

Guiding **Your** Gut

*A family resource
for living with*

Crohn's Disease



UNDERSTAND.

TAKE CONTROL.

LIVE BETTER.

Guiding Your Gut

A Family Resource
for Living with
Crohn's Disease

Guiding Your Gut provides families living with Crohn's disease with a brief overview of the condition, as it relates to children and teenagers.

Use **Guiding Your Gut** as a signpost to dig deeper on the particular symptoms, treatments or surgeries you may be facing.

Crohn's disease can be daunting. As you learn more about the disease, its treatments and effects on the body, you will become familiar and comfortable with terminology, tests and treatments. This guide will help you get started.

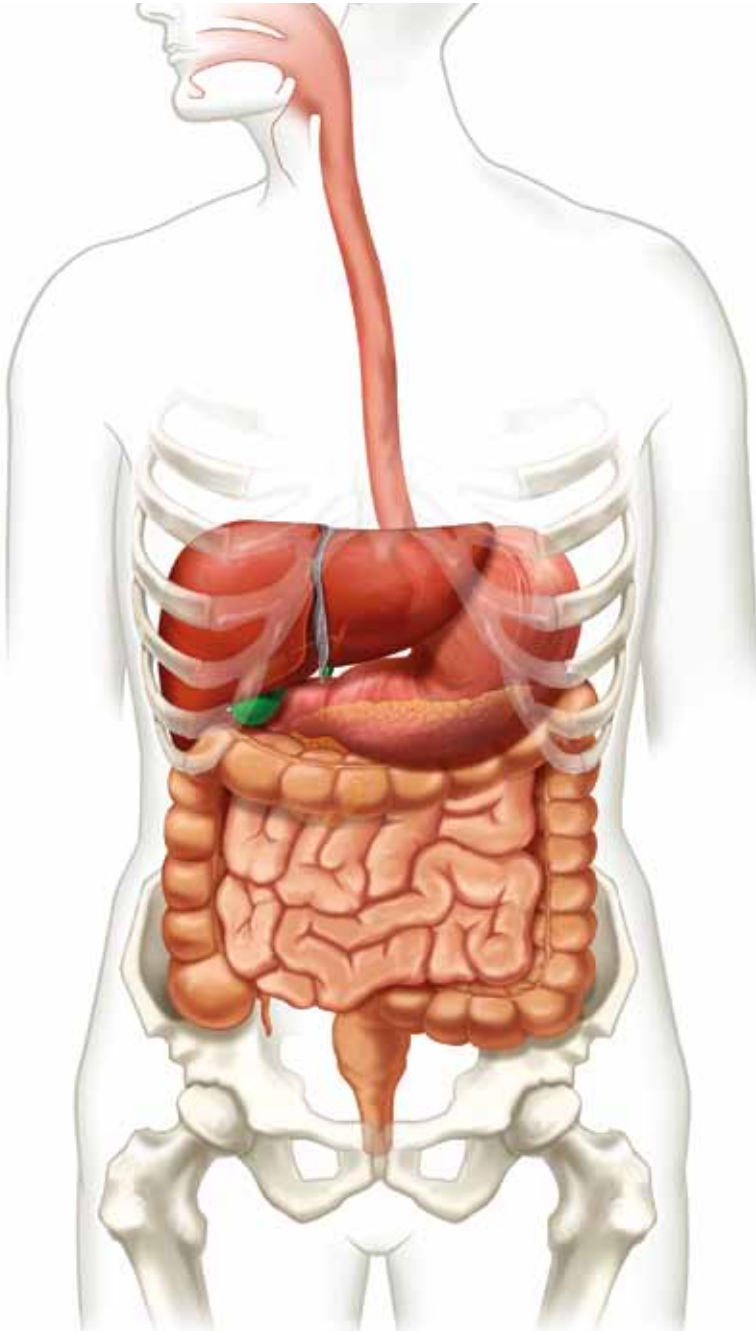
Remember that the course of the disease is different for everyone. Some of this information may apply to you and some may not. You may not experience all of the symptoms, have every test, nor need all of the treatments outlined in this resource.

Most people living with Crohn's disease go on to lead fulfilling lives despite the challenges of the illness. Equip yourself with information, use it to empower yourself to take control of your health and live your life with confidence and optimism.

Please note: The treatment options outlined in this guide are aimed primarily at managing Paediatric Crohn's disease. Different treatments may be used with adult patients.

