To the newest member of the IBD club:

There is clearly a lot going on for you right now and you're probably not very excited about it (understandably so). After being sick for so long you just want to feel better, not hear that your life is changing. But know that you're not in this alone, despite how it feels right now.

There is a lot to learn about and get used to with your new life. You may have to change how you eat, have tests done, take medicine, or be in the hospital sometimes. As overwhelming as it is right now, you will get through it. I did, and so can you.

Having Crohn's or ulcerative colitis will be a big part of your life now, but it doesn't have to run it. It probably feels like you're losing control of your life and body, but it doesn't have to be like that. You can still be as normal as you wish to be. Everyone can know or no one has to. You have that choice- to make this your focus or just another part of you.

Whether you have a ton of questions or you're too scared to even think of any- I hope you can use this book as a way to find answers and calm your fears. I've been through this and so have the other patients in here. So again, you are not alone and will get through this and come out cooler than you started.

-Emily, IBD club member for 16 years

Inflammatory Bowel Disease
Patient and Family Education Manual

Important Numbers:

University of Michigan Pediatric Gastroenterology Office	734-763-9650
For appointments, concerns/questions, and prescription refills (fax)	734-763-7359
Monday – Friday, 8:00 AM – 4:30 PM	
After hours, weekends, and holidays – for urgent issues only. Ask for the on-call Pediatric GI physician	1-800-936-4000
Pediatric Infusion Room	734-936-4184

Office Address (for mailing purposes only):
University of Michigan
Division of Pediatric Gastroenterology
1500 E. Medical Center Drive
MPB D5200, SPC 5718
Ann Arbor, MI 48109

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You can find this education manual online at:

http://www.med.umich.edu/mott/pdf/IBD-Education.pdf

Communicating with the Inflammatory Bowel Disease (IBD) Care Team

We believe that the best care is patient and family-centered. This means that communication between all members of the IBD care team (including the family and primary care physician) is important for successful disease management. We believe that creating an environment that is open to both asking questions and sharing concerns and problems is the key to providing the best care to each child.

Communication is always a two-way street. We are here to listen and learn from patients and families as well as to provide care and education regarding IBD.

We believe that families need to be involved in their child's care and understand as much as possible about their medical issues. In addition, we understand that living with and managing a chronic illness can be both disruptive and stressful. The stress and disruption caused by IBD often creates a need for support from members of the IBD team. Our main concern is a child's long-term health and well-being, so we often spend time discussing emotional and developmental issues with families and patients.

Finally, we believe that adolescents should be viewed as care team members and not just as patients. This means that instead of passively receiving medical advice, an adolescent should learn to take an active role along with the rest of the team in raising concerns, taking responsibility, and helping make decisions. This helps adolescents gradually develop ownership of their medical care, understand health-related issues, and live a healthier lifestyle. This is why we encourage education, discussion, and questions with families and adolescents to help them gain knowledge and skills necessary for long term success into adulthood.

We look forward to working with your family and encourage you to call us with any questions or concerns you may have as you learn more about IBD.

Pediatric GI Care Team

Division Director:

Dr. M. James Lopez

Attendings:

Dr. Jeremy Adler

Dr. Jacob Bilhartz

Dr. Chris Dickinson

Dr. Frank DiPaola

Dr. Julia Mar

Dr. Grace Lee

Dr. Haley Neef

Dr. George Zacur

Dr. Andrew Singer

Dr. Pam Brown

Dr. Dana Steien

Fellows:

Dr. Vanessa Cardenas

Dr. Tina Morhardt

Dr. Tony Ljuldjuraj

Dr. Shanthi Kandavel

Dr. Lindsey Lawrence

Nurse Practitioners:

Keri Gisslen

Anne Wuerth

Tina Garcia

(Not Pictured)

Nurses:

Malerie Kachenmeister

Jamie Price

Dietician:

Lacy Amor

Members of the Pediatric IBD Team

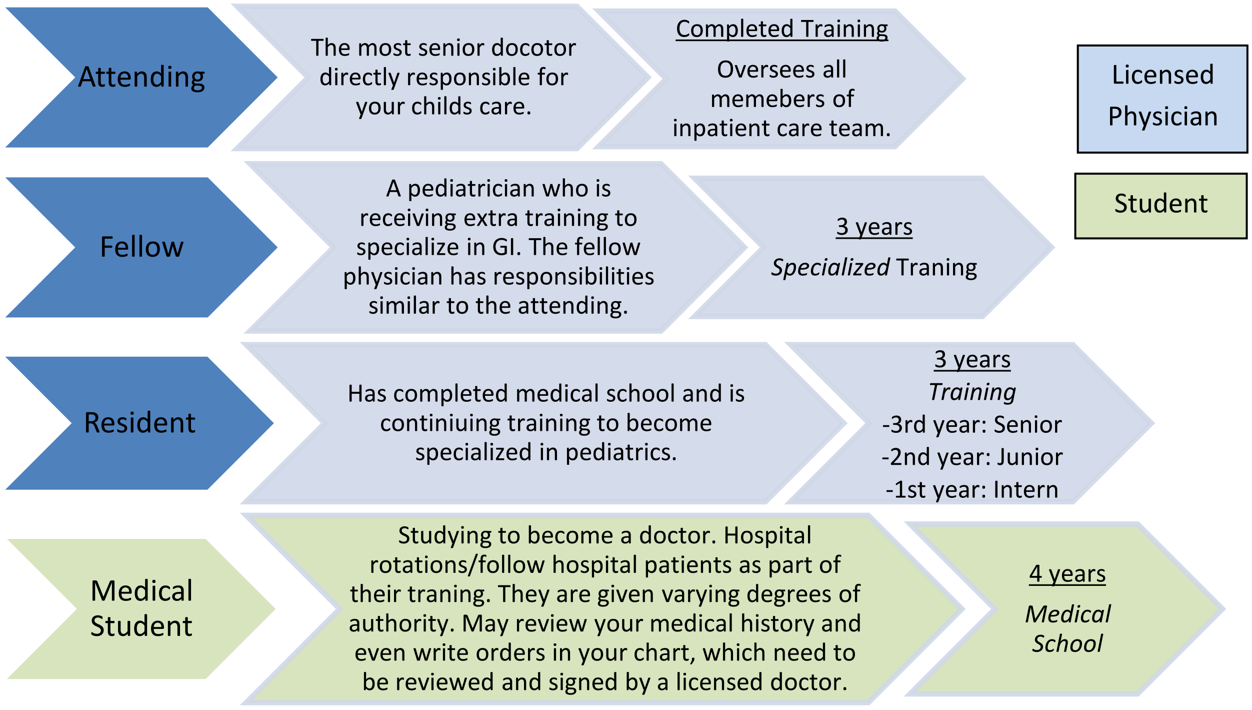
Attending physicians, fellow physicians, nurse practitioners, nurses, dietitians, social workers, office staff, and research staff: all are experts in caring for children and adolescents living with IBD. When a family comes for a visit or calls the clinic, they may interact with multiple members of the team. Each member has a different role in the care of patients.

Attending Physicians: Specially trained doctors who supervise a child's medical care in and out of the hospital. They evaluate patients, perform procedures, and discuss treatment plans. Attending physicians also play an important role in the education of medical students, resident physicians, and fellow physicians. They oversee the care of all patients in our practice.

Fellow Physicians: Fully trained doctors who have completed training in general pediatrics and are undergoing additional advanced training to specialize in the care of pediatric patients with gastrointestinal and liver diseases. They also evaluate patients, order tests, perform procedures, and discuss treatment plans. Fellows also care for patients both in and out of the hospital.

Resident Physicians: Residents and interns (house officers) are physicians who completed training to become general doctors and come to the University of Michigan to receive training in the specialty of general pediatrics. They work closely with and are supervised by the attending and fellow GI physicians to care for patients.

Medical Students: University of Michigan is a teaching institution; families will get to know different "layers" of the education process of becoming a physician. They can perform a physical exam and obtain a medical and family history. They will then report this to the attending physician, fellow and residents. They will discuss treatments with the team, but final decisions are made by the physicians.



Attending	The most senior docotor directly responsible for your childs care.	Completed Training Oversees all memebers of inpatient care team.
Fellow	A pediatrician who is receiving extra training to specialize in GI. The fellow physician has responsibilities similar to the attending.	3 years *Specialized* Traning
Resident	Has completed medical school and is continiuing training to become specialized in pediatrics.	3 years *Training* -3rd year: Senior -2nd year: Junior -1st year: Intern
Medical Student	Studying to become a doctor. Hospital rotations/follow hospital patients as part of their traning. They are given varying degrees of authority. May review your medical history and even write orders in your chart, which need to be reviewed and signed by a licensed doctor.	4 years *Medical School*

Licensed Physician

Student

Nurses: Nurses work closely with the doctors and with patients and families to ensure effective communication, education, and coordination of care. Nurses are very knowledgeable and can help give advice on medications, symptoms, and the need to seek further care.

Dietitians: Dieticians work with the medical team to maintain and improve a child's nutritional health. They provide information and education about how IBD impacts nutritional health and growth.

Social Workers: Social workers provide support to the patient and family and act as a resource for the IBD care team. The amount and type of involvement by the social worker varies widely depending on each family's situation and specific needs. The social worker may:

- Assist a family and their child with initial diagnosis.
- Offer support or counseling for family members.
- Help obtain needed resources during a hospital stay.
- Connect a family to ongoing resources at the time of discharge or during clinic visits.
- Assist with insurance concerns and enrollment.
- Assist with transportation to appointments and to hospital.

Surgeons: The pediatric surgeons become direct members of the pediatric IBD care team when they are consulted should your child require a surgical intervention. After a surgery for IBD, the surgeon will see families to follow up on surgical issues. It is important to know that even with the best care, some children still may need surgery for their IBD.

Psychologists: A pediatric psychologist is someone who has a PhD or PsyD in clinical counseling psychology, but has specialized training in working with children with medical conditions. They can provide support to patients and families in outpatient clinic and also consult with medical teams during hospitalizations. They are skilled at helping children and their families cope with chronic medical issues, develop strategies for dealing with chronic symptoms, and help in the areas of treatment adherence and mental health promotion.

Office Staff: Oversees and assists in the daily routine of GI clinic management and will usually be the first person a family will speak with when the office is called. Office staff is able to answer some general questions, help make clinic appointments, and direct calls to the care team.

Parents/Family/Patients: You are a member of the IBD team. Your contributions to IBD management is very important. We believe that with the help of patients and families in monitoring for symptoms of illness, side effects of medications, addressing challenges with taking prescribed medication (medication adherence), obtaining lab tests when needed, and communicating needs—the patients' health and long term outcomes will be improved.

Research & Quality Improvement Coordinators: We are constantly trying to improve how we take care of our IBD kids. This is called quality improvement (QI). The coordinators may speak with patients and families about special research studies and QI projects for which a child may be eligible, or ask patients and families for feedback on how we can improve care.

Chaplains: Many religious denominations are available to patients and families for spiritual support.

Host (Health Unit Coordinator): Greet you as you enter the unit. They are a great resource to answer questions and offer support for any needs or comfort measures that patients and families may have during an inpatient stay.

Occupational/Physical Therapist (OT/PT): Help strengthening muscles needed for feeding, development, and physical activity, as well as assist with physical recovery from prolonged chronic illness or malnutrition.

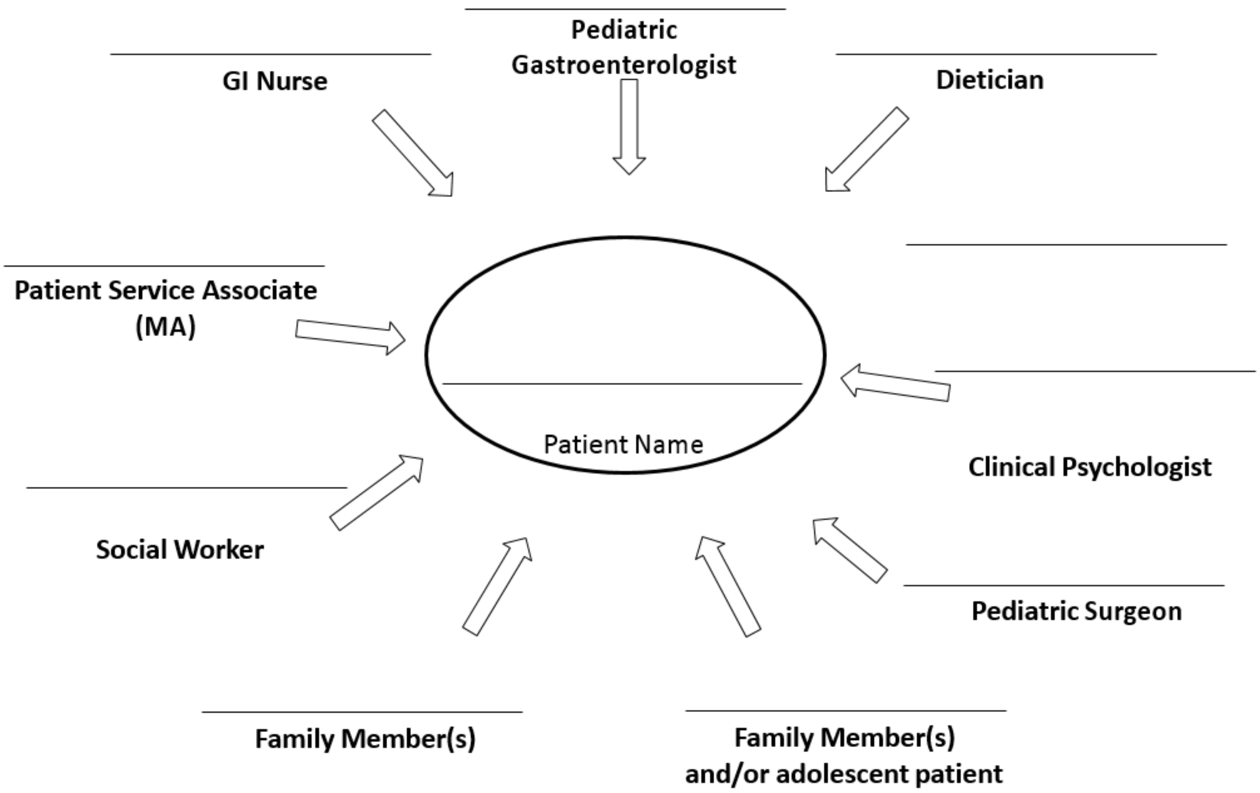
Patient Representative: provide information about patient rights and responsibilities, hospital procedures, policies, resources, and services. They serve as a link between patients, families and the hospital staff.

Pediatric Floor Nurses: Registered Nurses (RNs) will be assigned to each patient and family to coordinate and administer his or her care. On a day to day basis, they will give medications, obtain vital signs, perform a physical assessment and closely communicate with the inpatient care team.

Pharmacists: Specifically trained and licensed to prepare and review medications for a child.

Child & Family Life Professionals: These specially trained professionals coordinate programs and services designed to lessen the negative impact of hospitalizations on children and provide support to children through therapeutic play activities and peer interactions.

Your Pediatric Inflammatory Bowel Disease Care Team



Hi, my name is Kiersten K. and I'm going explain what it's like to live with Crohn's and my experience.

I was only 8 years old when I was diagnosed with the disease and it was pretty scary. I now know that it is not always going to be scary but there are a few things that you will have to get used to. For example, you may have to get used to needles and noisy blood pressure machines. Some advice I have for you is drink lots of water, keep your head held high and NEVER be afraid to let a trusted adult know if you're feeling pain or a sudden sickness in any way.

The doctors found out I had the disease when I had the scope procedure. Before I had the procedure, I felt really nervous about it and I didn't want to have it done. After the surgery I was a little sore, of course, but that's how they found out what was wrong with me and they put you to sleep so you don't feel anything during the procedure.

My feelings on starting different medications were mixed. I thought a lot of things like, how long will I take this medication? And what are the side effects to the medication? You might also have these thoughts and feelings as well, and not to scare you in any way, but the doctors might decide to put you on something called Remicade® or Humira®. Remicade® is taken through something called an IV. An IV is a needle that goes into your arm or hand but when it's injected into the skin the needle retracts and it's just a straw left in your arm so you can move it freely without pain.

When I was sick before being diagnosed, I always felt pretty crummy and it felt as if I had the flu. Feeling crummy lasted for a long time and it never got better, it only got worse with each passing day. We went to the ER and I still felt sickly so they sent me into surgery the next week. Today, I am doing VERY well. I feel as if I've never been sick, never had any problems in the world. And it's all thanks to a doctor's persistence at U of M Children's Hospital.

When you go back to school with the diagnosis of Crohn's you feel different and kind of embarrassed. DON'T BE! Crohn's is just another thing that makes you unique in your own way. Don't let anyone tell you you're abnormal because they're wrong. You don't have to tell anyone about Crohn's unless you really want to. My advice is - try to do things with the other kids like running, hula-hooping, etc. On the outside you don't look any different. Most importantly have hope that things will get better, because they will. I am living proof of that. I feel 100% better and am doing the things any "normal" kid would be doing.

I'm sure you will feel scared, just like I did at first. Remember Crohn's is not a disease you can die from. It is a disease that you will have for the rest of your life, and currently there is no cure. If you are scared, ask questions, do some research. Follow what the doctors say and it will make you feel better, even if it has to do with needles. That's pretty much it. Just remember to do whatever you have to do to keep from having a flare. Yes, I got it at a young age. I chose to fight through it, and look where I'm at today. I'm 11 years old and in 6th grade. Just keep going and don't let anything get in your way because I know you're a strong fighter.

Be brave. You can do this. When times get tough, remember to always have lots of hope and know that you are not alone.

