

## Patients at 17 Years and Older Taking Charge

- ✓ Can explain how IBD affects digestive system and rest of body.
- ✓ Knows why each medication is taken and can prepare medication in advance to accommodate trips, vacations, and overnights
- ✓ Knows what medications not to take as they might interact with current medication or might worsen disease.
- ✓ Knows when having flare-up and when to see a doctor.
- ✓ Knows how to get in touch with IBD nurse if questions or problems arise.
- ✓ Can schedule follow up appointments with gastroenterologist.
- ✓ Is comfortable asking my doctor/nurse why tests are required, whether there are other treatment options, the benefits and harms of various options, and the likelihood of them happening.
- ✓ Tell doctor/nurse if do not understand what they are talking about during medical appointments.
- ✓ Ideally would independently manage own healthcare (medications, immunizations, healthcare appointments, refill prescriptions and contact healthcare provider, etc.).
- ✓ Can communicate information about health insurance coverage and necessary steps to maintain coverage

In collaboration with the TRACC Network



# Transition of the Adolescent Patient to Adult Care

## A Guidebook for Parents



## Inflammatory bowel disease (IBD) is a life-long condition and by the age of 18, all of our patients must be transferred to adult gastroenterologists

Adult patients are expected to:

- ✓ describe their medical histories
- ✓ ask questions
- ✓ make decisions regarding their health
- ✓ manage their own illness

The transition from pediatric to adult care may be quite a **challenge** if you and your teen are not adequately prepared.

Transition is a **family matter** and in order to ensure that the transition to adult care goes smoothly, the team at the **Children's Hospital of Eastern Ontario (CHEO)** will be taking a gradual approach.



Starting at early to mid adolescence, your **CHEO team** will spend some time talking to your teen alone during the appointment. He/she will be encouraged to ask and answer questions and to talk about concerns. A variety of tools will be used by the members of the IBD team in order to teach your teen what he/she needs to know and develop his/her understanding of the disease, medications and health service resources. As parents, your role will change from being the decision maker to supporting your teen in his/her decisions, helping them to develop autonomy in health-related matters.

Be assured that our approach will take into account your teen's level of maturity and personal development and you will remain involved in his/her care. Our goal is to help your teen to become independent and self-reliant by building up his/her knowledge and confidence so that you he/she can successfully take charge of his/her own health care when entering the "adult world".

## Patients at 15-16 Years Building Knowledge and Practicing Independence

- ✓ Carries medical information regarding condition and medications (purse, wallet, backpack, phone, etc).
- ✓ Knows which websites and books contains credible information about disease.
- ✓ Understands risks of medication non-adherence.
- ✓ Can contact pharmacy to get medication refills.
- ✓ Can make changes to medication/treatments as recommended by IBD healthcare team.
- ✓ Knows what can trigger flares.
- ✓ Starts appointments unaccompanied, answers questions, and talks with IBD doctor/nurse when they don't like or have trouble following a treatment plan.
- ✓ Knows other health services available (social worker, dietician, psychologist, and family doctor).
- ✓ Knows names and purposes of routine tests (blood tests).
- ✓ Knows will be transferred to adults gastroenterologist when turns 18.
- ✓ Knows how to balance social life with school and health care management.
- ✓ Knows what to do cope with stress and who to talk to if depressed.
- ✓ Understands impact of drugs, smoking and alcohol on condition.
- ✓ Knows how disease and/or treatment may impact sexual health.

## IBD CENTRE TRANSITION PLAN

Following are recommendations for timelines and educational goals during the transition period, which are based on those developed by the NASPGHAN and other Pediatric IBD centres to meet important milestones between the ages of 12 and 17.

This is a general transition plan which will be adapted according to each individual's knowledge and needs.

All members of your IBD team will provide learning assistance, but your teen will also require your support in order to help him/her meet the following self- management goals.