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Life with Crohn's Disease

You or someone you love has just been diagnosed with Crohn's disease. This news can be daunting. Your diagnosis may be life-changing and can be difficult to accept and understand.

For now, there is no cure for Crohn's disease, so it will likely be with you for the rest of your life. Your journey with Crohn's begins with the onset of symptoms and a diagnosis which is confirmed through specialized tests. Because there is currently no cure for Crohn's disease, long-term treatment is often required. Your condition will need to be controlled by medications, lifestyle choices, and possibly surgery, when symptoms are too severe to be controlled by other means. You and your gastroenterologist will determine which strategies and treatment options are best for you.

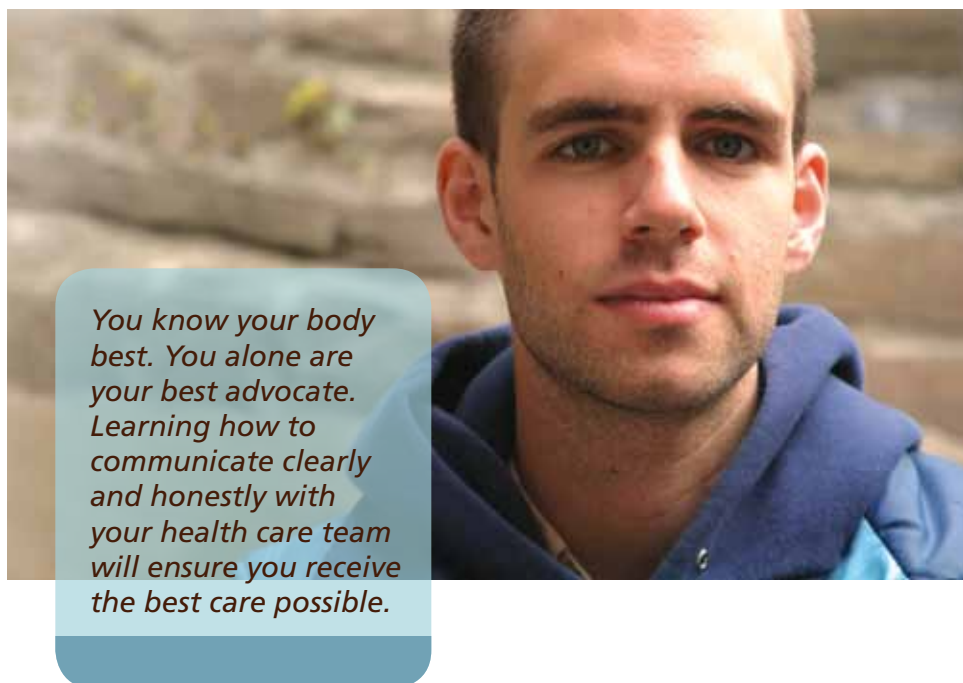
As a person living with Crohn's disease (or as an advocate for your child, teen, or loved one with the condition), it is important to develop the skills to recognize signs of a "flare" or that the disease is progressing. It's important to remember that your experience with Crohn's disease is as unique as you are. There is no clear roadmap of how the illness will progress over time. You will experience peaks and valleys of symptoms over the years.

The good news is, there is excellent information about Crohn's disease and effective treatments are available to help you on this life-long journey. Guiding Your Gut has been developed to help you understand what is happening inside your body and to better understand and manage your life with Crohn's disease.

Let's get started.

Please note: The treatment options outlined in this guide are aimed primarily at managing Paediatric Crohn's disease. Different treatments may be used with adult patients.

Please note: The information contained in this guide is not a substitute for the medical care and advice of your physician. There may be variations in treatment that your physician may recommend based on individual facts and circumstances. Always consult with your physician when you have concerns about your health.



What is Crohn's Disease?

Crohn's disease was first described by Scottish physician, Kenny Dalziel, in 1913, but was named after Burrill B. Crohn who published a scientific article on the disease with Oppenheimer and Ginsburg in the Journal of the American Medical Association in 1932.

Crohn's disease is one type of Inflammatory Bowel Disease (IBD). It occurs when a portion of your immune system is overactive. The role of the immune system is to fight disease by attacking foreign substances or intruders that enter into the body. If you have Crohn's disease, your immune system goes into overdrive and the disease-fighting cells that are supposed to attack intruders begin attacking the lining of your gastrointestinal (GI) tract. This attack leads to a range of symptoms, which can include stomach pain, diarrhea, frequent trips to the washroom, blood in your stool, weight loss and fever.