Testing at Diagnosis and Throughout IBD Management

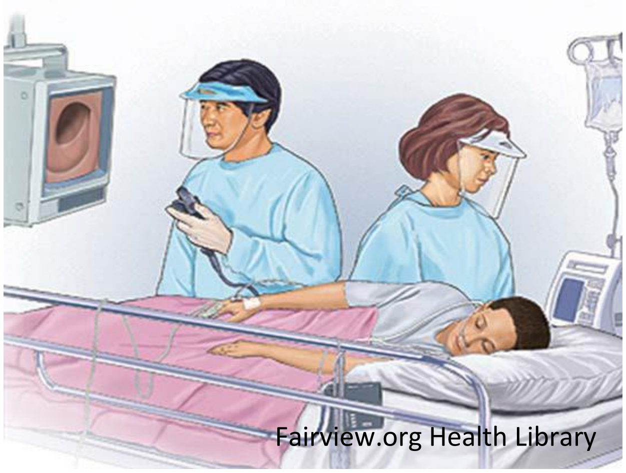
Esophagogastroduodenoscopy (EGD) and Colonoscopy:

In order to properly diagnose IBD, an EGD and colonoscopy must be performed.

An **EGD** (upper scope) is done with a small flexible tube that has a camera on the end that is passed through the patient's mouth, into the esophagus, stomach, and upper portion of the small intestine (duodenum) in order to visually inspect the lining of the upper GI tract. Biopsies (small pieces of tissue) will be taken from these locations and sent to pathology to look at the tissue under a microscope.

The physician will then pass a longer tube (lower scope) through the rectum, the large intestine (colon), and often in the last part of the small intestine (terminal ileum), in order to visually inspect the lining of the lower GI tract and collect biopsies from these sites as well. This is called a **colonoscopy**.

- The patient will have a bowel preparation, also called a "clean out" a day or two before the colonoscopy. This will allow the physician to better inspect the entire colon on the day of the procedure.
- The patient will be given medication by the anesthesia team to put him or her to sleep so that they are not awake or uncomfortable during this procedure.



Fairview.org Health Library

For the initial diagnosis of IBD, both of these procedures will be done at the same time. Afterwards, if the doctor feels another colonoscopy needs to be done to evaluate disease activity, a repeat EGD may or may not be done. This is completely dependent on the location of the disease and the symptoms. The patient, family, and doctor will discuss these decisions together.

What happens before a colonoscopy and/or EGD?

A GI doctor or nurse will tell the patient when and why a scope is needed and explain the procedure to the patient and family in detail. The family will be informed of the risks and benefits of the procedure and sign a form authorizing the procedure called informed consent. A nurse will call with the day and time of the procedure and give more information on how to do the clean-out prior to the procedure if a colonoscopy is being done.

A nurse from the Mott Pre-op call center will call on the day before the procedure. If the procedure or tests are scheduled for Monday, they will call on Friday. The nurse will inform the caregiver of the check-in time and when the child will have to stop eating and drinking. It is important that the nurse speak directly to a caregiver. The family may call 877-331-3330 in the morning and leave the name and contact number to ensure that we have the correct phone number. If a family has not heard from us by 7 pm the day before the procedure or if there are additional questions, please call pre-op at 877-368-1316.

What happens after a colonoscopy and/or EGD?

After the procedure, the patient will be taken to the recovery room. The physician will meet with the family briefly after the procedure to let them know what was seen during the exam and what they may be expecting.

Both the EGD and colonoscopy are generally very safe procedures. A patient may have a sore throat after the procedure which should go away in a day or two. Other potential complications to these procedures are very rare, but could include bleeding, problems with sedation, or a tear (perforation) in the esophagus, stomach, or intestinal wall. If there is a large amount of bleeding, or significant pain or a fever after a procedure, please call our office. If it is later than office hours, please contact the on call GI physician.

Other procedures

Flexible sigmoidoscopy ("flex sig"):

A flex sig is a procedure similar to a colonoscopy but the scope is only inserted a short distance into the colon. The bowel preparation usually requires enemas before the exam. A flexible sigmoidoscopy has the same risk of complications as a colonoscopy.

Capsule Endoscopy and Deep Enteroscopy:

Crohn's disease often involves the small intestine. Making the diagnosis of Crohn's disease can be hard when the affected portions of the small intestine are beyond the reach of the standard scopes used in EGD or colonoscopy. The small intestine is about 20 feet long, and recent advances including capsule endoscopy and deep enteroscopy have made it possible to see this area of the intestine.

- **Video Capsule endoscopy (pill camera)** is one way to look at the entire small intestine. The capsule, which is the size of a large pill, is swallowed or placed with a scope. The pill travels through the intestine, taking multiple pictures per second. A recorder worn on a belt saves the pictures. A doctor will review the pictures on a computer and send a report. The capsule will be passed in the stool. The pictures from this test may show signs of Crohn's disease. The capsule used is not able to take biopsies of the tissue. Because a narrowing (stricture) of the intestine may keep the capsule from moving, the patient may be asked to swallow a dissolvable "test capsule" first, to make sure the pill camera can safely pass.

- **Small Bowel Enteroscopy (Deep Enteroscopy)** is a test to look at the small intestine that is beyond the reach of a standard endoscope or colonoscope. Double-balloon enteroscopy, single-balloon enteroscopy, and spiral enteroscopy are all examples of deep enteroscopy. The deep enteroscopy technique uses a long scope with an overtube to move the scope deep into the small bowel. Deep enteroscopy can be used to find signs of Crohn's disease that were seen during capsule endoscopy or on the results of other tests, like a MRI or CT scan. It can be useful in the diagnosis of Crohn's disease because it makes it possible to do biopsies deep within the small intestine. Also, narrowed areas of the small intestine can be dilated to open them up and improve symptoms.

Imaging Tests

Abdominal x-ray: An abdominal x-ray is a picture of structures and organs in the abdomen. In IBD, an x-ray is helpful to look for dilation (enlargement) of the bowel which can be a sign of blockage or obstruction. X-rays can also help identify if someone has a tear (perforation) in the intestine, which can be a complication of the disease or rarely from a procedure. An abdominal x-ray can show if there is air in the abdominal cavity, which is a sign of a perforation.

Barium upper GI and/or Upper GI Small Bowel Follow Through (UGI/SBFT): This test is used to find narrowing (strictures) in the upper GI tract as well as ulcers and inflamed areas of the intestine in people with Crohn's disease. This test looks at the esophagus, stomach, and the first part of the small intestine. The patient will be given a barium solution to drink. A doctor watches the movement of the barium through the esophagus, stomach, and the small intestine. Several x-ray pictures are taken at different times and from different views during the exam.

Barium enema: A barium enema, also called contrast enema or a lower GI exam, is an x-ray exam of the large intestine (colon and rectum). Problems with the structure of the colon, such as narrowed areas (strictures), can be detected with this test. To make the intestine visible on an x-ray, the colon is filled with a dye containing barium. This is done by pouring the dye through a tube inserted through the anus into the rectum. X-rays are then done while the contrast is inside the rectum and colon to look for abnormalities.

Computed tomography enterography (CTE): This test is similar to a routine CT scan except that the patient drinks the contrast material (dye) before the CT scan is started. The contrast material allows the small intestine to be seen more clearly. Contrast material may also be given through an intravenous (IV) line, which shows the small intestine even more clearly. During the test, the patient will lie on a table that is attached to the CT scanner, which is a large doughnut-shaped machine. The

CT scanner sends x-rays through the area of the body being studied. While a routine CT can detect the complications of Crohn's disease, such as fistula and abscess, CTE clearly shows the small bowel inflammation that occurs in Crohn's disease. In children we try to minimize the use of CT and SBFT because of the exposure to potentially harmful radiation.

Dual-energy x-ray absorption (DEXA): Many IBD patients have malnutrition, low vitamin D levels, or have taken steroids, which can lower bone density. DEXA scans measure bone density to find out if *osteopenia* (abnormally low bone density) or *osteoporosis* (severely low bone density) is present. This test can help predict your chances of having a broken bone. DEXA scans use very little radiation. There are no known risks from having a DEXA.

Magnetic resonance imaging (MRI): MRI is often used instead of a CT so that the patient is not exposed to radiation. An MRI involves a powerful but harmless magnetic field. The magnetic field to produces very clear pictures of parts of the body such as the intestine. Liquid contrast is given through an intravenous (IV) line and also by mouth so that the intestine can be seen more clearly.

- **MR Enterography (MRE)**: An imaging test that is used to look for inflammation, abscesses, fistula tracts, and strictures. This test also allows the physician to inspect portions of the small bowel that are not visible during the scope. This imaging study helps define the type of IBD present (Crohn's vs. UC). This procedure can be done inpatient or outpatient depending on patient requirements and needs. If the patient is not able to lie still for the duration of the MRI due to age or being afraid of small spaces, sedating medication can be made available.
- **MR Fistulogram (pelvic MRI):** This test is done for people with Crohn's disease to learn about a fistula and its channel (tract). This test more clearly shows the site of the fistula; for example, from the bowel to the anus, bladder, muscle, or skin.

What to Expect During Clinic Visits and Inpatient Stays?

Outpatient Clinic Visits/Follow-up


Outpatient Clinic—8th Floor Mott

We encourage families to phone our office whenever questions arise regarding a child's care. Our office is staffed with pediatric gastroenterology nurses who can help you over the phone; we can help decide what to do if a child is not feeling well, contact the physician, as well as organize labs and other testing locally if needed.

A newly diagnosed patient with IBD is seen frequently after the initial diagnosis, and as the child begins to feel better and symptoms resolve, we will stretch out clinic re-visits to every 4 to 6 months, understanding that every patient is different and some may require more frequent monitoring.

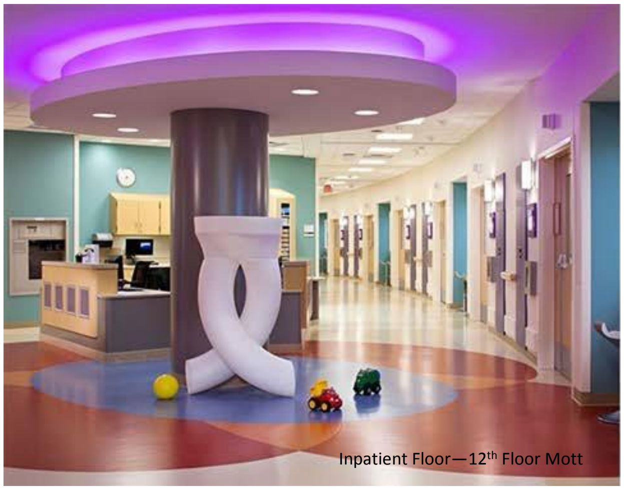
During a clinic visit, the child will have a physical exam which will include height and weight, as well as vital signs (temperature, heart rate, and blood pressure). The nurse and physician will ask questions regarding how the child is feeling. Before the clinic visit, both the patient and family members should create a list of questions to ask the doctor and care team. Lab work is generally done either the day before or the day of the clinic visit. When the patient is finished with a clinic visit, the family will receive a list of instructions and a plan in order to manage IBD from home. This will include medication changes and instructions, treatment plan, and when to follow up next in clinic.

**Please note that the University of Michigan is a teaching hospital and while a family is here, the child may see a fellow, nurse practitioner, nurse, resident, or medical student prior to seeing your primary GI doctor.*

Examples of questions to ask the GI doctor:

- What parts of the GI tract are affected and what does this mean?
- What tests are needed and what are they for?
- What are the options to help cover the cost of the medication or if my insurance won't pay for it?
- Should there be diet changes or any type of nutritional supplements?
- What symptoms are considered an emergency?
- When will a follow up visit be needed?
- Are certain tests needed during a flare or on a routine basis?
- How long should it take until there are signs of improvement?
- What happens if a dose of medicine is missed?

Inpatient Hospital Stay & What to Expect


Inpatient Floor—12th Floor Mott

Often our patients are admitted from the emergency room to the Mott Children's Hospital inpatient ward for further evaluation. Sometimes IBD symptoms can come on very quickly. Other times, feeling sick can be a very slow, lingering process. Either way, the doctor may feel that the best decision is admission to the hospital so that evaluation and treatment can happen more quickly and severe symptoms can be better managed. In the hospital, we can provide certain types of medical care that cannot be done in the home setting such as IV fluids, IV steroids, and surgical interventions.

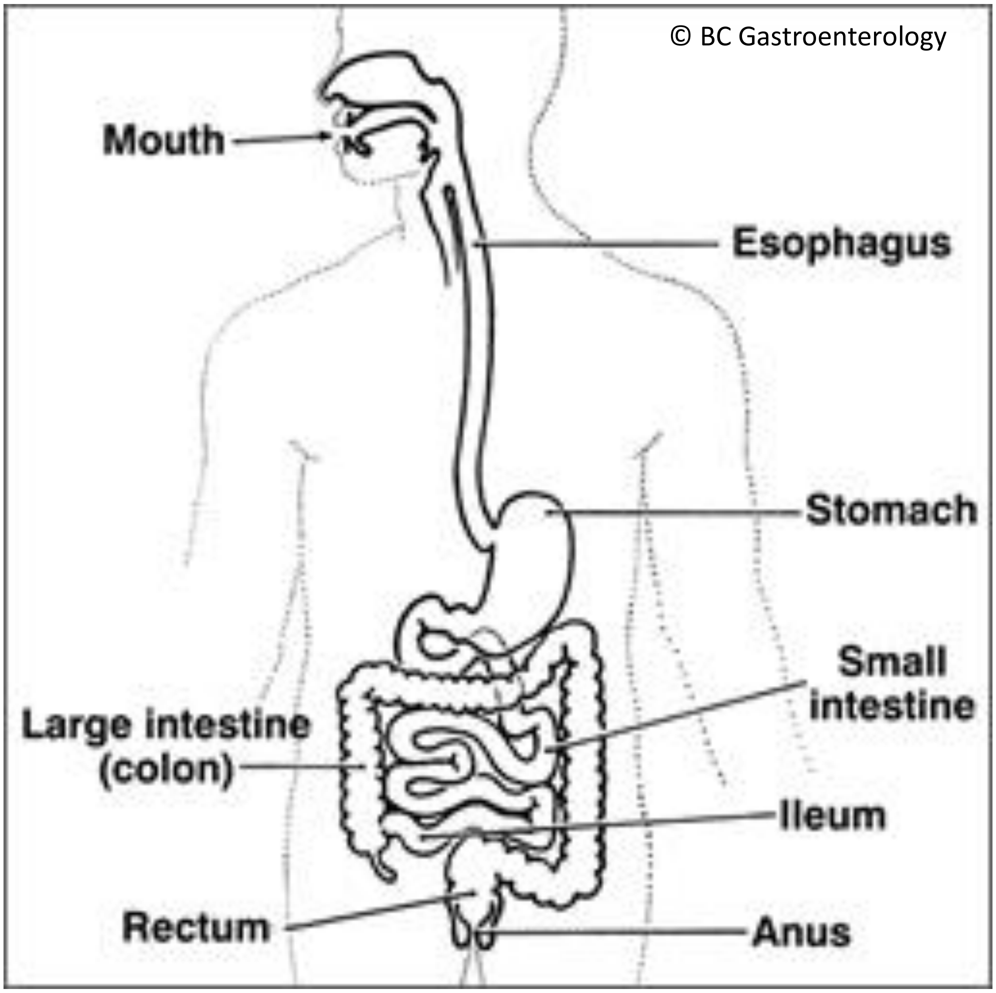
Once a patient is admitted to the pediatric GI inpatient service, families will meet many new people that will be taking care of their child, such as physicians and nurses that are part of the inpatient service but not necessarily members of the outpatient clinical care team. These caregivers are following the direction of your pediatric gastroenterology IBD team and are very good at caring for severely ill patients. The inpatient team will come and visit in the morning and discuss what the plan is for the day and during your stay.

Also, please remember that the University of Michigan C.S. Mott Children's Hospital is a teaching hospital. While staying with us, families may meet medical students, residents, fellows, and nursing students. Keep in mind that these caregivers are learning from patient and family. Just like everyone else taking care of patients and families, the goal is to make the patient as comfortable as possible while providing medical care and answering any questions they may have. Every effort is made to respect privacy during a hospital stay and also include families in the decision-making process.

Family members are encouraged to stay with the child while they are admitted to the hospital. Patient rooms are private with an individual bathroom and shower for each patient. They also include a mini fridge, TV, and internet access so families have many of the same comforts as they might have at home.

Diagram of the Gastrointestinal Tract

Ask your physician to draw the location of your disease or surgery on this diagram.



Date: ___________________

Extent of Disease: ____

Dates of Surgery: ____

Type of Surgery: ____

What is Inflammatory Bowel Disease (IBD)?

Inflammatory bowel disease (IBD) includes both Crohn’s disease and ulcerative colitis. Although these are two different diseases, many of the symptoms are the same, as well as the treatments used to control the disease and prevent flare ups.

It is estimated that approximately 1.6 million Americans have IBD and approximately 70,000 new cases are diagnosed each year in the United States. There may be as many as 80,000 children in the United States with IBD. While IBD can be diagnosed at any age, it is most often diagnosed between the ages of 15 and 35 but can be found in children as young as 18 months of age. IBD seems to affect boys and girls equally and while there does seem to be a hereditary factor (running in families), there is no way to identify with certainty who is more susceptible to developing IBD.

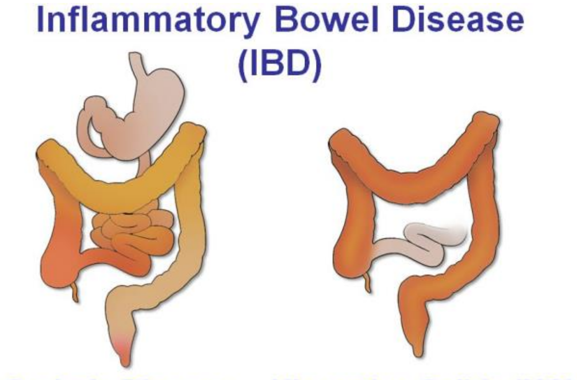
With IBD, the immune system, which is the system within your body whose purpose is to fight off infection, becomes hyperactive and damages the gastrointestinal (GI) tract.

When the immune system attacks a specific area of the body, the body begins to naturally try to protect this area by increasing blood flow and sending white blood cells to that area (in this case the GI tract). This reaction causes inflammation and if left untreated, this chronic inflammation causes narrowing of the GI tract, which can then make it difficult for food and stool to pass through, leading to pain. This inflammation can also cause ulcers to form, which can damage the intestinal wall and cause pain, bleeding and infections.

Currently there is no known cure for IBD, but medications and surgical procedures can help patients live full and active lives.

