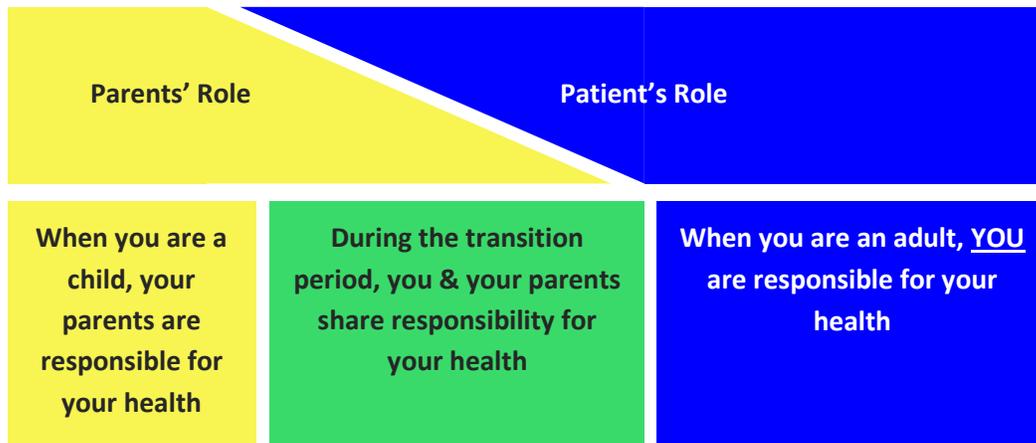


# TRANSITION SKILLS

## TRANSITION INVOLVES A NUMBER OF CHANGES

### 1. Patients taking responsibility for their own health, and healthcare decisions



What does it mean to be “responsible for your own health”?

Being responsible for your health means that you are the one who ensures that you do all the things that help keep you well:

- You keep track of, arrange transportation for, and attend all medical appointments – doctor’s appointments, endoscopy appointments, and blood tests. If you are not able to attend an appointment, you should call in advance to cancel or re-schedule. We understand that life is busy and things change, but if you cannot attend you should call so that someone else can be booked into that appointment time. The earlier you call to change the better.
- You know your medical history and monitor for symptoms of your disease - this means you need to listen to your body and know what symptoms could mean that your disease is flaring or is active. Depending on your disease, your symptoms may be different. Common symptoms of a “flare” include: abdominal pain or cramping, diarrhea, bleeding, fatigue and weight loss.
- Knowing what to do or who to call when you are having symptoms of a disease “flare” is VERY IMPORTANT. The first step is to tell someone and ask for help.

Who to call/What to do:

- Call the IBD Nurse – many IBD specialists will have a nurse you can talk to about your symptoms (this is similar to pediatrics). It is important for YOU to call – they will listen to

you and ask questions about what you are experiencing. Often they will ask you to get blood and/or stool tests done to assess how sick you are.

- Call your IBD Specialist/Gastroenterologist to make an appointment – if you are sick – you need to let the office know so that they can book you sooner.
  - Call your Family Doctor or General Practitioner to make an appointment – tell the office that you think your IBD is flaring.
  - If you are really sick or cannot wait until the office is open (e.g. Over a weekend or Holiday Season), go to emergency. It is best to go to the hospital where your doctor works, but we know that this is not always possible.
- Take your medication as prescribed (link to medication section).
  - Pay for your medications or find out about insurance coverage – Since the majority of patients with IBD are on some type of medication to get and/or keep them well, it is important that you have the money to pay for your medications. Most patients have an insurance plan(s) to pay for their medications. Depending on your age and your student status, you may or may not be covered under your parents’ insurance plan. It is your responsibility to know. If you do not have coverage to medications, each province has insurance that you can apply for to help cover the cost. In Alberta, it is Non-Group Blue Cross. You will need to pay the premiums associated with these plans, but often the premium is less expensive than the cost of the medication if you do not have an insurance plan.
  - Make decisions about your health – One of the ethical principles of medicine is the right to autonomy. Autonomy refers to the right to refuse or choose your treatment. You have a right to decide for yourself, provided that you have the capacity to understand the risks and benefits and have the ability to make the decision. When you are a minor, your parents are usually the ones who make decisions regarding your health. An example of this is providing consent for a procedure, like a colonoscopy – as a minor, your parents decide and sign the consent form and you only have to agree (also called “assent”). As an adult, you will be asked to sign the consent form when you go for endoscopy.
  - During appointments, you talk about any health issues you are experiencing – It might be helpful to jot down questions or notes as things come up between appointments, so that you remember to ask when you see the gastroenterologist. Speaking up during appointments also means that you answer all of the questions asked by the nurse or gastroenterologist, on your own.
- 2. Parents transfer the responsibility of their child’s health, and healthcare decisions to the child.**