Crohn's disease can affect your digestive system anywhere from your gums to your bum (see red areas on the illustration to the right) causing inflammation and ulcerations in the intestinal lining. Affected areas will become swollen, irritated and develop into patches of "canker-like" sores or ulcers which are seen during endoscopy.

Sometimes these ulcers make a pattern in the intestine wall called "cobble stoning" which is a classic sign of active Crohn's disease. The illustration below shows a healthy intestine on the left and the swollen, cobble stoning effect of Crohn's disease on the right.



Crohn's disease is most commonly found in the large and small intestines. The intestines are important tubes that carry food from your stomach and turn it into waste (stool) which you eliminate to the outside of your body through your anus. During the journey through our intestines, nutrients and water are removed and delivered to the rest of the body.

People with Crohn's often become malnourished. This occurs because nutrients are poorly absorbed through the damaged GI tract. Diarrhea, blood loss from inflammation and ulcerations, and reduced food intake due to the pain associated with eating can make the loss of nutrients even worse. Children and teens with Crohn's may suffer poor growth, weight loss or poor weight gain and "failure to thrive."

Due to the increased production of inflammatory proteins, other parts of the body, outside of the gut may be affected. Symptoms may include tiredness, sore joints, skin and mouth sores and red, inflamed eyes.

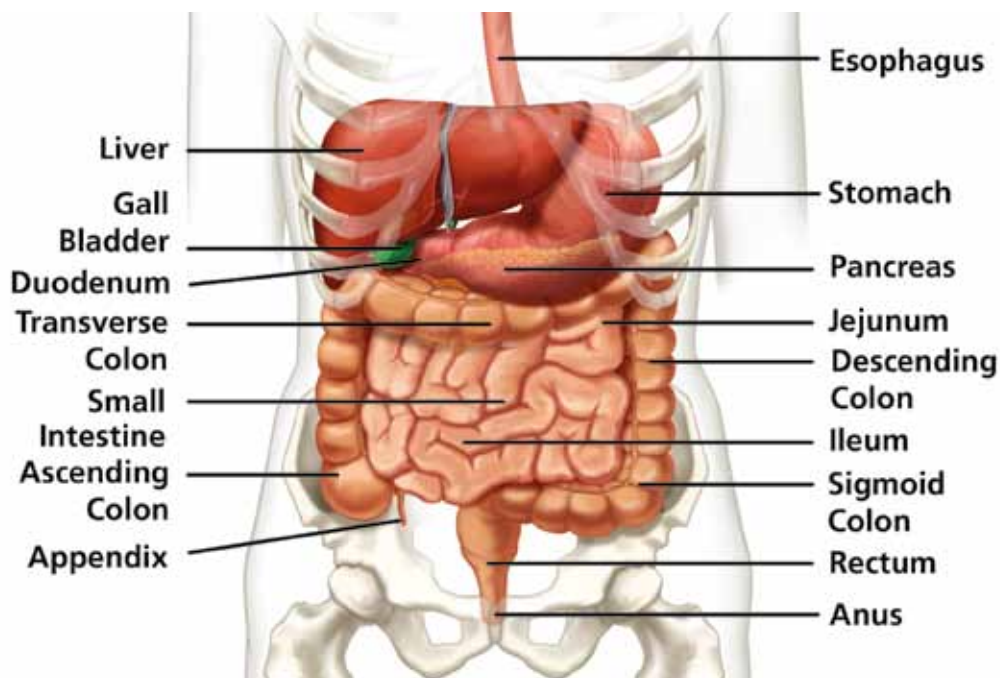
The average age for people developing IBD often coincides with the most important period of life when young people are in school, beginning careers, developing relationships, making lifelong friends, and developing a sense of who they are.

Your Digestive System

Your digestive system is made up of the digestive tract – a long tube that extends from your mouth to your anus (gums to bum) – and other organs in your body that play a role in digestion, such as the liver and pancreas.

Knowing the names of specific areas of your digestive tract can help you take an active role in your digestive health. Below is a labelled illustration of the main components of your digestive system.

Your small intestine is divided into 3 parts: duodenum, followed by jejunum, and then ileum. The terminal ileum (the last part of the small intestine that opens up into the colon) is the area that Crohn's disease most commonly affects.



Understanding Crohn's – Inside and Out

Let's take a look at the steps and stages involved in your journey with Crohn's disease. We'll start by identifying symptoms of the disease, summarizing the tests you may need to have, explaining possible treatment options, and considering strategies to help you live a full, meaningful and happy life.