Types of IBD

The two most common forms of IBD are **Crohn’s disease** and **ulcerative colitis** (UC). Sometimes it is difficult to sort out exactly whether the disease is Crohn’s or UC at the time of diagnosis. In these cases, we refer to the disease as **indeterminate colitis**. People with indeterminate colitis are treated with the same types of medications that treat both Crohn’s and UC.



©AGA

Crohn’s disease can occur *anywhere* along the GI tract from the mouth to the anus. The most common place for Crohn’s to develop is where the small and large intestines meet, which is called the terminal ileum. Crohn’s disease causes inflammation and/or ulcers through the full thickness (all layers) of the intestinal wall.

Ulcerative colitis involves *only* the large intestine (colon). It may affect the entire colon or only a part of it. The ulcers seen in UC are on the surface (inner lining) of the intestinal wall.

Symptoms of IBD

While there can be overlapping of some symptoms of Crohn’s disease and ulcerative colitis, the symptoms can be quite different as well.

With **ulcerative colitis,** patients may experience abdominal pain and cramping. This pain most often occurs during or immediately after a meal and a child may feel a need to have a bowel movement. After the bowel movement the pain may subside.

Bowel movements are usually watery (diarrhea) and may contain blood. Along with frequent bowel movements during the day, patients often awaken during the night to have a bowel movement.

Patients with **ulcerative colitis** are at risk for:

- Anemia (due to bloody diarrhea)
- Fatigue (from inflammation and interrupted sleep)
- Weight loss
- Dehydration (caused by watery diarrhea)
- Colon cancer

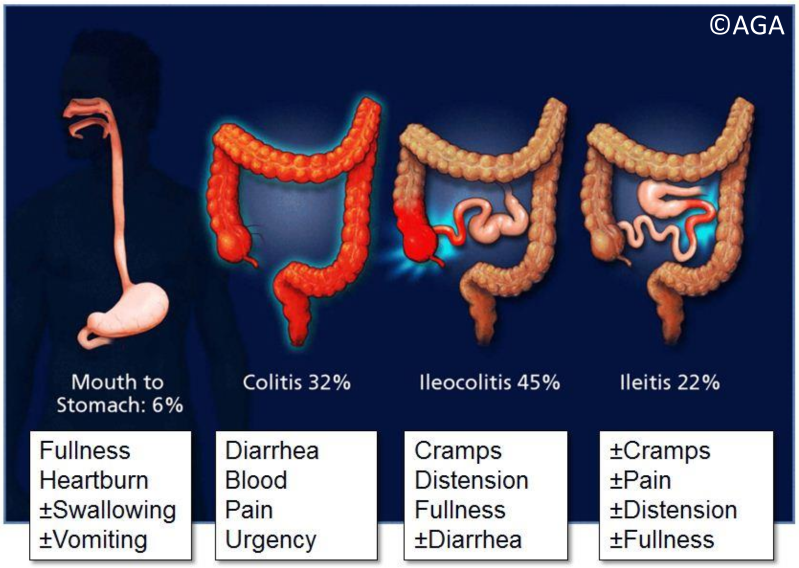
Patients with **Crohn’s disease** experience a wide range of symptoms that is dependent on the location of their disease (see image below). Symptoms may include:

- Cramping
- Abdominal distension (feeling of fullness/bloating/ nausea)
- Diarrhea
- Weight loss or lack of growth in younger children
- Fistulas (see section on fistulas for more information) and or pain or drainage around the anal area

If the disease is in the mouth and stomach, patients may experience:

- Mouth ulcers
- Heart burn
- Difficulty swallowing
- Vomiting
- Feeling of fullness

If the disease is in the colon, patients may experience symptoms similar to UC (see above).



Managing Disease Flares

IBD is a life long illness for which there is no cure. While we encourage patients to go about their daily lives, they will need to make some adjustments in order to make certain that they are able to cope with a disease that can flare at any time.

People with IBD go through periods when the disease is quiet, called **remission**, where there are no or very few symptoms. There may be other times when the disease is active and causing many symptoms, called a **flare**. Our goal is to maintain remission for as long as possible and limit the number of flares that happen.

Medications are necessary to keep the disease in remission and control symptoms

Physical and emotional stresses do not cause IBD. Stressful situations, however, can contribute to a flare for some people with IBD, much the same way that stress can often lead to gastrointestinal upset, stomach pain and diarrhea in people who do not suffer from IBD. It is impossible to completely eliminate stress from anyone's life. It is, however, possible to change the body's reaction to stress. Some people find it helpful to seek counseling to learn stress reducing techniques.

It is very important that patients take medications as directed, whether that is a medication by mouth or an infusion in the vein (IV). This may become increasingly difficult to remember or seem less important as symptoms improve. If a child is finding it difficult to take medications, it is important that families speak to a nurse or doctor about this honestly so that we can discuss ways to make this easier.

Remember that IBD is **not** caused by eating any particular type of food. However, diet and overall nutrition deserves close attention in a person with IBD. There is not a perfect IBD diet for everyone; different foods bother different people. Overall, a well-balanced diet and proper nutrition will help a child have more energy, promote healing of the digestive tract, and allow for proper growth and weight gain. Please see nutrition section for more details.

Staying healthy and free of other illnesses may prevent a flare of IBD symptoms. We recommend frequent hand washing and all scheduled vaccinations. The doctor will tell you if there are any vaccines that should be added. Some medications for IBD may make it dangerous for patients to get live vaccines. We have included a list in this book of vaccines that should not be received (see vaccinations and IBD section). We strongly encourage an annual flu shot, as catching the flu can trigger a flare.

It is also important that a child try to maintain an average of eight hours of sleep per night. When a child is ill, he or she may feel that more than eight hours of sleep is needed, which is also fine. The body needs the rest in order to heal. Routine bedtimes and awakenings will help promote good rest habits.

A flare of IBD can be very different from person to person. An individual's symptoms, triggers, and the diet that works best may be different from what works for someone else.

We have put together the remainder of this education book in hopes that it will help answer the many questions that patients and families may have.

Please feel free to call our office and speak to one of our GI nurses whenever questions or concerns arise.

A letter from Dr. Chris Dickinson:

Much like your children, I had no real idea what I wanted to do with my life. I liked science and took pre-med science classes with a friend in college who knew he wanted to be doctor. I missed part of my freshman year after going to the hospital for appendicitis and waking up with an ostomy bag and a diagnosis of Crohn's disease (probably the wrong diagnosis in retrospect). If you ask my mother, I was not a nice person but I thought I was fine. I graduated college but had to have a good upper GI series and note from my doctor stating that I was in good health before I could be accepted to medical school. In med school I gravitated to pediatrics because working with kids was so much fun. During the pediatric residency after med school I chose GI because of great role models. But maybe a part of it was my own prior experience.

I have 2 kids that are now married and 1 grandchild. So what does all this have to do with IBD?

First, although hearing that your child has a chronic disease that may never be totally cured can be devastating it does not mean that your child cannot have a wonderful and rewarding life. IBD is a setback but it can be overcome. The kids understand this more than the parents. Kids live their lives in the moment. They do not worry every time their belly hurts or they have a loose stool that the disease is back. Nor do the kids worry a great deal about medication side effects. "If I feel better, can get on with my life, and don't develop the rare side effect, then great."

Thus, the thing I love about my job is seeing each kid not only for who they are today but who they will become when they mature in their mid-20's. This means ensuring that they are thriving in whatever they want to do and not letting the disease keep them from ultimately attaining their goals. Yes, there may be setbacks. Life is full of them and IBD is one of many. But it can be overcome and I get my greatest enjoyment watching all of this happen over time. It is a great job.

Dr. D.

Diet and Nutrition

You may receive a lot of feed-back about what is "best diet" for IBD, or which foods to remove from the child's diet. IBD is **not** a diet or food-related illness. It is a myth that there are foods that cause the disease or that fix or cure the disease. There is no evidence that any food or diet can trigger a flare or cause remission. Some patients with IBD, however, may find that certain foods worsen their symptoms at times when they are already having an IBD flare. This is called food intolerance. Some patients have food intolerance while others never do.

<u>Dietary tips during IBD flares:</u>

- Eat smaller meals at more frequent intervals.
- Reduce intake of fatty, greasy, or fried foods.

  These foods can cause diarrhea and gas, and can cause the stomach to empty more slowly, leading to nausea or pain. Patients who have had surgical removal of small bowel may be more likely to have these symptoms with fatty foods.
- Avoid dairy if it increases symptoms.

  Some people develop an increase in diarrhea and abdominal cramping when they consume dairy products during a flare. This is because of an inability to digest milk sugar (lactose intolerance) when there is active inflammation in the intestines. It is not usually permanent. If this is the case, dairy should be avoided until the flare is under control.

  Once the disease is in remission, most people with temporary lactose intolerance can tolerate dairy again. Of course, lactose intolerance is common in many people without IBD, especially if it runs in the family. The best way to find out is to try dairy again. It is important to know that lactose intolerance is not the same as a milk allergy. If the patient has a milk allergy, this has nothing to do with IBD, and he or she should not try dairy without discussing with the doctor first.
- Limit intake of high-fiber foods.

  Certain foods like nuts, seeds, corn, popcorn, and raw fruits and vegetables contain a lot of fiber. These foods may cause cramping and/or diarrhea because fiber is not fully digested by the small intestine. The extra fiber may not move through the bowel easily when there is inflammation in the intestines. If there is a narrowing or stricture in the intestine, a patient may be more likely to have a blockage if nuts, seeds, or popcorn are eaten.

Our goal is to ensure a balanced diet and adequate calories to help with proper growth. We have a dietitian available to assist with any concerns that arise about a child's diet, growth, and nutrition.

On the following pages are examples of different food choices that may help with dietary needs that are common in patients with IBD.

A food journal or diary may be useful to determine whether or not a patient with IBD has any specific food intolerances. If food intolerance is identified, limiting the “trigger” food during a flare may help ease symptoms. It is important to know, however, that it can be unhealthy or even dangerous to remove foods or entire food groups from the diet to try to prevent IBD symptoms. Any potential dietary changes or limitations should always be discussed with the doctor and/or clinic dietitian. Children and adolescents need well-balanced nutrition to grow.

FOOD DIARY

Todays Date:____________

Calorie Goal: ____________

Time	Portion	Food or Beverage Description	Calories	Notes

Total Calories: ____________

High Calorie Meal and Snack Ideas

Breakfast	Lunch and Dinner	Fruits and Vegetables	Snacks
Scrambled eggs in margarine. Add cheese. Pancakes with butter and syrup French toast with butter, powdered sugar and syrup Waffles with butter and syrup Sausage links Toast with butter and jelly Cereal with whole milk Oatmeal with butter and brown sugar	Grilled cheese with extra cheese Macaroni and cheese Ravioli with grated cheese Chicken nuggets with ranch dressing Hamburger, turkey, ham, steak or pork chops Pizza with parmesan cheese Hot dogs with ketchup Sandwich with meat, mayo and cheese Chicken or beef pot pie	Strawberries with sugar and/or whipped cream Bananas with cool whip or peanut butter Peaches with cottage cheese Cooked apples with cinnamon and butter Mashed potatoes with butter and gravy Broccoli with butter and cheese sauce Carrots, corn or green beans with butter Tator tots or French fries with ranch dressing	Ice cream Pudding or custard Peanut butter Cheese sticks Cottage cheese Yogurt Granola bars Bologna, hot dogs and deli meats Tortilla with melted cheese Pretzels with dip

Just one tablespoon can add more calories…

Butter or margarine
Powdered milk
Shredded cheese
Cream cheese
Heavy whipping cream
Ranch dressing
Olive oil

Boost My Calories

High Calorie Ingredients to Add to Your Child's Food

Whole Milk**	1 cup = 149 calories	**Plain Yogurt (whole milk)**	1 cup = 149 calories
Butter or Margarine	1 T = 102 calories	**Fruited Yogurt (whole milk)**	1 cup = 292 calories
Grated Cheddar Cheese	1 T =37 calories	**Frozen Yogurt**	1/2 cup = 110 calories
Grated Parmesan Cheese	1 T = 22 calories	**Ranch Dressing**	1 T = 71 calories
Colby Jack Cheese	1 T = 112 calories	**Beef Gravy**	1/2 cup = 62 calories
Cheddar Cheese	1 slice = 114 calories	**Mayonnaise**	1 T = 99 calories
Mozzarella Cheese	1 slice = 86 calories	**Sliced Avocado**	1/2 cup = 117 calories
Cottage Cheese	1/2 cup = 103 calories	**Hummus**	1 T = 27 calories
Cream Cheese	1 T = 50 calories	**Olive Oil**	1 T = 119 calories
Cheese Sauce	1/4 cup = 200 calories	**Peanut Butter****	1 T = 94 calories
Alfredo Sauce	1/2 cup = 200 calories	**Egg****	1 large = 77 calories
Cream Soup	1 cup = 150 - 230 calories	**Rice Cereal**	1 T = 15 calories
Nonfat Dry Milk Powder*	1 T = 15 calories	**Brown Sugar**	1 T = 52 calories
Heavy Cream	1 T = 51 calories	**Sugar**	1 T = 48 calories
Half & Half	1 T = 20 calories	**Pancake Syrup**	1 T = 53 calories
Whipped Cream	1 T = 26 calories	**Jelly**	1 T = 51 calories
Sour Cream	1 T = 28 calories	**Chocolate Syrup**	1 T = 52 calories
Custard (Whole Milk)	1/2 cup = 127 calories	**Canned Fruit (Heavy Syrup)**	1/2 cup = 100 calories
Regular Ice Cream	1/2 cup = 138 calories	**Wheat Germ**	1 T = 27 calories
Premium Ice Cream	1/2 cup = 184 calories	**Honey****	1 T = 65 calories
Snack Pack Pudding	1/2 cup = 160 calories		

IMPORTANT:
*Not for children under 3 years of age
**Not for children under 1 year old

T= Tablespoon

Lactose Free Diet

If dairy is a trigger for GI symptoms, avoiding the following foods will eliminate lactose (milk sugar) from the diet:

Milk—This Includes milk and milk products such as:

- Cream cheese
- Sour cream
- Whipping cream
- Dips and vegetable spreads
- Half and half
- Ice cream

Cheese – this includes all cheeses and cheese based products

- Cottage cheese
- Cheese spreads and dips
- Cream cheese
- Powdered cheese
- Processed/blocked cheese product

Some people with lactose intolerance are able to have small amounts of lactose in their diets. Examples of this would be:

- Yogurt
- Aged cheeses such as Swiss, cheddar, or parmesan
- Small amounts of cream cheese or ricotta cheese

Another option is to try over the counter Lactaid tablets prior to eating a meal that contains dairy/lactose, which help to break down the milk sugar.

Low Residue Diet

A low residue (low roughage) diet may be recommended when a child is having a flare of IBD or if he or she has a chronic narrowing (stricture) present in the intestine due to IBD.

Food Group	Foods Not Recommended
Proteins	Tough or chewy cuts of meat All dried beans, peas, and nuts Chunky nut butters
Grains	Whole or cracked wheat or whole grain bread, rolls, crackers Brown rice and wild rice Quinoa Cereals made from whole grains Popcorn Whole kernel corn
Vegetables	Raw vegetables, especially leafy vegetables
Fruits	Raw fruits

Food Group	Recommended Foods
Dairy	Milk, smooth yogurt, cheeses, cottage cheese, Sherbet
Proteins	Tender, well-cooked meats, poultry, fish, eggs Smooth nut butters
Grains	White bread, rolls, crackers, and pasta White rice Cream of wheat Cereals made from refined grains without extra fiber
Vegetables	Well-cooked vegetables Potatoes without the skin
Fruits	Ripe banana or melons Peeled apples Most canned, soft fruits
Beverages	Caffeine free tea, pop, and coffee Water

High Iron Diet

Many people, including children with IBD, have iron deficiency anemia at some point during their disease due to poor intestinal absorption of iron and/or or blood loss from inflamed intestines. Iron helps carry oxygen throughout the body and is important for energy and growth.

The doctor may still prescribe extra iron supplementation in the form of a liquid or pill depending on a patient's blood count and iron stores.

Foods with at least 2 mg iron per serving

Food	Serving Size
Beef, veal	3 ounces
Clams, shrimp, oysters	3 ounces
Bran flakes	¾ cup
Cream of wheat	½ cup
Oatmeal	¾ cup
Baked potato with skin	1
Dried beans, cooked	½ cup
Soybeans	½ cup
Tofu	½ cup
Spinach	1 cup
Dried prunes	4 pieces
Carnation Instant Breakfast	1 cup

Foods with at least 1-2 mg iron per serving

Food	Serving Size
Poultry	3 ounces
Corned beef	3 ounces
Cooked kale	1 cup
Dried apricots	7 halves
Raisins	5 Tablespoons
Whole wheat bread	1 slice
Nuts: cashews, walnuts	1 ounce

Foods high in Vitamin C are also recommended with a high iron diet or when taking iron supplements, as these foods will help the body absorb iron. Examples include citrus juices and fruits (orange, lemon, clementine, grapefruit, and lime), melon, dark leafy green vegetables, and potatoes.

Foods high in Vitamin C are also recommended with a high iron diet, or when taking iron supplements; as these foods will help the body absorb iron. Examples include citrus juices and fruits (orange, lemon, clementine, grapefruit, and lime), melon, dark leafy green vegetables, and potatoes.

