

Transition: The basics for parents and caregivers

An information sheet on transitioning to adult-based care

Transition is an important process for you as a parent or caregiver of a young person who is stepping into adulthood. As your youth becomes more independent, other transitions will happen, too. New experiences might include starting college or university, moving away, living on their own, joining the workforce, or becoming a parent. Your youth could benefit from your guidance and experience with these adult transitions.

Although health care transition is like other transitions in your youth's life, it still comes with its own unique challenges. Your role as the primary caregiver will evolve considerably and it is important to remember that your youth will still need a lot of support. Sometimes you might find it hard to step back. This may happen when you are not sure if your youth is ready to take over certain tasks or responsibilities. You will need to find a balance between letting your youth manage their own condition with making sure they stay healthy. Talking openly with your youth and teamwork are vital during this time.

Aims of Transition:

- To provide high quality health care that is appropriate for your youth's age and development and is presented in a way they understand.
- To help your youth develop skills and be confident in communication, decision-making and self-care.
- To provide support and guidance for your youth.
- To provide support and guidance for you as parents/caregivers.
- Ensure that you are attending to your own needs during the transition process: self-care is important when big changes are occurring.
- As youth are preparing to transfer to adult-based care, it is important for the family physician to be involved in this process. He or she is a key player during transition and will be a lifelong resource.
- While in pediatric care, your youth's care team will offer support and guidance through this process. The adult team will orient youth to the new facility and care team. Your youth's family physician is a consistent presence throughout this process, helping to coordinate, navigate and provide their primary care needs.

Key points for parents and caregivers:

- Transition is a natural step for a young person and is best achieved with your support and encouragement.
- You and your youth have the right to participate in the whole transition process.

“Your involvement in your youth’s transition is important as it will help you to support them during this time of change.”

Transition steps:

Introduction

This is the time to start talking about the concept of transition. At this time, we will explore your youth’s skills, abilities and understanding on how to manage their health condition.

Planning/Preparation

This time is about developing your youth’s transition plan with the health care team and your youth.

The responsibility for your youth’s health care is now shifting from you and the health care team to the youth.

Transfer

This time is about exchanging information between your youth’s current health care team and their future health care team. When possible, an opportunity to meet your youth’s future health care team prior to transfer is arranged.

The point of transfer marks a time when you will no longer be receiving direct care from your pediatric team.

Transition challenges:

Transition from pediatric to adult-based care can be an exciting time for you and your family. It’s normal to feel emotions like fear, relief or even sadness. It helps to be prepared by knowing about how things work in the adult-based health care system and your role in preparing your youth for this transition.

Challenges may include:

- A changing role from managing your youth’s care to becoming more of a support and resource.
- The potential to feel excluded or out of the loop as your youth takes on more ownership of their care.
- Concern about your youth’s readiness to transfer to adult services and growing independence.
- Adjusting to adult health services and different processes and expectations.

Your youth will also face their own challenges:

- Going to an environment that is unfamiliar and a team that is not known.
- Questions about the differences between pediatric and adult-based care.
- The feeling of having to retell their health care ‘story’ when transferring to adult-based care.
- Balancing the management of their health condition with all of the other things that are important to them.