### Patients at 12-14 Years New Knowledge and Responsibilities

- ✓ Can name diagnosis, location of IBD, how IBD affects them on a daily basis, and how they feel when disease is active.
- ✓ Can name medications and/or treatments, dosage and timing of treatments (medications, vitamins, and nutritional products), possible side effects from medications, and how they remember to take medications.
- ✓ Can describe symptoms to doctor and healthcare team.
- ✓ Can list the foods and/or activities that make them feel bad or uncomfortable.
- ✓ Knows things to do to feel better (heating pad, hot bath, relaxation, etc).
- ✓ Can use and read a thermometer and keep a stool and/or pain calendar.
- ✓ Can prioritize health issues that matter most and share them with the team
- ✓ Is an active team player (asks questions, takes part in decision-making, and contributes to health care plan).
- ✓ Shares past experiences (successes and challenges) and what matters most.
- ✓ Is honest and communicates openly, tells the team about what is not working or if they are having trouble with health care plan.
- ✓ Knows name of their gastroenterologist and IBD nurse.
- ✓ Can answer and at least one question during healthcare visits.
- ✓ Is comfortable asking questions at clinic visits and can ask at least one question during healthcare visits.
- ✓ Is comfortable telling the team when they have trouble following a treatment plan or think that something isn't working
- ✓ Can manage their IBD when away from home (bathroom access, taking medications, diet, etc).

## TIPS FOR PARENTS:

### How to empower teens with IBD to manage their own health



IBD is a life-long medical condition. The TRACC network aims to provide your teen with care, information and support for his/her transition; however **you** play a very important role in helping your teen learn about his/her disease and gradually take charge of his/her own healthcare.

Here are a few tips that may be helpful to you.

### Understanding IBD

**Have discussions at home and enable your teen to ask and answer questions during clinic visits.** These are all ways that help him/her to understand their condition. The TRACC and your IBD Centre will provide your teen with tools to help him/her prepare for discussions during their visits.

**Help your teen keep a binder, notebook or folder in his/her smart phone to organize all medical information.** You can help him/her to update it after each visit or after any changes in treatment or medication. In the binder or in an application on the smartphone, include a diary when symptoms change.

**Help your teen practice describing his/her medical condition** so that eventually he/she can explain it to others.



## Health Information Summary

Your teen should carry a card with him/her at all times that lists his/her medical condition, medications, allergies, healthcare providers' names and numbers, etc. A passport is available from the SickKids website. Your IBD nurse can help your teen to complete this if he/she is missing some information.

## Knowing Medications, Vitamins and Mineral Supplements

Your teen should know his/her medications:

- ✓ what they do
- ✓ doses
- ✓ side effects
- ✓ how and when to take the medications
- ✓ what may happen if the medications are not taken as prescribed
- ✓ what foods or medications can affect how well the medication works

Encourage your teen to eventually become the main person responsible for remembering to take his/her medications. Don't forget that it is normal for him/her to make some mistakes so you should still check to make sure that he/she is taking the medications correctly. Using a container with compartments for each day and filling it once a week works well and allows you to keep an eye on things.

Your teen should gradually learn when and how to call in for medication refills.

## Red Flags: Signs of Getting Sick

Your teen should know what symptoms are warning signs (red flags) that he/she is getting sick or needs to seek help.

If he/she is having problems, your teen should take part in phone discussions with the IBD Nurse.

Keep a diary of symptoms.



## Healthy Nutrition is Important



Selecting, preparing and eating healthy nutritious foods should be encouraged.

### Identify Allergies:

Your teen should be able to identify their food allergies or foods that may be bothersome to his/her condition.

## Independence

It is important that you encourage your teen to participate in healthcare decisions.

Attending part of their visit alone with their healthcare providers encourages independence and responsibility. It is also an opportunity for the gastroenterologist to discuss behaviors which may put your teen at risk for disease flare-ups.



Encourage your teen to take charge of making follow-up clinic appointments. Make sure that your teen knows how to use public transportation so that he/she can get to an appointment alone if necessary.

## Adult Care

By the age 18, he/she will be transferred to an adult gastroenterologist. You should start to discuss this with him/her early, so that he/she can get used to the idea. Your gastroenterologist will help you choose an adult provider and provide the medical summary to the new team.

## Medication Insurance

Medications can be very costly. Your teen should learn about his/her health insurance coverage and discuss future plans for obtaining independent insurance.