Dear IBD patient,

I am a college freshman with Crohn's disease on Remicade®. I was 15, almost 16, when I was diagnosed with Crohn's disease and dropped down to 126 lbs from 145 lbs. My doctor put me on the Imuran® pill and that only somewhat worked, it got me up to 135 lbs and I only felt okay. Then I went on Remicade® a few months later which got me around 165 lbs and so far it has worked great. I am now 170 lbs and 18, almost 19, years old. Getting an infusion can be frightening the first time or so, "How am I supposed to lead a normal life if I have to get infusions every so often at a hospital? I hate needles! What am I going to do for hours during the infusion?" but after a few times, the whole infusion just becomes routine. My mom has always said I've been a "tough guy" with needle shots so I don't have much experience being afraid of them, but my advice to make the needlework easier is to drink water the day before (lots of it) and wear gloves in the car ride to the infusion, both of these will make your veins easier to target for the nurse so they won't miss. If the needle is really scary, just find something in the room to stare at it. Literally anything will do: the dots on ceiling tiles or floors, some blemish on a counter, a picture on the wall, just find something and stare holes into it, you'll be so focused on that random thing that the needle will be in before you know it. After the needle is in all that is left is the long infusion, which will be boring, but you can make it less boring if you bring something to do. Being prepared is always a good goal, so bringing homework (getting that boring stuff done while you're already bored really isn't so bad, plus you can have free time if you get it done during your time!), or a game, legos, or just watching TV can make time go by a lot faster. During K-12 it's kind of a hassle scheduling the infusions too since they're such an awkward period of time, but it is an important thing and your teachers should understand. I'm in college now and so far working around the infusion is easier since I can schedule my classes myself, so that's a handy thing to look forward to. Infusions are just a part of your day every couple of weeks that you'll have a bunch of free time to do stuff, and it is boring because it's such a long time, but as time goes on, treatments for IBD will improve and the infusion times will become less and less. So until then, have hope, it really will get better.

-Logan

Prescriptions Used to Treat IBD

Aminosalicylates

These types of medications are referred to as 5-ASA products and are used to treat mild to moderate ulcerative colitis. These drugs can be given orally or rectally and do not suppress the immune system. Occasionally these medications are not tolerated well and can make bleeding from UC worse. If this happens, it generally starts within the first few weeks of treatment. The other side effect sometimes reported is a headache, which usually goes away with time. These medications are broken down through the kidneys and have few side effects but rarely can cause kidney problems. Labs assessing kidney function should be done routinely. Once a patient starts taking a 5-ASA, they may start to feel better a week or two afterwards. These medicines are not effective for Crohn's disease.

Oral 5-ASA medications: Azulfadine® (sulfasalazine), Pentasa® (mesalamine), Asacol® (mesalamine), Lialda® (mesalamine), Apriso® (mesalamine), Colazal® (balsalazide)

Rectal 5-ASA medications: Rowasa® enema (mesalamine), Canasa® suppository (mesalamine)

Rectal medications are often used when the inflammation in the colon is limited to the rectum only. If the disease is farther up in the colon or throughout the whole colon, these medications cannot reach all of the inflamed colon and are of little benefit.

Corticosteroids

This group of medications, also known as steroids, is used with more severe cases of IBD at the time of diagnosis, or during periods of a flare that has not responded to other treatments. Corticosteroids are considered an immune suppressing medication and have many side effects so we try to avoid them or use them only when necessary. Steroids can be taken orally, as an enema, or given via an IV infusion.

Prednisone (Orapred®, prednisolone, Prelone®):

Prednisone is taken as a pill or liquid form and dissolves in the stomach to enter the bloodstream to heal inflammation throughout the body. It should be taken with food as it can cause GI upset in some people. It is also important to take prednisone exactly as it is prescribed, paying close attention to the dose, which may be changed over time. <u>This medication should never be stopped abruptly</u> but rather tapered off slowly with gradually decreasing doses. Prednisone is usually weaned completely off within two to four months after symptoms have improved and other maintenance medications have time to take full effect. Prednisone may be used again during a flare of IBD; the doctor will advise whether or not the benefit of prednisone for symptoms outweighs the side effects of the medication. Prednisone can be crushed and mixed with liquid or food. The doctor may prescribe an additional antacid medication to protect the stomach while the patient is taking it.

Some of the common side effects include:

- Facial swelling

- Increased sugar (increased thirst, increased urination)
- Moodiness/Irritability
- Headaches
- Acne
- Increased blood pressure
- Weight gain
- Sodium and water retention
- Difficulty sleeping
- Increased appetite

The above side effects go away as the prednisone dose is decreased and are not permanent.

Prednisone can work well for IBD flares for many patients but it is not a good medication to use to keep IBD in remission due to side effects. Long term usage or repeated frequent use of prednisone could result in the following side effects:

- High blood sugar
- High blood pressure
- Sodium and water retention
- High cholesterol
- Brittle bones and/or bone fractures
- Muscle weakness
- Vision changes, cataracts
- Poor wound healing
- Increased susceptibility to infections

To taper prednisone*: Decreasing the dose should **ONLY** be done under the care of the IBD team.*

Methylprednisolone (Solumedrol®):

This is a steroid given via an IV infusion. Methylprednisolone is given in the hospital and is even more effective for IBD symptoms than prednisone. As a patient's symptoms improve, he or she will be switched over to prednisone to take by mouth before discharge home.

Budesonide (Entocort®, Uceris®):

Steroids taken by mouth in a pill form that are specially formulated to dissolve further down in the intestine to target inflammation in specific areas. Because most of the medication stays within the GI tract, patients typically have fewer side effects of corticosteroids like prednisone and methylprednisolone that are formulated to enter the bloodstream and are more potent.

Entocort®: Entocort® targets inflammation located in the end of the small intestine (terminal ileum) and the beginning of the colon.

Uceris®: Uceris® targets inflammation towards the end of the colon.

Immunomodulators

The healthy human immune system is intended to protect the body against outside invaders, such as infection, that could cause illness. When a person has IBD, the immune system is overactive and causes damage to the GI tract. Immunomodulators work by calming the immune system enough to allow the

GI tract to heal and function normally. Immunomodulators do this by decreasing the amount of white blood cells in the bloodstream that are causing damage to the intestines. This type of medication has been widely used for children with both Crohn's and ulcerative colitis and has been shown to work well in preventing flares, maintaining remission, and eliminating the use of steroids, which have many more side effects.

Thiopurines 6-mercaptopurine (6-MP, Purinethol®), azathioprine (Imuran®, Azasan®, AZA):
The side effects of these medications are rare and include increased risk of infection, pancreatitis, elevated liver enzymes, and lymphoma. All patients on immunomodulators should be monitored very closely for side effects. The benefits of having well controlled IBD with prevention of IBD-related complications generally outweigh the low risks of medication side effects. Families are encouraged to discuss this further with their GI doctor.

Methotrexate (Trexall®, MTX, Rheumatrex®):
This medication is a slightly different type of immunomodulator and is frequently used to treat IBD. It is often used as an alternative to azathioprine and 6-MP when the physician feels a combination of therapies would be helpful or if a patient develops side effects while on 6-MP or azathioprine. The side effects of methotrexate are similar to those seen with use of 6-MP or azathioprine, with the exception that methotrexate also causes severe birth defects and/or loss of pregnancy and therefore should be used only with extreme caution in females of child-bearing age. Methotrexate is usually given once weekly either by mouth or by subcutaneous (under the skin) injection. Please see the methotrexate injection education materials at the end of this section for more information. If the doctor recommends methotrexate injections, our GI nurses will teach the patient and family how to give the injections at home after practicing in clinic until the family is comfortable with the task.

Biologics

Biologics are typically used in patients with moderate to severe IBD. Biologics work particularly well to heal the fistulas and/or perianal disease that are present in many patients with Crohn's disease. Biologics are given via subcutaneous injections or as IV infusions.

Because biologics cannot be taken by mouth, patients and families may feel that this type of IBD medication is "stronger", or could have worse side effects than other medications that are given in pill form. This is not true. The decision to use a specific type of medication is always made based on the type, location, and severity of IBD a patient has and the complications it may or may not have caused.

The most common side effect of biologic medication is an allergic reaction, which can range from mild to severe. This happens in about 2% of patients, so it is uncommon. Patients are monitored closely during infusions and can be treated immediately if a reaction occurs. All biologics work by removing inflammatory proteins that cause damage to the GI tract that also may help protect against infection, so they have an immune suppressing effect. For this reason, rare serious side effects include increased susceptibility to certain infections and rarely certain types of cancer (see section on IBD and cancer).

Biologic infusions:
The biologic medications that are given as IV infusions are given in our outpatient infusion room. The nurses that work there are very experienced and come from a variety of backgrounds, including the pediatric intensive care unit and the emergency room. They are skilled at starting IV lines, drawing blood, and giving injections. Often, the GI doctor is able to see the patient for a visit in a private room in the infusion center at the same time the medication is being given.

Our infusion room has separate areas for each family. There is a lounge chair for the patient to relax in, as well as chairs for family members/parents who come along. This area also has a TV and a computer. Often, patients will bring homework or hobbies to keep them entertained during the infusion. There must be a family member or legal guardian present for the entire infusion if the patient is under 18 years old.
The patient may eat prior to or during the infusion. Drinking plenty of water and staying well hydrated prior to coming for the infusion will make it easier for the nurses to start the IV. The infusion room offers juice, popsicles, and light snacks for patients. Patients generally tolerate infusions very well, and typically return to school, work, or sports games as soon as they are finished.

The outpatient infusion room is located on the 7th floor of Mott Hospital. Because the dose of biologic medication is prepared by the pharmacy department, it can take some time to have the medication delivered to the infusion room once the patient has arrived and checked in. The family should call the infusion room prior to leaving home on the day of the infusion appointment so that the medication can be prepared and ready upon the patient's arrival. This step can save the patient up to an hour of waiting time. The infusion room number is 734-936-4184.

Infliximab and vedolizumab are both started with an induction phase, meaning that when starting the medication, it is given more often so it can start to work faster to heal inflammation. The patient will receive the second infusion two weeks after the first infusion. The third infusion is given four weeks after the second infusion. This means that the patient will receive the first three infusions in a six week time period. Once this induction phase is completed, the patient will receive regular infusions that are usually given every eight weeks. It is very important that once infliximab or vedolizumab treatment has started, it is given at regular intervals without delay. If there is a longer delay between doses, the patient may have an allergic reaction to the medication or it may be more likely to stop working over time.

Infliximab (Remicade®, IFX):
The most commonly used biologic medication is infliximab, which is given as an IV infusion in the pediatric outpatient infusion room. Infliximab is often used at the time of diagnosis as the treatment of choice if the patient has Crohn's disease with severe malnutrition and growth delay and/or significant perianal inflammation or fistulas as a result of the disease.

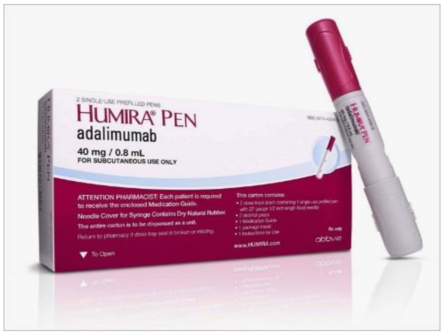
The first four infliximab infusions will be given over two hours, so plan on three hours from start to finish because it takes some time to start the IV and send labs. The patient will be monitored closely throughout the infusion; vital signs will be taken every fifteen minutes for the first hour and then every thirty minutes in the second hour. If the patient has completed the first four infusions without any problems, he or she can then receive the infusions over one hour (2 hours total for the visit).

Vedolizumab (Entyvio®):

Vedolizumab is another type of biologic medication used less commonly for pediatric IBD, but may be recommended by the GI doctor if other types of biologics have not been effective or have caused side effects. Vedolizumab is given over one hour, so plan on two hours from start to finish. Vital signs will be monitored closely throughout the infusion.

Biologic injections (Adalimumab (Humira®, ADA), Certolizumab (Cimzia®, CMZ), ustekinumab (Stelara®):

Adalimumab and certolizumab are slightly different types of biologic medication that are also very effective in treating IBD, especially Crohn's disease. Sometimes after treatment with infliximab over time, the medication will lose effect or the patient may have an allergic reaction. If this happens, adalimumab may be prescribed; if IBD symptoms subsequently flare up on adalimumab, certolizumab or ustekinumab may be considered in certain patients. Adalimumab is the most commonly used injectable biologic medication for IBD. It is given as a subcutaneous (under the skin) injection every 2 weeks. The dose will be higher for the first two doses.



Antibiotics

Antibiotics are often used to treat various infections of the GI tract. These types of infections could be an abscess in the abdomen or in the perianal region (around the anus), or other infections that cause diarrhea. Below, the most common antibiotics used are listed, but there are many different types of antibiotics besides these and the doctor will decide which antibiotic is appropriate.

All antibiotics can cause stomach upset, diarrhea or can cause c. difficile infection. They also increase the risk of developing infections that are resistant to antibiotics in the future. For these reasons and others, we try to minimize the use of antibiotics. However there are times when antibiotics are still necessary.

Metronidozole (Flagyl®):

Common side effects of taking metronidazole include nausea, vomiting and a metallic taste in the mouth. Metronidizole can also decrease the effectiveness of birth control pills and should not be taken by pregnant women. Patients must avoid alcohol when taking metronidazole. A rare side effect is a condition called peripheral neuropathy, which is numbness or tingling of the hands or feet. Should this occur, stop taking the metronidazole and call our office immediately.

Ciprofloxacin (Cipro®):
Ciprofloxicin may cause a skin rash. Rarely, ciprofloxacin may cause pain or injury in the tendon in the back of the ankle. Should you experience these symptoms, stop the medication and call the GI office.
Vancomycin (Vanco, Vancocin®):
Vancomycin is an antibiotic most often used in patients with IBD that have severe Clostridium difficile (C. diff) infection, which is bacteria that causes diarrhea. This antibiotic is usually well tolerated with minimal side effects.

All antibiotics can cause stomach upset, diarrhea or can cause c. difficile infection. They also increase the risk of developing infections that are resistant to antibiotics in the future. For these reasons and others, we try to minimize the use of antibiotics. However, there are times when antibiotics are still necessary.

Over the Counter Medications

Miralax (Glycolax®, MiraLAX®, polyethylene glycol 3350):
Miralax is a medication that is sold over the counter and is used to treat constipation. Constipation is quite common in people with IBD, particularly once the inflammation is under control. If a patient with IBD becomes constipated, Miralax is a safe and effective treatment. Miralax comes in a powder form that dissolves when mixed with **clear liquid; it stays within the colon and is not absorbed into the system, and exits the** GI tract along with the stool. One dose of Miralax is equal to one capful (17 grams) mixed in 8 ounces of clear fluid such as juice or water. It should always be mixed in this ratio to make sure the patient does not become dehydrated. Miralax may be prepared in a pitcher and can be safely kept in the refrigerator for up to 10 days. It does not dissolve well in milk or juice with pulp. Miralax is often part of the preparation for the colonoscopy as well.

Loperamide (Immodium®):
Loperamide is generally not recommended for use in any children, including patients with IBD. However, it may be recommended in certain situations, such as if patients have had surgical removal of the colon (colectomy). If a patient has had a colectomy, the GI doctor or the pediatric surgeon may prescribe loperamide to help patients have fewer bowel movements.

Probiotics (VSL#3®, Culturelle®):
A probiotic supplement is a pill or powder containing healthy bacteria that can help prevent recurrent GI infection or inflammation in the intestine after colectomy. However, probiotics alone do not work as sole therapy for IBD. They also should be avoided, or used with caution in patients who have indwelling hardware such as a central IV catheter (central line) or artificial heart valve, etc., since they may cause infections.

Pain Relievers:

For general over the counter pain relief, patients with IBD should **not** take Non-steroidal anti-inflammatory drugs (NSAID)

- NSAIDs can cause irritation to the stomach and GI tract and may trigger a flare of IBD or make a flare worse.
- Tylenol® (acetaminophen) is a safe medication for pain relief in patients with IBD.

Remember:

If a patient or family has questions about medications being used for IBD, over the counter medications, or medications prescribed by another doctor, they should not hesitate to call the GI office to ask.

It is always helpful to bring an updated list of medications that the patient is taking when he or she goes to another doctor or the ER for any reason.

Pain relievers patients **CAN take:**	Pain relievers patients **should NOT** take: NSAIDs
Tylenol® (acetaminophen)	Motrin®
	Advil®
	Ibuprofen
	naproxen sodium
	Aleve®
	Naprosyn®

You can keep a log—example below

Name of Medication	Form (pill, liquid, injection)	Start Date	Stop Date	Dosage/Strength	Times Taken Daily

WHEN SHOULD I CALL MY GI NURSE?

1. Fever of 101° or greater without other symptoms (sore throat, cold)
2. New onset abdominal pain that interrupts daily activities
3. Abdominal pain that wakens your child from sleep
4. Weight loss or significant change in appetite
5. Significant change in stool patterns
6. Waking at night for bowel movements
7. Unable to control bowel (leakage of stool in underwear)
8. Blood in stool
9. Rectal pain
10. Vomiting
11. Sores or drainage from around the anus
12. Exposures (chicken pox, tuberculosis)

The nurse may need more information. When your nurse calls back, be ready to talk about

- Stool changes, frequency and form of stools
- Whether or child is able to eat and/or drink
- Pain
  - Location
  - How often it occurs
  - How long it lasts
  - What makes it better
  - How severe the pain is on a number scale of 1 (mild) to 10 (severe)
- Whether your child has a fever and, if so, how high the temperature is.
- All medications that the child is taking, including prescriptions, over the counter medications, and herbal supplements

Dear Fellow IBD Patient,

I was diagnosed with Crohn’s when I was 10. My family was on a spring break trip to Disneyworld, and despite my emerging symptoms, my parents and I were determined not to let this ruin the trip. After the trip, I was admitted to the hospital for a few weeks before getting a colonoscopy and finding out I had Crohn’s. My parents did a great job of protecting me from details, but I remember feeling happy that they could finally make me feel better. For weeks, my parents felt bad that they said they’d “figure out what was wrong and fix it,” when in reality I will have Crohn’s for the rest of my life. This never bothered me, though; I thought of it more in a day-to-day way. The first medicine I was on didn’t work well, and I was on the classic dosage of Prednisone. This came with the typical side effects, and it was difficult to see my body change so drastically. The most important thing was for my parents/ friends to give others some forewarning about my looks before seeing me for the first time. This was especially important at sleep away camp, where I returned for the summer looking completely different than I did the summer before. The counselors handled this really well, and I don’t remember the summer being any different than the summer before. Later on, I was on methotrexate shots. These weekly shots made me feel nauseous for the entire next day, sometimes causing me to miss school. My advice for this medicine is to get the shot right before bed and have lots of movies ready for the next day. Teachers are so understanding, so don’t worry too much about that! After a few years, methotrexate wasn’t working perfectly, so I switched to Remicade® infusions. This was a big decision for my family because at the time, it was a brand-new medicine, and the idea of receiving infusions was scary. However, I’ve now been on Remicade® for seven years, and it’s one of the best choices I’ve made. In high school, my mom, sister, or friends would always join me for infusions. I saved my favorite TV shows from the week for that afternoon and would get my favorite peanut butter cookies from the cafe downstairs. I’m now in college, and it’s the same thing- my friends beg me to bring them because they want to support me. It’s a great time to have in-depth conversations or take a nap! Luckily, I haven’t been symptomatic in a while. For me, living with IBD is completely normal, I just have to be more careful and aware about how I’m feeling. It has taught me independence and really made me appreciate all those who take care of me!

