





A time of transition

Many young people that are treated at the IWK Health Centre will eventually need to be transferred to adult-based care. The process that supports this transfer is called transition. Transition helps your youth to develop increased independence and responsibility for their health.

Transition involves a process that eventually results in your youth's health care being transferred to the most appropriate adult service. Throughout transition, your youth will be given an opportunity to develop skills and knowledge in areas that are relevant to navigating a new health service.

Transitions are journeys that all people go through, individually or with others important to them. Going from pediatric to adult-based care is another transition that youth experience with their families. It is part of growing up.

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 adultbased system and the role you have in preparing your youth for this transition. While in pediatric care, your youth's care team will offer support and guidance throughout this process. The adult team will orient you and your youth to the new facility and care team.

How will care change?

Just like your pediatric care team has expertise in pediatric care, the members of the adult-based care team have specific skills and expertise in the health conditions and challenges experienced by adults.

One of the biggest changes for you as the parent/caregiver is the gradual shift in responsibility for managing your youth's health condition. Your youth may already have begun to take greater responsibility, having developed greater knowledge and skills over time.

Continued care is important

Primary Health It's likely that the health care team at the IWK has followed your youth for a while. Families who receive specialized pediatric care do not always have regular appointments with their primary care provider(s) (family physician and/or nurse practitioner). As youth are preparing to transfer to adult-based care, it is important for their primary care provider(s) to be involved in this process. They are a key player during transition and will be a lifelong resource.

Your primary care providers are there to support and oversee your youth's overall health (for example, management of a common cold, vaccinations and contraception). The family physician or nurse practitioner needs to receive up to date information on your youth's condition and plan of care. This is important so that they can best support and manage your youth's health.

Specialized Care

Attending appointments with the adult care specialist is also very important. The adult care specialist is an expert in their chosen specialty (for example, cardiology, rheumatology or orthopedics). The adult care specialist will offer focused attention on the body system involved in your youth's health condition. Alternatively, the family physician or nurse practitioner looks at the body in its entirety to ensure optimal overall health.

Together, your youth's primary care provider(s) and the adult care specialist will offer your youth better understanding of their health condition and how to maintain optimal health!

"Meeting new team members and developing trusting relationships takes time"



Your role in helping transition

Your role as the parent/caregiver will evolve considerably from the mid-teen years and onward but it is important to remember that your youth will still need a lot of support. Your role will change from managing your youth's care to becoming more of a support and resource. 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. It is important to find a balance between letting your youth manage their own condition with making sure they stay healthy. Talking openly with your youth is vital during this time.

As your youth becomes more independent, many transitions will happen. New experiences might include starting college or university, moving, living on their own, joining the workforce or becoming a parent. Your youth could benefit from your guidance and experience with these adult transitions.

Things to consider before your youth's first adult-based appointment

Communication and Information Sharing

It is important that your youth learns how to communicate and share information with their health care team. As a parent/caregiver, one of your roles is to provide opportunities for your youth to learn and practice effective communication skills.

Many youth have found the "GLADD" method to be a helpful tool to guide communication and information sharing.

"GLADD" can be used to help youth talk with health professionals as well as to help youth share and receive information with members of their health care team.



GLADD

Give

Encourage your youth to write down how they have been feeling before they attend their clinic appointments and discuss this with the health care team.

Listen

Encourage your youth to listen carefully to their health care providers so that they can learn all they can about their condition and opportunities for self care.

Support your youth to consider how they will remember the information that has been provided during their clinic appointment (for example, to bring a support person or to write down the information shared by their health care team).

Ask

Support your youth to ask their health care team any questions they have about their health. Emphasize that their questions are important.

Remind your youth that they can ask the team to provide clarity if they have any questions about their care. You may need to support your youth to help them visualize the future. Start to ask questions about how their health care condition will affect things such as future schooling or employment.

Decide

At every visit with a health care professional, decisions need to be made about what to do next. Make sure that your youth is involved with the plan of care.

Prior to leaving pediatric care, gradually allow your youth to make more decisions about their health care (for example, whether they want to take a short acting or a long acting medication).

Do

Help your youth carry out their responsibilities for their health care.

Ask your youth how things are going with any changes in their health care plan. Ask how they would like to be supported in remembering to follow through with their responsibilities.



Planning ahead

- Help your youth know about their condition and past medical history
- Prior to a health care appointment, encourage your youth to think about their health care concerns
- Practice with your youth about how they will communicate their concerns to the team
- Help them to be knowledgeable about their medication (For example, do they need new prescriptions or refills? Could they communicate information about their dosage?)
- Encourage your youth to identify a support person to accompany them to their adult clinic appointment (this could be you, a significant other or friend)
- Help your youth to plan and navigate getting to their adult appointment (bus schedules, parking, general way finding, and time considerations for registration)

Things youth should be asking the adult-based care team

- What is the clinic's policy on cancelled or missed appointments?
- Will the doctor call in a prescription if I run out of medication?
- Who do I see if I need to see a physiotherapist, occupational therapist or social worker? Who coordinates this?
- Where do I go for blood work or x-rays?
- Who can I call with a problem related to my condition?
- What are the clinic phone numbers and when is the clinic open?
- When will I have my next appointment?
- Is my adult team communicating with my family physician? How is information relayed?

Final tips

- Stay involved in the various aspects of your youth's health and medical care
- Provide guidance and support as they take on more responsibilities
- Foster independence to help them confidently take control of their health
- Assess their knowledge, skills and progress as they near the time of transfer to adult based care
- Continue to provide support after transfer of care and through the young adult years

Resources

Here are some great resources that may help you and your youth prepare to move to adult care:

http://www.gottransition.org/youthfamilies/index.cfm

http://www.headspace.org.au

http://www.prevnet.ca

http://kidshealth.org/teen/your_mind/problems/deal_chronic_illness.html

http://teens.drugabuse.gov

www.cmha.ca

www.teenmentalhealth.org

Your teams at the IWK Health Centre and at your adult-care clinic wish adult-care clinic wish adult-care step your family the very best your family the very best your family the very best toward adulthood.



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