Symptoms you may experience

Active Crohn's disease, also called a "flare," indicates that the disease is not under control. Symptoms are not likely to go away or get better on their own, so treatment is usually necessary.

When you are in a flare, you may experience one or more of the following symptoms:

- Abdominal pain. This is generally a consistent symptom of Crohn's disease described as a deep, throbbing and cramping feeling within the gut that is most intense minutes or hours after eating or before a bowel movement. The pain is well beyond a normal 'tummy ache.'
- Diarrhea
- Unexplained loss of appetite
- Nausea and vomiting
- Large amounts of foul-smelling gas

Alarm symptoms

A change in your symptoms may mean that additional treatment is needed. Talk to your doctor immediately if you experience a new symptom, a change in your current symptoms or any of the following:

- An unusual amount of cankers or sores in your mouth
- Unexplained or unintentional weight loss
- Failure to gain weight (especially in children)
- Delayed puberty in teens
- Drainage of pus or an abscess (a pus-filled sore) near the anus
- **Anemia** – this blood condition results in fatigue and weakness. It is usually caused by heavy blood loss or a lack of dietary iron
- Rectal bleeding, blood in stool*
- Unexplained fever or a fever that lasts more than 3 days*
- Change in bowel habits
- Eye redness / pain
- Severe joint pains
- Nausea / vomiting - inability to keep food / drink down

Tests You May Need

Diagnostic tests can provide your health care team with important information about what is happening inside your body. The results of these tests can guide your treatment and help you get better faster and stay better (in remission) longer. Below are some of the tests that may be recommended for you. By using one or more of the investigative techniques, your gastroenterologist can better understand your health status, the cause of your symptoms, and create a treatment plan that meets your specific needs.

1) Blood Tests

When you have Crohn's disease, you will undergo many blood tests – sometimes on a regular basis, and other times only when specific problems arise. Blood tests can show if there is any active inflammation in the bowel, if you are anaemic or have any vitamin deficiencies, and identify other more specific, important changes in your body. Luckily, blood tests can usually be done quickly and with minimal discomfort.

2) Stool Tests

Stool tests are used to look for possible bacterial infections such as *Clostridium difficile*, *Salmonella*, *Yersinia*, *Campylobacter*, *E. coli* or parasite infections. Stool can also be tested for blood or potential inflammation.

Collecting stool samples can be messy. Your doctor, nurse or lab will provide you with instructions and tips on how to properly collect samples which are usually collected into clean, dry, plastic jars with screw-cap lids provided. The specimen provided to the lab must be clean to be properly analyzed. If urine or the inside of a toilet contaminates the stool sample, you will have to provide another sample so you want to get it right the first time. It is important to carefully mark down the date/time the specimen was collected. For best results, the stool should then be brought to the laboratory immediately. Be sure to wear latex gloves when collecting your sample and wash your hands well afterward.

3) Radiology Tests

a) X-rays: There are several types of X-rays, each with a specific purpose. Although not used often in cases of Crohn's, an X-ray can be a quick way of determining if there is a blockage or hole in the intestine, or if you are badly constipated. X-rays are most likely taken if you go to the hospital Emergency.

b) Barium tests: A chalky liquid, called barium, is used with an X-ray to help doctors see the organs in your GI tract more clearly. Barium is swallowed for a test called an "upper GI series" or "small bowel follow-through." Barium is a metallic compound that shows up as white areas on the X-ray and highlights any abnormalities such as ulceration, narrowing or enlargement of the bowel, and fistulas (abnormal links between different parts of the bowel). Before an upper GI series, you will need to fast for approximately four hours before your appointment. When you arrive for the test, you will be asked to drink a large cup of barium.

As the barium passes through the stomach and intestines, X-rays will be taken at regular intervals. The radiologist or technician may reposition you and move your tummy to help get the best images of your intestines.

c) CT (Computerized Tomography) scan: A CT scan can capture many X-rays of your intestines in just a few minutes. While a CT scan uses more radiation than a simple abdominal X-ray it can provide your doctor and you a lot more information. Almost every patient with Crohn's disease will need at least one CT scan. A CT scan will show the doctor the same information as an MRI scan (see below).

d) MRI (Magnetic Resonance Imaging): An MRI is a relatively new scan that provides detailed images of the GI tract without exposing you to radiation. An MRI can detect active Crohn's disease and show where Crohn's is located in your intestines and how much of the intestine is affected. It can also help determine if there is a thickening of the bowel wall, (strictures), abscesses, and perianal fistulas. You will be given an intravenous (IV) injection just before the scan that contains a special dye to help the technician see internal tissue. The MRI scan takes 30 minutes to complete and you must lie very still in order for the technician to capture the best images. On the day of your scan, you will need to fast for approximately six hours before your appointment.