Sincerely,

Ali Meisel, 20

University of Michigan Student

Hello, I am the mother of 3 wonderful children; 2 daughters and a son. I am writing to you about my son who is my youngest child. He was diagnosed with Crohn's disease late September 2013. He started feeling sick just one month prior to his diagnosis. Before that he was a happy, healthy 15 year old boy looking forward to his sophomore year in high school. The first symptom he mentioned to me was that he had pain in his bottom. At the time I didn't think much of it and just told him to let me know if it continued. Soon after the school year started he began vomiting every morning shortly after waking and the pain in his bottom became more persistent. My husband and I thought he possibly had allergies and it was all the drainage making him sick. We began treating him with an antihistamine and figured he would be feeling better soon. A few days passed and there wasn't any change so I took him to see his pediatrician. She felt that it was a sinus infection and the pain in his bottom was hemorrhoids. She gave us instructions on how to treat both and we were hopeful that he would be back to normal soon. No such luck, he continued to feel terrible and sitting caused him so much pain that he was starting to miss a lot of school. He started to run a fever and have awful night sweats where he would wake up soaking wet. During our next visit to the doctors they discovered he now had strep throat and a large mass in his groin that turned out to be a very swollen lymph node. He was prescribed antibiotics and once again we hoped and prayed that he would start feeling like his old self. Needless to say, he didn't. The pain in his bottom had become unbearable and his fevers continued with temperatures reaching 104 degrees. His pediatrician, just like us, became quite concerned with his symptoms so she decided to send us to Mott's E.R. to have some tests run. To say I was extremely worried at this point is an understatement. Little did we know when we walked into the E.R. that afternoon that our son would not be leaving the hospital until almost 5 weeks later.

We spent many hours in the E.R. while he had countless tests and exams. These later revealed that our son had a very large horseshoe abscess in his rectum that was going to have to be drained in surgery the following day. He was admitted to Mott's and my husband and I were extremely relieved to finally know what the problem was and that it was going to be resolved soon. After the 2 drains had been placed in the abscess, the surgeon came to talk to us. He told us that during the procedure they found that our son showed signs of having Crohn's disease and they wanted to schedule a colonoscopy and an endoscopy to get a better look at what was going on. My husband and I were in shock to hear that our son most likely had IBD. Up until he first mentioned having pain in his bottom just a month earlier, he appeared to be a healthy teenage boy.

The endoscopy and colonoscopy revealed that not only did my son have Crohn's disease, but he had it quite severe. There was also a very strong chance that the large abscess had infected his tailbone. An MRI showed that he did indeed have osteomyelitis and he began what was to be a very long course of antibiotics along with many other medications. Due to the infected tailbone he couldn't start on Remicade® infusions which was the best treatment for his type of Crohn's. Instead, his team of doctors decided to start him on the steroid, prednisone and an immunosuppressant, Imuran®. These medications helped , but not as much as expected. At that point we were given the very difficult decision of whether or not we wanted our son to have a temporary colostomy. The doctors had tried every other option and he was not getting better and the pain continued to get worse. After much discussion, my husband, son, and I decided that a colostomy was the best option in order to start his road to recovery.

He had his colostomy surgery in the middle of October, which was three weeks into his hospital stay. The days following were very challenging and it was a big adjustment. I spent quite a bit of time researching colostomies and Crohn's disease to find out as much information as I possibly could. This helped me to cope during our long hospital stay. It made me feel like I had some kind of control during a time when I felt so completely and utterly helpless, while my child continued to suffer. Thankfully, having the colostomy began to help and my son's health started to improve little by little. We felt like we could finally start to see the light at the end of the tunnel. After a couple more weeks in the hospital he showed significant improvement in his health and we finally got to take our boy home.

It has been a year now since his diagnosis and I am thrilled to be able to tell you that he is doing exceptionally well! He had his colostomy take down this past June, eight months after it was first done. Five weeks later he spent 10 days with our family in Colorado. He hiked 5+ miles a day in the Rocky Mountains, went whitewater rafting, and celebrated his 16th birthday in the beautiful outdoors while he fished for trout in a mountain stream.

He is now enjoying his junior year of high school where he just finished playing on the varsity tennis team and plans to run track this spring. His medications have been significantly decreased and he now only takes Imuran® once a day and goes every 8 weeks to Mott's for his Remicade® infusions. He does have his bad days here and there, but for the most part he is back to living a very normal life. I won't tell you that I don't worry because I do and I probably will continue to do so for many years to come. I will tell you however, that it does get easier and you just have to stay strong, have faith, and take it day by day. It is that and the wonderful staff at Mott's that helped us through the roughest year of our lives. My family and I couldn't have been happier with all the doctors and nurses during our stay at the hospital and are beyond THANKFUL for the amazing care they gave our son. It still brings tears to my eyes just thinking about it and I will be forever grateful.

Hugs and Blessings,

Deanne (Mother of the bravest boy I know.)

Beyond the Gut: When IBD Travels Elsewhere

Arthritis

Arthritis, or inflammation of the joints, is the most common complication outside of the GI tract for patients with IBD. It may affect as many as 25% of people with Crohn's disease or ulcerative colitis. Although arthritis is typically associated with advancing age, in IBD it often affects the youngest patients. In addition to joint pain, arthritis also may cause swelling of the joints and decreased flexibility.

Peripheral Arthritis

Peripheral arthritis usually affects the large joints of the arms and legs, including elbows, wrists, knees, and ankles. The discomfort may move from one joint to another. Peripheral arthritis tends to be more common among people who have ulcerative colitis or Crohn's disease of the colon. Fortunately, IBD-related peripheral arthritis usually does not cause any lasting damage to the joints.

- **Diagnosis:** It is not always easy to determine whether arthritis is linked to IBD. In general, arthritis that complicates IBD is not as severe as rheumatoid arthritis, which is a separate autoimmune disease. The joints do not undergo destructive changes, and joint involvement is not symmetric (meaning it does not usually affect the same joints on both sides of the body). Arthritis that is associated with IBD usually improves as the disease becomes better controlled.
- **Treatment:** People without IBD that have peripheral arthritis may use nonsteroidal anti-inflammatory drugs (also called NSAIDs) such as ibuprofen, naproxen, Naprosyn®, Aleve®, Advil®, or Motrin® to reduce pain and swelling of the joints. However, as a rule, NSAIDs are not recommended with IBD because they can prompt a disease flare by irritating the intestinal lining and intensifying inflammation (see Medications section).

In many cases, doctors manage the symptoms of peripheral arthritis by first controlling inflammation within the intestines. Once that has subsided with IBD medications, joint pain often improves. Similarly, the newer biologic agents such as infliximab (Remicade ®) have also been effective in reducing joint inflammation and swelling related to IBD.

Arthritis is typically treated by a rheumatologist. We work closely with the pediatric rheumatologists at C.S. Mott Children's Hospital

Skin Complications of IBD

After arthritis, skin disorders represent the next most common complication outside of the GI tract of IBD. These affect about 5% of people with IBD.

Erythema Nodosum
The name of this rash literally means “red bumps”. These tender red nodules, which usually appear on the shins, ankles, or arms, occur most often in people with ulcerative colitis, although they may also affect those with Crohn’s disease of the colon. Women are more commonly affected than men. Erythema nodosum generally appears with a flare-up of GI symptoms of IBD, but may also occur just before a flare-up. It tends to improve when the bowel disease is brought under control.

Pyoderma Gangrenosum
This condition is marked by severe inflammation of the skin associated with deep ulcerations (sores). Like erythema nodosum, pyoderma gangrenosum is most often found on the shins or ankles, but sometimes occurs on the arms. Beginning as small blisters, these lesions eventually join together to form into deep, chronic ulcers. The disorder is somewhat more common among people with ulcerative colitis (5%) than those with Crohn’s disease (1%). Pyoderma gangrenosum often follows a similar course to the pattern of the IBD itself, and may heal as the GI symptoms of IBD are brought under control. Pyoderma is often more difficult to treat then erythema nodosum. Antibiotics, injections of medications into the ulcers, and topical ointments all may be used as treatments.

Aphthous Stomatitis
These small mouth ulcers, also known as canker sores, are most often found between the gums and lower lip or along the sides of the tongue. They are usually seen during flare-ups of IBD and generally subside as the bowel disease comes under control. Medicinal mouthwashes may be helpful, along with a balanced diet and multivitamin/mineral supplement.

Psoriasis
This is a scaly itchy skin disease, and it is occasionally linked with IBD. Patients may respond to ultraviolet light therapy and/or oral medication. Some IBD medications may be effective in treating psoriasis. However, psoriasis can also be a side effect of some medicines used to treat IBD.

Fistulas and Crohn's disease

What is a fistula?

Crohn's disease causes inflammation that can involve all layers of the bowel, from the inner lining all the way through to the outer surface of the bowel. Sometimes this inflammation can lead to deep ulcers that can tunnel through from the bowel to other organs or tissues around the bowel. When this happens, this creates openings called fistulas. Fistulas are abnormal openings from the bowel to other places in the body.

Who develops fistulas?

It is unclear how often fistulas happen, but several studies in adults have showed that around 30-40% of people with Crohn's disease develop fistulas. The risk in children appears to be similar at any moment in time. But since Crohn's disease is a lifelong condition, many doctors and researchers are concerned that over time, children actually have a higher risk of developing a fistula. The chances of developing a fistula are lower if inflammation is kept under control.

What types of fistulas are there?

When fistulas do develop, around 2/3 of them develop around people's bottom. The most common type of fistula is a perianal fistula. This is an opening from the bowel to the skin surrounding the anus. Some fistulas leak mucus or pus. Some are large enough to leak stool. Sometimes the fistula tunnels through the sphincter muscle that allows people to control their poop. This can be serious, because if the sphincter muscle is damaged, this can lead to stool accidents, and sometimes permanent fecal incontinence (leaking stool).

In boys, fistulas occasionally develop to the scrotum or to the bladder. In girls they can go to the labia, to the vagina or the Fallopian tubes. These can be very disturbing, create serious infection, and be very difficult to treat.

1/3 of people with fistulas have internal fistulas. This means that the fistula goes somewhere inside the body (like from one loop of bowel to another) including to other organs like the kidneys. They can go to the skin, causing leaking of stool from the skin of the belly. This is also unpleasant and often difficult to treat.

Internal fistulas can also go to the muscle or just to a pocket inside the abdomen. If this happens, they can cause an infection called an abscess. This is the most common reason for abscesses in someone with Crohn's disease. Fistulas sometimes can go to the bone, leading to serious infections in the bone.

How are fistulas treated?

Fistulas need to be treated quickly and with care. It is most important to stop the inflammation from Crohn's disease. The most effective medications to get inflammation under control and to start fistulas healing are the anti-TNF medications, also called biologic medications such as infliximab (Remicade ®) adalimumab (Humira®) and certolizumab (Cimzia®). It is often helpful to have a second immune suppressing medication such as azathioprine or methotrexate. Please see section on medications for more information.

Fistulas always have bacteria (germs) from stool in them, so it is important to use antibiotics. The antibiotics kill the bacteria in the fistula to allow it to heal. The most commonly used antibiotics are metronidazole (Flagyl®) and ciprofloxacin (Cipro®). [other antibiotics- but these are the most common]

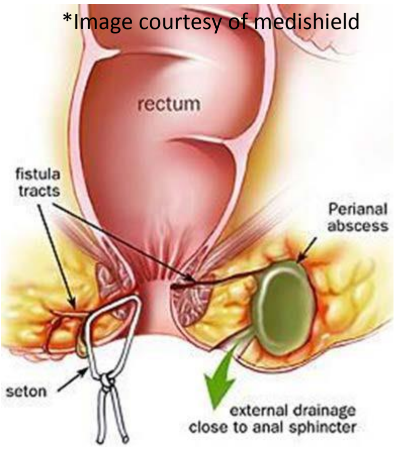


*Image courtesy of medishield

For perianal fistulas, setons are often helpful. A seton is a thread (like the threads used for stitches) that is put inside the fistula. The purpose of this thread is to keep the fistula open. This may sound backwards, but it actually helps the fistula heal. The idea is that by keeping a tiny pathway open, it allows the germs and pus to escape while the fistula is healing. The reason this is important is that sometimes as the bowel heals and as the fistulas close, there are still bacteria in the fistula (antibiotics don't usually kill every last germ). When this happens, as soon as the bowel and skin close, the bacteria are trapped and grow into an infection. This makes pus which pushes its way out, and opens the fistula again. This is the reason that fistulas are hard to treat, and the reason that they often open even after they are healed. Several studies have shown that the combination of anti-TNF medicine, antibiotics, and seton placement is the most effective treatment for perianal fistulas.

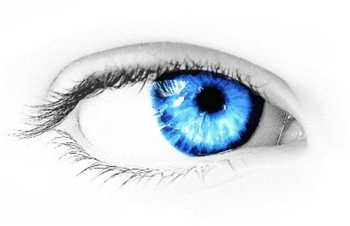
Other fistulas are less common, but they are more difficult to treat. Internal fistulas almost always require surgery, and may require hospitalization and/or IV antibiotics. Fistulas that involve the vagina are particularly difficult to treat. This is why they are especially important to prevent with the right medication to control inflammation from Crohn’s disease.

Can fistulas be prevented?

The short answer is - we think so. There are no studies that have looked at one treatment compared with another for prevention of fistulas. What we do know is that with more recent availability of more effective medications, the rate of fistulas seems to be decreasing. We are currently involved in several research studies trying to learn more about how to prevent fistulas. If families are interested in more information or in being involved in these studies, please let the GI doctor know.

Currently, we think the best strategy to prevent fistulas is to keep Crohn's disease under control. This means taking medication as the doctor has prescribed. It also means getting regular blood tests (and stool tests if recommended) to monitor the inflammation in the bowel and having the doctor examine the anal area at clinic visits on a regular basis, at least every other visit.

Some people with Crohn’s disease develop skin tags around their anus. There is a relationship between skin tags and fistulas. Fistulas often develop at the base of skin tags. If a patient develops pain around skin tags, increasing size of skin tags, or drainage or oozing from the anal area, tell the doctor right away. These can be early signs of fistula development. If a fistula is found early, it may be possible to prevent it from getting bigger or getting into other surrounding organs or tissues. If you note a skin tag or hemorrhoid, talk with the GI doctor about this. It is generally not recommended that these be removed surgically. This may increase the risk of developing fistulas.



Eye Complications in IBD

Uveitis

Uveitis is the most common eye complication in IBD and is a painful inflammation of the uvea, which is the middle layer of the eye. Symptoms of uveitis can include pain, blurred vision, sensitivity to light, and redness of the eye. The symptoms can come on gradually or suddenly. It is very important that the GI office be notified if a patient has any of these symptoms, so that we can arrange for an urgent appointment with an ophthalmologist, a doctor that specializes in eyes. If left untreated, uveitis may progress to glaucoma (an increase in pressure inside the eyeball) and possible vision loss.

Episcleritis

This condition is an inflammation of the outer coating of the white part of the eye. The symptoms are redness, caused when the tiny blood vessels on the outside of the eye become inflamed. When this happens, the vessels dilate (become larger) and turn red. There may also be eye pain. Again, please call the GI office if eye irritation or redness develops so that we can help arrange proper referral to the ophthalmologist.

Cataracts

Cataracts can be a result of long term steroid use. For this reason and others, we try to avoid or minimize the use of steroids.

Malnutrition and Stunted Growth

Nutrition is an important area of focus for children and teens with IBD for multiple reasons. First, a child with active inflammation due to IBD may have pain and poor appetite, which may lead to not taking in enough calories. Second, a child with active inflammation due to IBD generally burns more calories than a healthy child as the body tries to repair itself from injury. Third, when the small bowel has active inflammation from Crohn's disease, it may be too sick to absorb the nutrients, vitamins, and minerals that it normally would. This is why the IBD care team will follow growth and weight gain closely and involve a nutritionist on a regular basis.

If you do not receive enough nutrition for a long period of time, you may not grow as tall as an adult if you have been healthy. Additionally, taking steroids for IBD may also cause a child not to grow well. Both steroids and poor nutrition over time can lead to short stature and weak or brittle bones.

Although no diet can trigger an IBD flare or cure IBD, good nutrition helps the body recover from any illness. In addition, you may be prescribed extra supplements, such as iron for low red blood cell count (anemia), calcium, vitamin D for strong bones, and/or high calorie supplements to help them take in enough energy and make up for previous state of illness.

-Please see the diet and nutrition section for more information-

Liver Disease

People with IBD can develop liver disease for various reasons. Some types of liver disease occur due to autoimmune damage, similar to IBD, so are more common in people who have IBD. A patient could also have liver disease that is unrelated to IBD and the immune system. Finally, certain medications given for IBD can cause injury of the liver as a side effect. Below are some examples of liver disease that may occur in people with IBD.

Medication Effects

Some medications used to treat IBD may, in rare cases, affect the liver. This effect is usually noticed because of laboratory abnormalities suggesting that the liver is being injured. This is one of the reasons to check labs regularly. It is important to know that these effects are usually not permanent when found early. This may be managed by changing the dosage or type of medication. If a family is concerned that medications may affect a patient's liver, ask the doctor about any specific concerns. Medications should not be stopped without first discussing concerns with the pediatric GI office.