“Growing up” means that your parents will need to allow you to take responsibility for yourself, including your health. This is a part of life, where your parents prepare you to be independent members of society.

This is a process, which occurs as you begin to take responsibility for yourself. The best way to get your parents to transfer this responsibly to you is for you to show them that you are responsible and can be trusted. Taking responsibility does not mean that your parents are not involved – parents are excellent resources throughout life, for example:

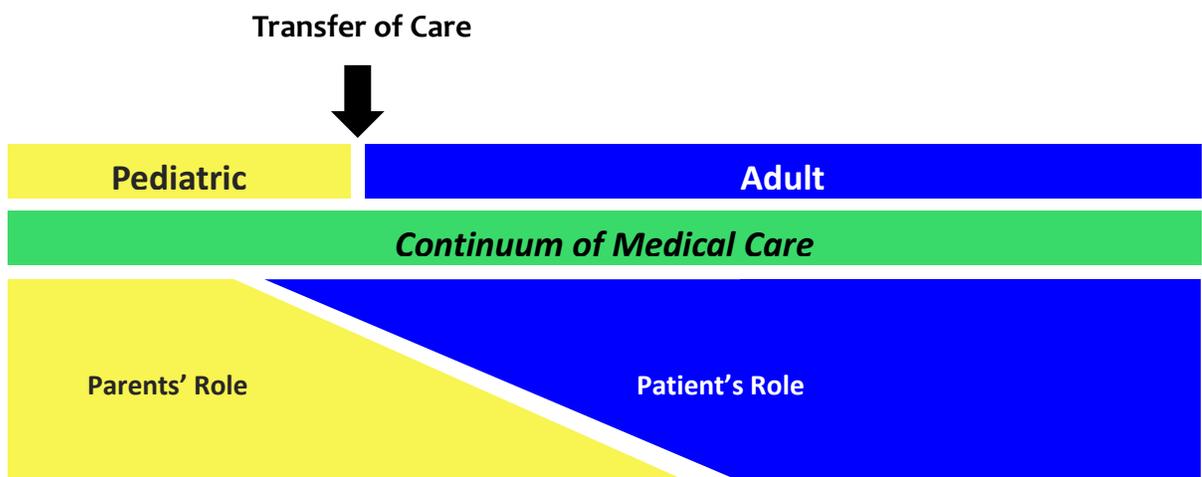
- a) they provide good advice to help you make decisions,
- b) are a source of emotional support, and
- c) may even help you pay for medications or other healthcare related expenses.

Sometimes parents have difficulty giving up this responsibility, so be gentle with them as you become independent and take responsibility for your health.

### 3. Transfer of care from pediatric to adult care providers

Transfer of care from pediatric care providers to adult care providers. In this event, your chart and responsibility for your care moves to the adult IBD Specialist/Gastroenterologist. Until you have your first appointment with the adult provider, you are still under the care of the pediatric team. After you see the adult IBD specialist in person, they will take responsibility for your IBD care.

In most parts of Canada, including Alberta, transfer of care from pediatrics needs to occur prior to your 18<sup>th</sup> birthday. Pediatricians are not allowed to continue to care for patients after you turn 18 years old.



