid-20s. The last things that develop are the ability to plan ahead, resist impulses, and tune out distractions. These skills come with practice. Now is the time that your child can start practicing to make decisions about their health.

Teens and young adults differ in their abilities and challenges. Some will one day be able to assume full responsibility for their health care oversight. And others might always rely, at least partially, on other adults to help manage their health. **Regardless, the aim is to prepare them to live as independent and full lives as possible for them!**

You might have noticed that your child is becoming more independent. You might not like their hair colour or taste in music, but that’s okay! Teens and young adults try new things to figure out who they are, what they like, and what they want to do. Becoming more independent is an important part of development. We know this can be scary for parents who might wonder whether their children are ready for this. **In order for teens to gradually take charge of their health, they need opportunities for practice** - they might do things differently than you and may make mistakes. But these are important parts of the learning process. Be patient – give them a chance to make mistakes and learn from them.

We know it’s not always easy to “let go,” but we think it’s important that teens and young adults begin to take steps to manage their own health care. **This will help them realize the importance of life-long cardiac care and be able to better handle health-related situations that arise in the future.** Now it’s time to teach and encourage your teen to speak up to get what they need.

How to be a transition coach

- Remember what it was like when you were a teenager! It's natural to seek a bit of independence!
- Provide your teen and young adult "child" with support and guidance as they take on the responsibility of managing their heart condition.
- Maintain open lines of communication, but still let your child maintain their privacy.
- Help your child develop the skills to manage their heart condition and increase independence by giving them responsibilities at home.
- Work toward gradually shifting your role as the manager of your child's health care. It's time for your child to learn how to take increased responsibility. But it's still important that you continue to provide emotional support.
- Help your child learn about their cardiac condition, treatment, and future health. Be patient and repeat your message in different ways.
- If your child hasn't done so already, they might want to create a portable health summary they can carry in their wallet (check out www.sickkids.ca/myhealthpassport).
- Give your child time to talk to doctors and nurses on their own at clinic visits. This will help them develop the skills to communicate with their medical team.
- Help your child develop other self-management skills like:
 - Booking (and showing up for) medical appointments
 - Calling to refill prescriptions
 - Keeping a record (like a file or binder) of medical info
 - Keeping a list of questions to ask their doctor or nurse
 - Knowing what to do in an emergency
- Help your child prepare to talk to new health providers (including in the ACHD team) by practicing to say the following:
 - A summary of their medical condition
 - How they have been feeling lately (any symptoms?)
 - Their most important questions for the medical team
- Celebrate graduation from pediatric care and the process of transitioning to ACHD care! **This is an exciting new chapter in your child's life...and your life!**