Primary Sclerosing Cholangitis (PSC)

This is a disease that causes inflammation and scarring of the bile ducts. Bile ducts are very small tubes that drain bile out of the liver into the intestines. When the bile ducts get sick, the liver does not drain bile normally. This can cause abnormalities of liver tests such as liver enzymes (also known as transaminases or AST & ALT) and bilirubin. If bilirubin is high, then a patient may have yellow eyes or yellow skin (jaundice). In some cases, PSC can lead to severe liver disease, but there is not a good way to predict how rapidly individual patients may worsen. If lab testing suggests that a patient may have PSC, the doctor will consider further testing to determine what the problem is. These tests could include a special MRI of the liver (called an MRCP) or a liver biopsy. Around 5% of patients with IBD also have PSC. Of the pediatric patients with IBD who also have PSC, the majority (about 74%) have ulcerative colitis. These patients have an increased risk of colon cancer over time, so they will require more frequent colonoscopies than patients with UC who do not also have PSC. While there is a medicine (Actigall®, ursodiol) that may help some patients with PSC, it is not a cure. If a patient has PSC, he or she needs close monitoring, just as they will with IBD.

Autoimmune Hepatitis (AIH)

AIH is a disease where the body's immune system attacks the liver cells. Like PSC, it may be suspected based on certain lab abnormalities or by a patient appearing jaundiced. However, the symptoms of AIH can also be similar to the symptoms of IBD, including abdominal pain, fatigue, and poor appetite. That is why it is important to discuss with the GI doctor any symptoms that occur, even if the patient has had them before. AIH is far less common in patients with IBD than PSC is—typically only around 1% of patients with IBD also have AIH. It can only be diagnosed by a liver biopsy. It can cause severe liver disease, but it usually responds to treatment far better than does PSC. In fact, some of the same medications used to treat IBD—such as prednisone or azathioprine—are commonly used to treat AIH. Just like with IBD, it is important to continue taking medicines prescribed for AIH even if the patient is feeling great. If medications are stopped, the disease will come back and can be harder to treat than before.

Fatty Liver Disease (Non-alcoholic fatty liver disease, Non-alcoholic steatoheaptitis, NASH)

Patients who have fat building up in their liver have what is called “fatty liver” or steatosis. This means that there are extra globs of fat when looking at a piece of liver under the microscope after a liver biopsy. This build-up of fat can cause liver inflammation and, over time, scarring and permanent damage.

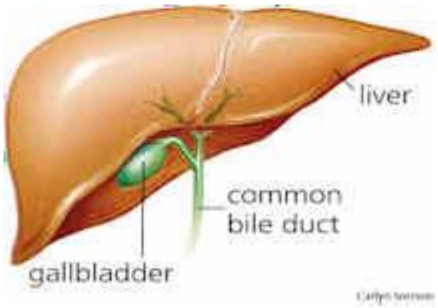
Though many people with IBD are underweight, more and more people are being seen with IBD who are overweight. Being overweight increases the risk of developing fatty liver disease. Whether overweight or underweight aiming for a healthy body weight is the best for a patient’s overall health and liver health.

Prednisone is a medicine that can cause unhealthy weight gain, which is one reason we try not to use it for any longer than we have to. Patients on prednisone may experience rapid weight gain. With prednisone, this weight gain continues as long as patients are on high doses of the drug, whereas with attention to a healthy diet and exercise routine, patients can remain on infliximab indefinitely without going above a healthy weight. One side effect of prednisone and the rapid weight gain it can cause is a build-up of too much fat in the liver.

On the other extreme of the spectrum, patients who are severely malnourished may also have a build-up of fat in their liver cells. The treatment in this case is to make sure disease control is improved and that they work closely with the medical team to improve their nutrition.

Gallbladder Disease

Patients with Crohn’s disease are at risk for a certain type of gallstones called cholesterol stones. This is because patients with inflammation in the terminal ileum, or who have had the terminal ileum removed, do not reabsorb bile salts very well. Bile salts are chemicals that help keep cholesterol dissolved in the bile, and so without them, cholesterol gallstones form more frequently and stick around longer. Some patients with gallstones may never develop symptoms, but if the stones begin to block drainage from the gallbladder, then patients may experience abdominal pain, jaundice, and / or fevers. The treatment for a patient with gallstones that are causing problems is to remove the gallbladder with a surgery. However, most patients with gallstones never have issues that require a surgery.



Infections in IBD

Clostridium difficile
Clostridium difficile (C. diff) is the leading cause of diarrhea in the healthcare setting. It is also becoming a common cause of diarrhea in the community. Any medication or process that changes the normal bowel bacteria or bowel motility can increase the risk of a C. diff infection. Chronic conditions such as IBD and patients on medications that weaken the immune system are associated with higher risk of C. diff infection. A C. diff infection can resemble a flare of IBD with the patient having abdominal pain, diarrhea, and blood in the stool. This infection is often treated with antibiotics (please see medication section). There are times when this infection can trigger a flare, and different medications need to be used in addition to the antibiotic.

Cancer Risks and IBD

We hear a lot of concerns about cancer risk in those with IBD. There are several cancers that are important to be aware of.

Colon cancer
Colon cancer is a cancer that starts in the colon (large intestine). All people have a risk of developing colon cancer at some point in their life. For people without IBD, the risk of developing colon cancer usually begins in older adult years. Among people with IBD, there is an increased risk of colon cancer in anyone with IBD affecting the colon. This means both people with ulcerative colitis and those with Crohn's disease that involves the colon (Crohn's colitis) have increased risk of colon cancer.

The exact risk of colon cancer in people with IBD is difficult to know for sure. Years ago, before immune suppressing medications (azathioprine, infliximab, etc.) were routinely used, the risk of colon cancer was found to increase slowly for the first few years of colitis. Then it was found to increase more quickly after 8-10 years of disease.

Newer information in people who are treated with immune suppressing medications, suggests that the risk of colon cancer is lower than what was previously found, if the disease is well controlled. But, the risk is still higher than in people without IBD.

What can I do to decrease my risk of colon cancer?
First of all, it is clear that the risk of colon cancer is less when colitis is well controlled. In fact, the risk of colon cancer in people with colitis is lower if they are taking 5-ASA medications than if they are taking no medication. Patients taking azathioprine have an even lower risk of colon cancer than those taking 5-ASA medications. Basically, the better controlled the colitis, the

lower risk of colon cancer. However no medication can take away the risk of colon cancer completely.

Colon cancer screening

If someone develops colon cancer, or has pre-cancerous growths in the colon, they are much more treatable if caught early. In fact, most colon cancers that are caught early are completely treatable. For this reason, screening for colon cancer is the best way to further reduce the risk of colon cancer. Currently the recommendations are to start having screening colonoscopies 8-10 years after the diagnosis of colitis (ulcerative colitis or Crohn’s colitis) has been made. There is a debate about how often to have screening colonoscopies after that. If there is active inflammation, everyone agrees that patients should have the next screening colonoscopy 1-2 years later. If there is no inflammation and everything looks normal, then some doctors suggest that patients can go 3-5 years before the next colonoscopy. There are many groups of patients and doctors trying to collect more information to answer this question. Hopefully we will have a more clear answer to this question in the next couple of years.

Primary sclerosing cholangitis (PSC) and colon cancer

PSC is a disease of the liver that causes scarring of the bile ducts ***(see liver section)*** For people who have both colitis and PSC, the risk of colon cancer is much higher than others with colitis who do not have PSC. For this reason, the recommendation is to start screening colonoscopies 1-2 years after diagnosis and continue screening every 1-2 years. The goal is to catch any pre-cancer growths early – that way they are treatable. This is the best strategy we know of in situations like this where there is no treatment that is known to reduce the risk of colon cancer further.

Colectomy

Some people recommend colectomy, or surgery to remove the colon, as a way of preventing colon cancer. While it is true that it is much less likely to develop colon cancer without a colon, this is not a procedure without risk. This decision should be made with careful thought and discussion with the surgeon and GI doctor.

Lymphoma

Lymphoma is a cancer originating in the bone marrow and blood that can affect other parts of the body, especially the small intestine. Lymphomas are very rare – so rare that it is hard to often tell what causes them. Several things are known to increase the risk of developing lymphoma. Inflammation of the gut can damage the lining of the bowel and increase the risk of developing lymphoma in the damaged bowel. Certain medications can also increase the risk of lymphoma. There are also some viruses that can cause lymphoma.

For people with Crohn's disease who have inflammation of the small bowel, the risk of lymphoma is approximately 2 people out of every 10,000 people per year. This is a very small number, but these cancers do occasionally happen. This is about the same risk as the risk of an average person dying in a car crash each year.

Thiopurine medications including azathioprine (Imuran®) and 6-mercaptopurine (6MP or Purnethal®) have been associated with a slightly increased risk of lymphoma. The risk of developing lymphoma in someone on a thiopurine medication is around 4 people out of every 10,000 people per year. This is still a very small number of people. This is around the same risk as the risk of dying of an unintentional injury [4.2 per 10,000 per National safety council].

Epstein-Barr virus (EBV), the virus that causes mononucleosis (also called "mono"), rarely causes a type of lymphoma. This is more likely to happen in people taking either Imuran® or 6MP. If someone on either of these medications develops lymphoma, it is more likely to be EBV-related than other types of lymphoma. This is important because EBV-related lymphoma is often more easily treatable. The other thing that is important to know about EBV is that it is easy to prevent. Though EBV is often called the "kissing disease", a person does not need to kiss someone to get mono. EBV is a virus that travels in saliva and other body fluids. It does not travel through the air. The best way to prevent EBV infection is good hand washing and not sharing cups or bottles or bites of food. Of course, kissing can transmit EBV, just like any other virus.

The risk of lymphoma related to other medications is harder to figure out because those cancers are so rare. Methotrexate seems to have a slightly lower risk of causing lymphoma than or 6MP. This may be because it is less of a problem if someone develops EBV infection.

Biologic medications like infliximab, adalimumab, and certolizumab may increase the risk of lymphoma slightly, but this amount is so small that it's hard to tell if it is real or the IBD itself. A few of the first studies looking at cancers looked as if infliximab might have caused more cancers. But when larger studies were done involving thousands of people, when they could compare people with severe disease to each other, it turned out that the risk of getting lymphoma from infliximab was smaller than it originally seemed.

Anti-TNFα medications are often used in combination with either azathioprine or methotrexate, etc. This may help the anti-TNF alpha medication work better and longer.

One more thing about the risk of lymphoma – it is also important to realize that undertreated

IBD inflammation also increases the risk of cancer. It's hard to know exactly what the risk is because so few people are not treated for IBD.

Hepatosplenic T-cell Lymphoma

One rare type of lymphoma is worth singling out for discussion. This lymphoma, called hepatosplenic T- cell lymphoma (HSTCL) is a very aggressive lymphoma that is hard to treat. This is a very serious cancer that is fortunately extremely rare. It has been reported with nearly every immune suppressing medication, including steroids and others not used for IBD. Early reports seemed to suggest that it was found in people more often if they were taking more than one immune suppressing medication. To date there have only been 37 cases ever reported in the world. This is out of millions of people who have been on these medications. A close look at the cases of people developing this very rare cancer showed that many were on azathioprine (Imuran®) and mercaptopurine (Purnethal®). Some were on only those medications alone, and others were on those in combination with an anti-TNFα (biologic) medication. These cancers mostly occurred in young men. Though we are all concerned with this type of cancer, it is extraordinarily rare. Far less than 1 person in 10,000 on medications will develop this cancer.

IBD-related surgeries

There are many medicines that are used to treat the symptoms of IBD to keep a patient feeling well. Despite advances in medical therapy many patients with IBD will require surgery. About half of patients with ulcerative colitis (UC) and ¾ of patients with Crohn's disease will eventually have surgery during their lifetime. Some patients choose to have surgery (called "elective surgery") while for others, surgery is a medical necessity.

Necessary or Urgent Surgery

Severe Colitis:

Patients with UC sometimes develop such severe inflammation in the colon that medication cannot control the disease. In this situation, a patient may develop uncontrolled bleeding from the colon, a very enlarged and sick colon ("toxic megacolon"), or a tear in the wall of the colon (called "perforation") that causes stool to leak into the abdomen and cause life-threatening infection. In these situations, surgeons may need to remove the colon or damaged part of the bowel right away (see "colectomy" below).

Intestinal Obstruction:

Patients with Crohn's disease can develop thickening of the wall of the intestinal tract that makes the intestine too narrow for food to pass through. This causes blockage, which is also called obstruction. Crohn's disease causes this obstruction either due to severe inflammation of the intestine, which may or may not get better with medication, or due to a scarring of the intestine (called a "stricture") that causes a narrow area that does not get better with medication. A patient with obstruction has symptoms that include abdominal pain, repeated episodes of vomiting, nausea, difficulty eating, or weight loss. Patients with intestinal obstruction that do not get better with medication may require surgery to remove or widen the narrowed area of intestine.

Infection:

Because Crohn's disease causes inflammation through the whole thickness of the intestinal wall, the intestine can develop a tear or hole that allows feces to leak into the abdominal cavity (called "perforation"). This may cause serious infection inside the abdominal cavity (called "peritonitis") or a collection of pus inside the abdominal cavity (called an "abscess"). Patients with these types of infections may require a surgery to remove very sick bowel that has torn or to drain the pus out of an abscess. Some people with abscesses at the edge of the anus or inside the rectum may need a small drain placed in the infected area ("seton") for a matter of months to allow the area to drain pus while medication takes effect to heal the area (***see fistula section).***

Elective Surgery

You may choose to have a surgery after discussion with their gastroenterologist and pediatric surgeon if medications are no longer controlling symptoms well enough to enjoy everyday activities and live a normal life. Some patients may have side effects from medications, or there are medications that for various reasons they prefer to avoid, and choose surgery instead. If patients and families have questions about whether surgery could be an option for treating IBD symptoms, feel free to ask the care team. The most common types of elective surgery are: colectomy with ileal pouch-anal anastomosis (usually for

UC) and diverting ileostomy (usually for Crohn's disease). Surgery is not a cure for Crohn's disease, and patients with crohn's disease will continue to need medication after surgery.

Surgical terms to know:

- *Colectomy or Colectomy:* The most common surgery for ulcerative colitis is removal of the colon and rectum, which is called a colectomy. Some patients with Crohn's disease may require a colectomy as well.
- *Ileostomy*: Also known as an ostomy or a stoma, an ileostomy is a surgically created hole in the abdominal wall connecting the small intestine to the outside surface of the skin to allow stool to drain into a collection bag. The surgery done to create a stoma is called an ileostomy. An ileostomy may either be temporary or permanent and may be done for patients with UC or Crohn's disease. The collection bag that holds stool is called an ostomy bag and is stuck to the skin around the outside of the stoma using adhesive.
- *Colectomy with Ileal pouch-anal anastomosis (IPAA)*: This is the most common series of surgeries for patients with UC because it eliminates the need to permanently wear an ostomy bag. Colectomy with IPAA is performed in 1, 2, or 3 separate stages. The gastroenterologist and pediatric surgeon will decide what the safest way to perform this surgery is depending on how severe the inflammation is, what the patient's overall nutritional status is like, and what medications have recently been given, all of which can affect healing. In general, sicker patients may benefit from doing the surgery in more stages.

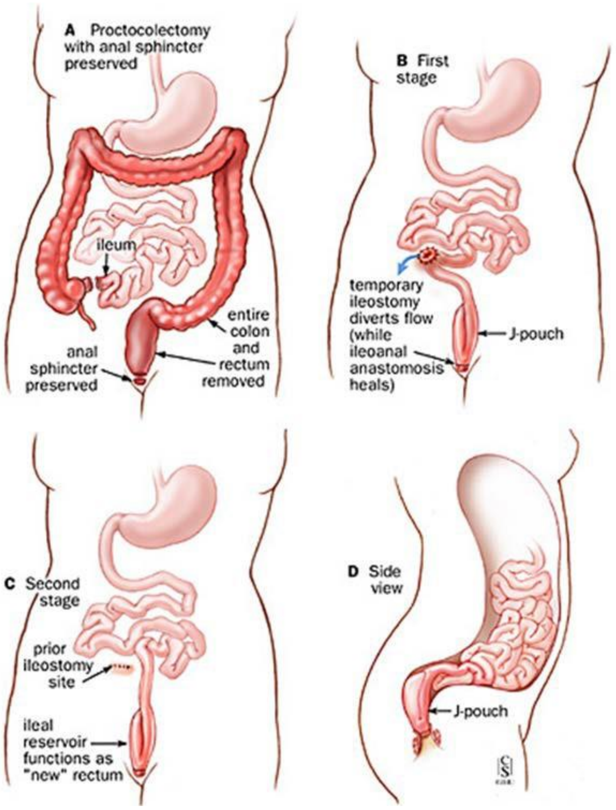
Living with an ileostomy

An ileostomy may be temporary or permanent. As described above, patients with UC may need an ileostomy for a period of time if they undergo a colectomy. Some patients with Crohn's disease may have an ileostomy with or without a colectomy if they have a lot of inflammation in the colon and/or recurrent infection or fistulas around the anus that will not heal with medication. Patients with Crohn's disease may have a temporary ileostomy or a permanent ileostomy.

A patient with an ileostomy has effortless, painless drainage of stool into an ostomy bag that sticks on to the skin around the stoma using adhesive. The bag will need to be emptied several times a day. The stoma is usually located on the lower abdomen. An ostomy bag is not visible under most clothing and people will not notice it. A patient with an ileostomy can be active in school, work, sports, and play just like any other young person. For the most part, patients with ileostomies do not have specific dietary restrictions, although they do need to drink plenty of fluids. Patients with ileostomies should ask their caregivers and dieticians about what foods they can include or avoid in their diet if they have problems with high stool output, too much gas production in the ostomy bag, or stool that is very thin in consistency. For more information, refer to the United Ostomy Associations of America website (www.uoaa.org)

Living with a J-Pouch

After colectomy with ileal pouch-anal anastomosis (IPAA), patients will store and pass stool out of the J-pouch, made of small intestine, rather than their colon. The pattern of having bowel movements will therefore be slightly different. Most people with a J-pouch will have stool that is a looser texture and not quite as formed. They will have on average 5-8 stools a day and may need to get up at night to have bowel movements on occasion. Patients with J pouches can work with their surgeons, gastroenterologists, and dieticians to thicken the stool texture and minimize the number of stools they have each day using medication and diet.