Watch a video of the final appointment in pediatric care

**Listen to people's experiences of transition (Coming soon!)**

**HOW IS ADULT CARE DIFFERENT?**

	<b>Pediatric</b>	<b>Adult</b>
Who Provides Care?	Multidisciplinary team of physicians, nurses, dieticians, social workers	Gastroenterologist/IBD Specialist and possibly an IBD nurse specialist
Focus of Care	Family	Patient
Who makes decisions?	Focus on collaboration (parents, physicians, patients)	Focus on autonomy (patients making decisions)
Resources	Many resources are available to patients & families at <u>no cost</u>	Patients are responsible to pay for medications, or have insurance to pay for medications
Procedures	An anesthesiologist will be present to put you to sleep for the procedure	Some gastroenterologists may use conscious sedation for your procedures or an anesthesiologist may be present to put you to sleep
Hospitalization	You will stay in the pediatric ward and your parents can stay overnight if they choose to	Family and visitors are allowed to see you during visiting hours only

## PLANNING FOR INSURANCE CHANGES

### Public Insurance

This is your provincial health plan that covers doctors' visits and hospitalization – All basic, necessary medical treatment

### Private Insurance

This covers costs outside of those covered by public insurance and is usually organized through an employer or college/university

### Your Employee Benefits

Some companies offer a comprehensive benefits package

### Your School Plan

If you are enrolled in university or college, your tuition likely includes the cost of a health plan

### Parent Employee Benefits

Your parent's company may offer benefits that cover you – ask them what age you are covered until

**When you transition to adult care, biologic medications will no longer be covered by the provincial health plan. If you are not in school, your parents' plans may not cover your medications. It is important to look into insurance to help you cover costs, BEFORE you turn 18. You may need to purchase your own plan.**



### Supplementary Health Benefits

These are health insurance plans (usually government subsidized) which you can purchase to cover the costs of medications, if your private plans do not cover 100%. They are offered by different companies in each province, so ask your nurse or gastroenterologist what insurance provider provides the best coverage for your medications in your province. If you are on a biologic, you will have a support coordinator that is able to help you and your parents with this insurance transition.

## NON-GROUP BLUE CROSS – FOR ALBERTA RESIDENTS:

All residents of Alberta over the age of 18 can apply and will qualify for Alberta Non Group Blue Cross Insurance. Information regarding this coverage is available online at <http://www.health.alberta.ca/services/drugs-non-group.html>

Alberta Non Group Blue Cross is Government Sponsored Health Expense Insurance and is not an individual coverage plan with options to pick your plan.

Applications for Non-Group Alberta Blue Cross (medications only) coverage are available online at <http://www.health.alberta.ca/AHCIP/forms-Blue-Cross.html>. The patient mails or faxes the completed application to Alberta Blue Cross.

There is a 3-month waiting period for all new applications counting from the first day of the following month. An application can be submitted on any day but will only be processed by Alberta Blue Cross on the first day of the following month. For example, it does not matter if you apply on January 1st or the 30th day of the month, all applications that are in the office on the day prior to the first day of the month will be considered accepted on the 1st of February and coverage will be effective May 1st

If you have private insurance that does not cover 100% of the cost, you can also apply for Alberta Non Group Blue Cross coverage as a supplementary insurance to cover the remaining cost of medication.

You pay the monthly premium. If the premium is not paid, the insurance will be cancelled without any notice from Alberta Blue Cross.

Insurance coverage is for 70% of the cost of the medication with a maximum patient co-pay of \$25.00 (e.g. any medication costing more than \$85.00 will only cost the patient \$25.00)

If you are married or have dependents (children), you must pay for family coverage and cannot choose single coverage.

Special Authorization is when additional forms are required to be sent in from your doctor's office to confirm why a certain medication is needed. It is important to ask your pharmacist if you notice a medication is not being covered under your insurance

- Medications not listed on the medication benefit list (6-Mecaptopurine)
- Biologics (Remicade, Humira, etc)
- Antibiotics (Vancomycin, etc)