In a one stage surgery, the colon and rectum are removed and the portion of the small bowel called the ileum is made into a J-shaped pouch which is sewn to the anus. There is an increased risk of infection if the surgery is done in one step so a patient must be relatively healthy for this.

In a two stage surgery, the first step includes removal of the colon and rectum and formation of the J-shaped pouch. In the first step, the part of the small bowel that is not sewn into a J-pouch is brought up to the outside surface of the skin to form an ileostomy (see above). This diverts the flow of feces away from the new J-pouch to allow the pouch to heal well. After about 2-3 months, during which the patient has an ostomy bag, the second step of the surgery is done. During the second step, the ileostomy is removed and the two parts of the small bowel are sewn back together to allow feces to be eliminated from the rectum again. This is called an ileostomy takedown. After the second step, the patient will no longer have an ileostomy.

Sometimes patients with a very sick colon, poor nutrition, or who are taking medicine that suppresses the immune system a lot will need a **three stage surgery** to avoid infection or complications from the surgery. In the first stage, the colon and rectum are removed and an ileostomy is created. In the second stage, a J-pouch is created from the small intestine and sewn to the anus, but the ileostomy is left in place. In the third stage, an ileostomy takedown is performed. After the third step, the patient will no longer have an ileostomy.

Complications after surgery

Any patient who has had a surgery on the intestine, including a surgery for infection, intestinal obstruction, fistula repair, or colectomy/ ileostomy, may develop problems or complications after the surgery.

Infection inside the abdomen shortly after surgery due to a leak at the spot where the surgery was performed can occur. This can cause abdominal pain and/or fevers and require medications or surgery to repair the area and treat the infection. This is uncommon but important to recognize and treat right away.

Weeks, months, or years after a surgery, a patient can develop scarring at the area where the surgery was performed which can cause a blockage or obstruction in the intestine. This may cause abdominal pain and/or repeated vomiting. This often requires another surgery to open or remove the blocked area of the intestine.

Patients with Crohn’s disease may develop active inflammation from recurrent Crohn’s disease at the area of intestine where a surgery was previously performed. This is not actually a surgical complication but is the nature of Crohn’s disease. It is more common if the disease is not appropriately treated after surgery. This may cause infection, perforation (tear in the intestine), or obstruction. Medication and/or surgery may be required to treat this problem.

Cuffitis

Patients with UC who have a colectomy can often stop taking immunosuppressive medication after their surgery because the sick colon has been removed. A small ring of rectal tissue is left behind during a colectomy to allow attachment of the J-pouch and to preserve the anal sphincter muscle that allows for fecal continence (voluntary control over passing stools). This is called the rectal cuff. In some patients who have had colectomy with IPAA, the cuff may still have inflammation related to UC, which is called cuffitis. These patients may have blood in their stool, urgency to have a bowel movement, or difficulty with fecal incontinence. This may require medication or another surgery.

Pouchitis

Because the small intestine normally does not hold stool the way the colon does, bacteria in the stool may cause inflammation within the pouch. This may cause diarrhea, blood in stool, urgency to have a bowel movement, or difficulty with fecal incontinence (leaking stool). This is called pouchitis. Patients who develop pouchitis are usually treated with medication. Pouchitis may be cured with medication or it may come back again and require multiple courses of medication. In severe or recurrent pouchitis, another surgery such as an ileostomy may be required. Pouchitis may happen less often in patients who take a daily probiotic.

IBD and Fertility

It is normal for adolescents with IBD and the parents of children with IBD to wonder about the long-term impact IBD may have on the ability to have children in the future. There are many ways that IBD can affect fertility.

Females

- Women who have active, symptomatic IBD flare are less likely to become pregnant, and if they do become pregnant, may have a higher risk of having a miscarriage, having premature delivery, or giving birth to an unusually small baby. The risk of infertility or difficulties with pregnancy varies based on how severe the active IBD is and how it is affecting overall health during the flare.
- Women with IBD who have had a surgery in the abdomen or pelvis are less likely to become pregnant. In particular, a woman who has had a colectomy with a J pouch (see Surgery section above) is at higher risk for difficulty conceiving a pregnancy due to scarring inside the abdomen that occurs after surgery. Post-surgical scarring also increases the risk of having a tubal or ectopic pregnancy.
- Certain medication prescribed for women with IBD (such as methotrexate) can cause miscarriage or harm a fetus during pregnancy, which can cause birth defects. Females who take menthotrexate for IBD must use 2 forms of birth control if they are sexually active. It is important to speak with your doctor about these risks.

Males

- Men who have well-controlled IBD can conceive a pregnancy just as easily as men who do not have IBD.
- Men with active IBD may have more difficulty conceiving a pregnancy.
- Men taking sulfasalazine may have more difficulty conceiving a pregnancy.
- There is some evidence to suggest that methotrexate may be associated with birth defects when taken by men too. This appears to be a rare side effect of this medicine.

The most important thing for young people with IBD to know is that they should avoid unintentional pregnancy. When you do decide you want to start a family, work with your doctor before trying to conceive, to make sure you are healthy and taking safe and effective medications. Parents of teens with IBD should discuss sexuality and family planning with their children, and should always feel free to ask their IBD care team about these issues.

IBD and Mental Health

Inflammatory bowel disease (IBD) and depression can go together. After all, IBD doesn't just affect you physically. It can take a toll on your self-confidence, your relationships, your work life, and your zeal for new adventures and activities. Even if your symptoms are mild, it can be difficult to be out in public. The concerns about psychological distress, depression and adjustment to your disease is common. You are not alone. If you are feeling down about adapting to your new diagnosis (or anything going on in life), we are here to help deal with these concerns, and can find appropriate coping strategies and good plan for you. We are *alway*s here to listen.

When you're depressed, symptoms occur most of the day, or nearly every day, and may include:

- Feelings of sadness, emptiness or unhappiness
- Angry outbursts, irritability or restlessness
- Loss of interest or pleasure in activities that you normally enjoy
- Changes in your sleep patterns, including insomnia or sleeping too much
- Changes in your appetite
- Trouble thinking, concentrating or remembering things

If you experience any of these symptoms, talk to your doctor.

Psychology Today

www.psychologytoday.com	Type in your zip code and look for providers in your area

National Suicide Prevention Lifeline 24/7 free and confidential support	1-800-273-8255

Finding a Mental Health Provider for Your Child and Teen with IBD

Mental Health Providers can assist your child as he/she deals with IBD

Your child with IBD may experience many changes to their life, including incorporating regular visits to the GI Clinic, recurrent symptoms, and distress about their condition.

Why is Mental Health Important?

- When a child has a chronic medical condition, the emotional adjustment is as important as the medical care.
- Intervention services for children, teens, young adults, and their families assist in learning positive coping skills and ways to manage their condition

How Can a Mental Health Provider Help You and Your Child?

- Assist with coping and adjusting to a long-term medical condition
- Change behaviors to help minimize the impact of the illness and maximize treatment protocol
- Promote health behaviors, such as life-style changes, good sleep habits, and regular school attendance
- Follow through on medical recommendations, including medicine, procedures, and therapies
- Assist with parenting and sibling adjustment

Therapy (Individual, Group)

-Psychologist
-Clinical Social Worker
-Counselor
-Pastoral Counselor

Medication Prescription & Monitoring

-Psychiatrist
-Psychiatric
-Nurse Practitioner
-Mental Health Pracitioner

PDF Version Available

Sources: American Psychological Association; National Alliance on Mental Illness; KidsHealth.com

Finding a Mental Health Provider: Steps to Take

Talk with your Child

- It is important that your child is “on board” with pursuing mental health services and what sort of provider they would prefer to see.
- For example, some children may be more comfortable seeing a psychologist in a traditional office setting, while others may be more comfortable with a peer specialist or group/therapy setting.
- Your child will plan an important role in the ultimate decision in who he/she would like to see for their mental health.

Visit with you GI Physician

- Discuss your concerns with your pediatrician.
- Your pediatrician may be able to conduct assessments of what sort of mental health service is needed and/or provide recommendations for local mental health providers.
- He/She may also be able to provide a referral for mental health services, which may or may not be required by your insurance company.

Contact Insurance Company

- Ask whether your insurance plan will cover mental health services and how much coverage is available.
- Ask for a list of all the mental health providers in your area that are covered by your insurance.
- If you do not have insurance, you can choose to pay out-of-pocket or contact your local community health center to find services available.

Find a Provider in Your Area

- Research online, in the phone book, or from a list provided by your insurance company to find mental health providers in your area, or visit: http://locator.apa.org/
- If the wait for your top choice is too long, go ahead and make the appointment anyway. You can always cancel it later.
- Try your next provider of choice. Sometimes finding the right provider can take a little time. But it is important find a provider who can form a strong bond and relationship

Sources: American Psychological Association; National Alliance on Mental Illness; KidsHealth.com

Finding a Mental Health Provider for Your Child and Teen with IBD

It is okay to ask questions before and during the first appointment. Providers know that you are "shopping" for the best fit and are willing to help you find it.

Questions to Ask Before the 1st Visit

- What experience do you have working with children/adolescents?
- What experience do you have working with children with IBD or chronic medical conditions?
- What are your credentials? How long have you been doing this work?
- What kinds of treatment do you use to help people with their condition and concerns? Have they been proven effective for dealing with my child's condition and concerns?
- What is your appointment availability? Do you have after work or early morning appointments?
- What are your fees? Is there a sliding scale fee policy?
- What types of insurance do you accept? Will you accept direct billing to or payment from my insurance company? Do you accept Medicare/Medicaid?

What Happens in Therapy?

- Your mental health provider will ask you and your child about his/her feelings, thoughts, friendships, school, and other important parts of their lives.
- During your first session, the mental health provider will ask a lot of questions in order to learn about your child and better understand what concerns you and your child have.
- After a few sessions, you can expect the mental health provider to share with you and your child their understanding of the problem, how therapy can help, and what will happen in therapy room.
- You and your child may also be asked to help set goals for treatment.

Questions to Ask During the 1st Visit

- Will you coordinate my child's care with other providers? If yes, how so?
- What does successful therapy look like to you?
- How often will you meet with my child and/or me? How long will each session be?
- What will be the goals of treatment?
- What communication methods are preferred? Are emails or phone calls between appointments acceptable?

Sources: American Psychological Association; National Alliance on Mental Illness; KidsHealth.com

Understanding Lab Results

All the labs that we follow in patients with IBD matter, but these are the most important ones that patients and families should learn about.

Blood Tests

White Blood Cell (WBC): The white blood cells are the cells in our body from the immune system that help fight infections. They are also involved in causing inflammation in IBD. The WBC count helps monitor the activity of immune suppressing medication such as azathioprine, and also may indicate active infection in the body.

Albumin (ALB): Albumin is a protein that is measured in the bloodstream. Many people with IBD have a difficult time absorbing the nutrients found in the foods they eat, including protein. If patient's albumin is abnormally low, it may indicate poor nutritional status due to active IBD. When the intestine is inflamed protein can be lost in the stool. This can also result in a low level of albumin in the bloodstream.

Hemoglobin (HGB): Hemoglobin is a part of the red blood cell that helps carry oxygen around the body in the bloodstream to nourish active and growing organs and tissues to allow us to have energy. The mineral iron is an important part of hemoglobin's ability to carry oxygen. Hemoglobin may be low if a person is not absorbing enough iron due to inflamed intestines and/or if they are losing blood through sick intestines. If a person has low hemoglobin, this is called anemia. Controlling active IBD inflammation and giving supplemental iron may help treat anemia and restore health.

AST/ALT (transaminases, liver enzymes): AST and ALT are two enzymes found in mainly inside of liver cells, but also in other tissues of the body. When the values are abnormally high, this may indicate inflammation or damage to the liver cells, which can happen for many reasons. These reasons range from the common cold to liver injury from medications to hepatitis. If the AST and ALT are elevated, the GI doctor will help decide what further testing may be needed to make sure the liver is healthy.

Erythrocyte Sedimentation Rate (ESR, Westergren Sedimentation Rate, "sed rate"): ESR is one nonspecific marker of general inflammation within the body. If it is elevated without other signs of illness, this may indicate inflammation in the GI tract due to IBD.

C-reactive protein (CRP): CRP is also an inflammatory indicator, sensitive to inflammation. Like ESR, CRP is nonspecific, but if elevated without other signs of illness, may indicate inflammation in the GI tract due to IBD.

**Please note: The ESR and CRP can be elevated for many reasons, including common colds, viral infections etc. It does not always mean that disease is active if these numbers are elevated. Please ask the doctor about how he or she interprets these results.*

Stool tests

C. diff testing: The most frequent stool test that a patient is asked to do--sometimes over and over!-- is a collection for Clostridium difficile (C.diff) testing. The stool sample can be collected at home and taken to a local lab for testing. The results will be sent to our office and the patient will be called with the result, usually within 48 hours of dropping off the sample. It is very important to test for a C. diff infection when a patient with IBD has GI symptoms, because a C. diff infection can cause identical symptoms to a IBD flare but they are treated different ways so it is important to clearly figure out what is happening. C. diff occurs more often in patients with IBD and also more often in patients on immune suppressing medications, it can be acquired easily out in the community and is treated with antibiotics.

Fecal Calprotectin: This stool test looks at the number of inflammatory cells that are shed from the lining of the intestine and found in the stool. The number helps the doctor determine how active inflammation is within the intestine over time to make sure IBD medications are effective.

Other stool studies that patients may be asked to do include a **stool culture**, which screens for other types GI tract infection, and **stool ova and parasite** (O & P),which looks for parasitic infections, or is used to detect white blood cells in the stool.

Vaccinations and IBD

Vaccinations are designed to protect people from preventable illness and contagious disease. In general, patients with IBD should receive vaccinations on the same schedule as other children. This is particularly important because many of the IBD medications can suppress the immune system. Infections can be more serious for patients that are taking these medications.

Vaccinations ALL patients **SHOULD receive:**	Vaccinations patients on immune suppressing medications **SHOULD NOT receive:**
Diphtheria (via DTaP)	Chickenpox (varicella or VZV)
Haemophilus influenza type B (Hib)	Measles-mumps-rubella (MMR)
Hepatitis A	Yellow fever
Hepatitis B	Oral Typhoid
Influenza injection ("flu shot"; every year)	Nasal Flu-mist®
Pertussis (via DTaP)	Smallpox
Polio injection	Oral Polio (no longer available in the U.S.)
Pneumococcal	Bacille Calmette- Guérin (BCG, not available in U.S.)
Tetanus (via DTaP)	Japanese encephalitis
Human papilloma virus (HPV)	Rotavirus
Meningococcal (Menactra®)	Typhus

Medications in the 5-ASA class (see Medications section) do not influence the ability to receive virus vaccines, so all vaccines are safe as long as the patient is not also taking immune suppressing medication. If a patient or family is unsure whether a medication impacts the immune system and is not listed above, please contact our office and ask the GI doctor or nurse before getting the vaccine.

If a patient is taking a medication that affects the immune system, people who live with them can safely get the Flu-mist® nasal spray, MMR, and chickenpox vaccines.

If a patient is taking a medication that affects the immune system, people who live with them **SHOULD NOT** receive the smallpox vaccine or oral polio virus vaccine (this is different than the polio injection given in the U.S.; the oral polio vaccine is given by mouth and is no longer available in the U.S.).

If a person with IBD is traveling out of the country, additional non-routine vaccines may be needed. Please notify the GI office so that we can help to determine what vaccines will be appropriate to receive. It may be helpful to consult with the University of Michigan Travel Medicine clinic prior to travelling out of the country to decide what vaccines are recommended that most doctors' offices don't carry.

Tuberculosis test (TB test, PPD)

When a patient with IBD needs to start an immune suppressing medication, we will often ask that he or she have a TB test done.

- TB is a highly contagious infection that involves the lungs and may spread to other organs in the body that is relatively uncommon in the USA.
- People can sometimes carry the TB germ in their body without having any symptoms.
    1. This is called *latent TB*.
- Because many effective medications for IBD are immune suppressing, it is important to be sure that there is not a hidden (latent) TB infection present in the body that could flare up if the immune system is suppressed with medications for IBD.
- The TB test is done in 2 ways
    1. PPD Test
        a. by injecting a tiny amount of specific protein under the top layer of skin on the forearm
        - This needs to be read 2-3 days later by a health professional
            - If there is a latent TB infection, the skin will react by developing an enlarged red bump at the injection site within 2-3 days.
    2. Quantiferon Gold
        a. Blood draw to help detect hidden (latent) TB infection.

-Keep in mind the PPD test requires the initial injection, **then** having the skin test read by a health professional (doctor or nurse) 48 to 72 hours after it is placed.

-Once this test has been read, please have the results documented and faxed to the GI office

There are reasons why the doctor may choose the skin test (PPD), the blood test (Quantiferon Gold), or both. The doctor will explain to a patient and family what the best way to test for TB is.

VACCINE RECORD

C.S. MOTT CHILDREN'S HOSPITAL
UNIVERSITY OF MICHIGAN HEALTH SYSTEM

Vaccine	Date
Hepatitis B (HepB, Hib-HepB, HepA-HepB, DTaP-HepB-IPV)	
Diptheria, Tetanus, Pertussis (DTaP, DTP, DT, Td, Tdap, DTaP-HepB-IPV, DTaP-IPV/Hib, DTaP-IPV, boosters	
***Haemophilus influenzae* type b** (Hib, Hib-HepB, DTaP-IPV/Hib, DTaP/Hib)	
Pneumococcal (PCV7, PCV13, PPSV23)	
Polio (IPV, OPV, DTaP-HepB-IPV, DTaP-IPV/Hib, DTaP-IPV)	
Rotavirus (RV1, RV5, RV [unknown])	
Measles, Mumps, & Rubella (MMR, MMRV)	
Varicella (chickenpox) (VAR, MMRV)	

Vaccine	Date
Hepatitis A (HepA, HepA-HepB)	
Meningococcal (MCV4, MPSV4)	
Human papillomavirus (HPV4, HPV2)	
Zoster (shingles)	
Influenza (yearly) (TIV, LAIV)	
Tuberculosis Test (PPD, TB Test)	

Please note any vaccine reactions:

Transitioning to Adulthood with IBD

A common question from teenage patients and their families is “how long can the patient keep coming to the pediatric GI clinic.” As pediatric doctors, we know that all of our patients will someday reach a point when they will be transferred to an adult GI clinic. However, we also know that readiness for this transfer and readiness to be an independent adult are not skills that come overnight. That is why we work hard to ensure that the process of transition—one that begins long before the transfer to a new clinic, and continues afterwards— is effective for our patients. The path from childhood to adulthood is a challenging one, especially for those with a chronic health condition such as IBD. Older teenagers and young adults are at increased risk for injuries and serious health-related problems due to many different causes and studies have shown that if they are also dealing with a chronic disease such as IBD, the risk for poor control of that disease goes up as well. Our goal is to guide patients through a transition process that decreases the risk of IBD flares and increases the chance of being successful and healthy upon transferring care to an adult-based GI clinic.

What is transition?

Transition is a word used to describe the process that helps patients with IBD learn what they need to know and do to take care of themselves; this is also called “self-management”. In the beginning, for many patients, the parents will do most of the work. Transition helps them gradually move to the point where the patient has most of the responsibility but can still have parents to help with some parts of care. Transition is a process that occurs over many years, while transfer is the actual switch to going to a new clinic and medical care team.

When does transition begin?

There is no hard-and-fast starting point that works for everyone. In general, we start discussing transition- related issues at clinic appointments when a child is around 10-12 years old. However, some patients are interested in self-management earlier while others may need more prompting. At any age, if we do not talk about something a patient or family is interested in at the appointment, please ask.

When will transfer happen?

The transition process is different for every patient. Usually, we plan to keep seeing patients in the pediatric GI clinic until they are in their early 20s. This is so patients do not need to get to know a new doctor or clinic at the same time he or she is graduating high school, moving out of home, and starting college or a job. There might be reasons why some patients are transferred earlier, but just like people do not automatically become independently functioning adults at 18, we do not automatically send patients to a new clinic when they turn 18. The important thing to remember is that transfer does not depend just on the age of the patient, but on the ability to take care of his or her own medical needs. The patient, family, and GI doctor will decide together when transfer is appropriate.

What will be different about appointments during transition?

Once patients are 10-12 years old, we will start spending more time at appointments talking about long-term issues related to transition. We will still want to discuss how they are doing right then, but we will also start working on making sure they are developing the knowledge and skills they will need to be an independent adult when the time comes.

We may also ask to speak with patients alone, without parents and/or other family members in the room. This is *not* because we are worried about the patient or because he or she is in trouble. We do it because learning to discuss certain issues independently is an important part of learning how to someday being able to manage them independently.

What kinds of things will we talk about?

- Knowing what a patient's disease is called.
- Knowing what parts of the GI tract it affects.
- Knowing the symptoms when the disease is active / in a flare.
- Knowing the names and doses of all of medications, as well why each medication is important and what side effects may occur.
- Knowing which labs are important and why for monitoring IBD status while on medications.
- Being able to describe any surgeries or procedures that a patient has had and why.

What else will be important to work on during transition?

- Remembering when it is time to take medicines. Think about setting an alarm on a watch or cell phone to help with this, or keeping the medication near something that is used at the same time every day, like a toothbrush.
- Calling for refills—it is important to remember to do this *before* medications run out.
- Organizing medications, perhaps in a pillbox, every week.
- Remembering when it is time to get labs drawn.
- Scheduling clinic appointments and planning ahead to make it on time.
- Knowing how medical care and medicines get paid for—when a patient will need to get his or her own health insurance, where to get insurance from, and what steps to take to remain insured. Our social workers are available to help families and patients with insurance-related issues.
- Calling the office on own with questions or concerns that need to be brought up in between appointments.
- Discussing issues on own with doctor during the appointment rather than always relying on family.
- Coming to each appointment with questions to ask the medical team about anything related to care. This is important to become engaged and thinking about IBD and what is being done to treat it. It can be helpful to write down questions that come up before an appointment to help remember them.

How will the doctor help work on all of these things?

- First of all, a patient will not be expected to master all of the issues in the previous two sections right away!

  Just as an 18 year-old who has not assumed responsibility for any of the above issues would be concerning, so would be a 10 year-old who is unsupervised in managing his care. Remember, transition is a process that does and should take years.
- The nurse and doctor will pick a few things to work on at each visit. We will discuss these with the family, answer any questions, and provide suggestions for how to work on them between then and the next appointment.
- Just like it is important for doctors to prepare to see patients before we actually walk into the exam room, a successful transition process can only happen if a patient and family spend time on transition related issues outside of clinic

What happens when it is actually time to transfer?

We can easily set up a referral to our adult gastroenterology clinic here at the University of Michigan. This means that the new doctor would be able to see all of the records from care in our clinic which can make things easier.

However, since there are more adult GI doctors in Michigan than pediatric GI doctors and since many of our patients come from far away, some patients will transfer their care to an adult clinic closer to home. If a patient would prefer to switch to a clinic closer to home when it is time to transfer, please let us know. We will work with patients to arrange this and to pass all medical records on to the new provider.

There is nothing simple about living with a chronic illness, but that does not mean it has to be problematic. It is not something that defines a person, though through diagnosis and management a person encounters defining moments.

I became part of the IBD family in the year 2000. It was not a quick diagnosis, but two years' worth of numerous doctor visits, tests, and many different theories of why I was ill. After ruling out many diseases through analysis, I was diagnosed with Crohn's Disease and began my path to remission. A path made up of biological factors, physical factors and mental factors.

My doctors and nurses found a medicine that, biologically, works for me. I have been on this medicine for 13 years and contentedly, it continues playing its role in my symptom management. There will be a day when it is no longer working, and there will be a different medicine that will fill the void. When I change medicine, I know I will be ready, because the medication I am on is not the only element in my symptom management.

An important aspect of my life, like many people with IBD, is my diet. I know what to eat, when to eat, how much to eat, and obviously what to avoid eating. Food is the fuel of all animals, and a proper diet is best fuel for me—someone living with IBD. My diet is not something I was told, but something I had to discover. Doctors and dietitians make suggestions, but only I know the effects of my diet on my body; it was very important to figure out how my diet would best benefit me. Keeping my body nourished has always been important, especially as I remained very active, but most importantly it kept my mind clear.

When being diagnosed with Crohn's Disease, it was never a question of "why me," or "how come this happened to me." Those questions cannot be answered and it was important to focus on essential questions in regards to moving forward. Focusing on things I could control kept my mind free of anxiety and stress, but it was not always easy. I would focus on the very moment I was in; focusing on breathing in, and breathing out; focusing on what I could do in the next few minutes, as a small step, to carry out the process of what I wanted to achieve. It was important to focus on factors I could influence and to keep my mind clear and positive.

For every thought, there are two ways of processing it. For me, there only became one way to process, and that was through optimism. I credit the majority of my remission to my optimistic state of mind. Things are not always great, or even good, but things seem worse if they are painted in pessimistic light. This is damaging to the mental state of mind. A negative way of thinking does not keep you in the moment, but sends you spiraling down a tunnel of what ifs and stress; leading to a loss of hope. I would always find the good in any situation; there is no need to harvest the negative. If someone thinks badly, they feel bad. When I think well, I remain in good health. As an avid golfer, when my golf ball ends up in the rough, I do not dwell on the fact that I missed the fairway, but consider what it will take to put my next shot

on the green; I give myself
an opportunity at making birdie.

Through my life, receiving medication from my doctors, eating healthy, and keeping my mind clear and positive have kept me in remission. They also helped me develop a stress free lifestyle. Focusing on the here and now, and only considering what I can control has significantly controlled my stress. By limiting my stress, I have kept my digestive track free of disruption. My digestive system continues to perform above par, and it has given me the satisfaction of a normal life. I still receive infusions every eight weeks, but my disease has not restricted my lifestyle. I attended school regularly; I played on varsity sports in high school; I played rugby, founded a fraternity, and graduated from college with a degree in education. I have not been burdened by my IBD, nor have I let it define me. I continue to live a strong, healthy life, and the very same is possible for anyone diagnosed with inflammatory bowel disease.

Financial and Insurance Matters: Planning Ahead

When the GI appointment is scheduled at time of diagnosis of IBD or transfer of care to our clinic, the financial office will verify insurance coverage for care and treatment. It is important to understand the child's insurance coverage and potential out- of-pocket expenses going forward.

Health insurance is a program that helps lower the cost of health care. It helps pay for things like medication, clinic visits, and hospital stays. It helps families to afford the costs of staying healthy. People may get health insurance through private companies, employers, or through government programs like Medicaid or Children's Special Health Care Services.

What to consider ensuring financial success throughout the treatment process:

- What is the child's insurance coverage? Would he or she benefit from state-based insurance supplementation?
- Does a patient's family have a long-term financial plan?
- Does the patient have a good understanding the medical plan to stay well so he or she can finish school and get a job?

You are encouraged to contact financial coordinators for assistance at (734)763-1528 or (800)333-9013 as often as you need help. The clinic social worker may also help discuss financial and social barriers for care.

Medicaid

Medicaid is a state-funded insurance program available for children up to age 21 whose families meet financial need criteria. All children who receive Medicaid are assigned a caseworker through the Department of Human Services, who will work with parents regarding questions about the child's Medicaid coverage. If the child has Medicaid, please bring the state ID card to hospital or clinic visits. If there are questions about whether a child may qualify for Medicaid, please call our office or ask us at a clinic visit and we will contact social work for you for further assistance.

Children's Special Health Care Services (CSHCS)

When a child has a chronic disease, such as IBD, in the state of Michigan, he or she may qualify for CSHCS. The cost to families for this supplement is based on income. The social worker can provide information and assistance in applying for this program.

What does CSHCS provide?

- Coverage and referral for specialty services based on the patient's health problems
- Family centered services to support the primary caretakers of the child
- Community based services to help offer care for the child at home and maintain normal routines
- Culturally competent services which demonstrate awareness of cultural differences
- Coordination of services from any different providers who work within different agencies

Who is eligible for CSHCS?

- Michigan residents
- U.S. citizens or documented non-citizens admitted for permanent residence
- Children with qualifying medical condition (including IBD) and younger than 21 years of age
- An MDCH (Michigan Department of Community Health) medical consultant reviews each case to determine eligibility. Severity and chronicity of the person's condition as well as need for treatment by a specialist are factors considered.

What is not covered by most insurance?

Even with adequate health insurance coverage for a child, there may be services that insurance will not cover, such as:

- Transportation to and from the hospital or clinic
- Temporary lodging and meals for family members during inpatient stays
- Parking fees for visits to the clinic or hospital
- Insurance premiums, co-pays, and deductible amounts

Online Resources

The internet has become an excellent resource for education about IBD. We encourage patients and families to learn all that they can about the diagnosis. We recommend the following websites that provide medically accurate information and resources about IBD.

www.ccfa.org : Crohn's and Colitis Foundation of America

CCFA offers many handouts including:

- Information to prepare to transfer from pediatric to adult care practitioners
- Teen guide dealing with Crohn's and Colitis
- Information for teachers and other school personnel
- Parent's guide
- Checklists for independent management of IBD

www.naspghan.org : North American Society for Pediatric Gastroenterology, Hepatology & Nutrition

www.GIKids.org : Children's Digestive Health Information for kids and parents

http://www.justlikemeibd.org/: Just Like Me! Teens with IBD: Information aimed specifically at teenagers living with IBD

www.crohnsandme.com : Crohn's & Me: Each year, UCB offers scholarships opportunities to patients diagnosed with Crohn's disease that are seeking an associates, undergraduate, or graduate degree. For an application and more information, visit www.crohnsandme.com/crohns-scholarship

https://improvecarenow.org/ : ImproveCareNow: an international pediatric IBD collaborative partnering with patients and parents to improve care for children and families living with IBD. Our GI division has been a part of ImproveCareNow since 2008.

www.twitter.com/umkidsibd: Our pediatric GI division maintains an active Twitter account providing news, updates, and articles of interest aimed at kids and families living with IBD. Our handle is @UMKidsIBD.

Many colleges have student IBD support groups on campus. If a patient is interested, he or she should inquire with a Student Activities representative.

The University of Michigan students have a student group called the Crohn's and Colitis Student Initiative (CCSI). They can be found at https://maizepages.umich.edu/organization/ccsi or on Twitter https://twitter.com/michiganccsi @MichiganCCSI

Quality Improvement and Research

An important part of our IBD program is to make sure that the care we give patients with IBD is always getting better. An important way that we try to do this is through a process called quality improvement (QI).

QI is an effort that promotes improvement in all levels of healthcare and quality of life for patients with IBD. When thinking about how to give high quality care, the main focus is, of course, the patient's well-being. In order to make a change for the better, the medical team must think carefully about the details of how care is being provided to the patient and family, and work to identify the areas that need improvement. Ultimately, the goal is to make changes in how health care is delivered that will improve our patients' health and quality of life, and to make the care we give more efficient to allow families to enjoy their time outside of the clinic and hospital.

QI is very important to the IBD care team, which includes the patients and families. We are always looking for ways to improve care for our patients and address their personal needs. A good portion of our QI efforts includes working with patients and families in a variety of ways. Someone in our IBD care team may interview patients or families that are willing to give feedback based on their experiences, ask if they would like to be a part of different quality improvement projects, or just come and talk to them about QI projects or research we are working on. We ask that you be honest with us, as we cannot possibly improve IBD care without the input and help of the patients and families we care for that live with IBD every day.

One of the many quality improvement efforts is being involved with an international collaborative chronic care network called ImproveCareNow (ICN). The long term-goals of ICN are to transform the health outcomes, quality of care, and costs for all children and adolescents with Crohn's disease and ulcerative colitis by allowing patients, families, clinicians, nurses, dieticians, and researchers to work together in a learning health care system. We have been involved with ICN since 2009, which currently includes over 80 pediatric IBD care centers across the United States and England, working with over 600 pediatric gastroenterologists who are caring for over 20,500 children and adolescents with IBD.

ImproveCareNow network goals:

1. Improve the care and health of all children and adolescents with Crohn's disease and ulcerative colitis.
2. Engage and empower patients and families to participate as true partners in all aspects of the ImproveCareNow Network.
3. Transform care through innovation and discovery.
4. Achieve the best care at lower cost.
5. Ensure the sustainability of the ImproveCareNow Network.

If you would like to learn more about ImproveCareNow or get involved as a patient or parent partner, let your GI doctor or nurse know and visit www.improvecarenow.org

Glossary

A

Absorption: The process of a substance, like nutrition or medications, entering the bloodstream from the small intestine.

Adverse Reaction: An unintended side effect from a drug.

Albumin: A protein made by the liver and found in blood. It is important for health and helps carry certain mediations around the body in the bloodstream.

Alkaline Phosphatase: An enzyme that may be increased in some liver and bile duct diseases, but is also released by the bone during times of rapid growth. Alkaline phosphatase comes from many tissues in the body, especially bowel, liver, and bone.

Anemia: A low red blood cell count. Anemia can be due to loss of blood, low iron content in the blood, or chronic inflammation.

Anus: The area between the buttocks where the stool comes out of the large intestine (colon).

Appendix: A small finger-like pouch connected to the first part of the colon.

B

Biologic agents: Medicines that block certain proteins that cause inflammation in the lining of the GI tract.

C

Calcium: A mineral that is important for building strong teeth and bones; found in milk and soy products.

Chronic: Ongoing, long-lasting, continuous.

Colon: Also called the large intestine or large bowel, it absorbs water and forms stool.

Constipation: Hard stool; not pooping regularly, or stool that is difficult or uncomfortable to pass.

D

Duodenum: First part if the small intestine; it helps digest food and absorb nutrients (fats, irons, proteins, and sugars).

E

Enema: Liquid medicine given through the anus into the rectum.

Esophagus: A muscular tube that allows food to move from the mouth to the stomach.

Exacerbation / Flare of IBD: Startup of GI inflammation symptoms after a time without symptoms in a person with IBD.

F

Folate: Helps you make new red blood cells; found in green leafy vegetables, vitamins, and cereals.

G

Gastroenterologist/ GI doctor: A physician specializing in the diagnosis and treatment of problems with the gastrointestinal tract and liver.

Gastrointestinal (GI) tract: The mouth, esophagus, stomach, small intestine, large intestine, rectum, and anus.

I

Inflammatory bowel disease (IBD): May include crohn’s disease, ulcerative colitis, and indeterminate colitis.

Ileocecal (IC) valve: Opening from the end of the small intestine into the beginning of the large intestine (colon); prevents backup of feces into the small intestine. This is a common location for crohn's disease.
Ileum: Last part of the small intestine before the ileocecal valve that absorbs up vitamin B12 from food.
Immune system: The system of cells in your body that helps you fight infections. In IBD, the immune system is overactive and attacks the GI tract.
Incontinence: Not being able to hold your stool inside; having involuntary stool accidents.
Inflammation: Swollen, injured, damaged.
Intestine (bowel): The tube that absorbs nutrition and water from what we eat and drink.
Iron: A nutrient that helps make new red blood cells and support growth; found in red meat, green leafy vegetables, and cereals.
IV: A tube inserted with a needle under the skin into a vein (blood vessel) to give the body fluids or liquid medicine into the bloodstream.

J

Jejunum: Second part of the small intestine; absorbs protein, sugar, fat, and minerals.

L

Liver: A large organ in the abdomen that cleans the blood of toxins, makes proteins, and stores energy. It also makes bile, which helps with digestion.

N

Nausea: Feeling queasy, or the sensation that one is about to throw-up.

P

Pancreas: An organ in the abdomen that helps with food digestion, control of blood sugar level, and secretion of other hormones.

R

Rectum: The last part of the colon; holds stool before having a bowel movement.
Remission: Free of IBD symptoms; disappearance of IBD symptoms. Being in remission means that inflammation from IBD is controlled (quiescent).

S

Small Intestine: Also called small bowel; made up of the duodenum, jejunum, and ileum; it is about 20 feet long and is covered with tiny fingers called villi that help absorb nutrients from food.
Stool: a polite word for poop (also called a bowl movement or feces).

T

TNF-α: Tumor necrosis factor alpha. A protein which acts as a signal that the immune system uses to trigger inflammation.