4) Endoscopy Tests

Endoscopy tests (scopes) allow a doctor to view your digestive tract from the inside. Using a slim, flexible tube equipped with a small camera, doctors can view your intestines through one of two pathways: from the "top down" (through the mouth) or from the "bottom up" (through the bum). The name of the test you will have depends on where the scope enters your body and the length of the tube used. You are put to sleep during an endoscopy and will be asked to fast before you have the test.

From the "Top Down"

a) Gastroscopy is the most common type of "top down" test. During this form of endoscopy, you will be put to sleep and the doctor will guide the endoscope into your mouth, down your throat, through your stomach and into the first part of your small bowel (duodenum). The endoscope has a camera for viewing the intestines and a special tube through which instruments can pass to take biopsies (tiny samples) of the bowel wall.



b) Balloon assisted endoscopy is another "top down" test that uses a special scope with balloons attached to go much further into the bowel. When the balloons are inflated, they grip the inside of the bowel wall to help move the scope further into the bowel.

From the "Bottom Up"

c) Colonoscopy is the most commonly used "bottom up" type of endoscopy. The colonoscopy is able to reach all areas of the large intestine and usually the

bottom part of the small bowel (terminal ileum). During a colonoscopy, you will be put to sleep and the doctor will guide the colonoscope into your anus, through your rectum, into your large intestine, and finally, into the bottom part of your small bowel. Biopsies can be taken, as well as pictures of the lining of the colon.



Before a colonoscopy, you will need to take a special laxative to stimulate bowel movements one day before the test. During the “bowel prep” process, you will not be able to eat solid foods and will need to drink large amounts of clear fluids to flush the bowel of fecal debris. Cleaning out the bowels is a very important step before a colonoscopy to allow the physician to see clear images of your bowel and intestinal wall.

d) Sigmoidoscopy is similar to a colonoscopy, however, it only examines the final 30-60 cm of the large intestine known as the “sigmoid colon”. A sigmoidoscopy can be administered with little to no preparation beyond the insertion of an enema (the insertion of a liquid into the bowels via the rectum).



e) Capsule Endoscopy is a procedure which involves swallowing a disposable capsule that looks like a pill. The capsule contains a miniature video camera with a light, transmitter and batteries that provides your doctor with images of your digestive system as the capsule travels through your GI tract.



These images are transmitted through sensor leads or a sensor belt to a recording device.

A capsule endoscopy takes several hours to complete, but once the capsule is swallowed, it is possible to carry on with your normal day-to-day activities. Later the same day, you will return to the clinic to return the recording device and have the sensors removed. The capsule will be expelled through a normal bowel movement after about 2-3 days.

Note: This method of testing is currently used in teens and adults only. Smaller capsules are in development for younger patients.



Most cases of Crohn's are diagnosed before the age of 30. 10% of bowel disease patients are under the age of 18.

Taking Proactive Steps to Control Your Crohn's Disease

Crohn's is a chronic yet manageable disease. It is serious and will require you to be aware of, and knowledgeable about, your body and the disease. Your best strategy is to be informed, proactive and involved in your care.

Now that we know what Crohn's disease is and how it can be diagnosed, it's time to look at solutions for treating and living with the disease. There are two primary goals to treating Crohn's disease:

- 1) **Control inflammation** to put the disease in "remission" **and** keep it there
- 2) **Maximize nutrition** for overall good health and to ensure healthy growth for children and teens

There are many strategies to help you achieve these goals. Medications are used as needed to achieve remission and to get you better. Once remission is achieved, long-term maintenance medication is needed to help keep you healthy.

As with everything else associated with Crohn's, treatment options are as individual as you are. Your treatment may include one or a combination of the following:

- dietary changes
- over-the-counter (OTC) or non-prescription medications
- prescription medications
- surgery

Taking Control of Your Life – Treatment Options

As we know, there is currently no cure for Crohn's disease and no one treatment works for everyone. The goal of therapy is to reduce the inflammation that triggers your symptoms and limit complications to maximize your overall health. Ultimately, we want your treatment to lead to symptom relief and long-term remission.

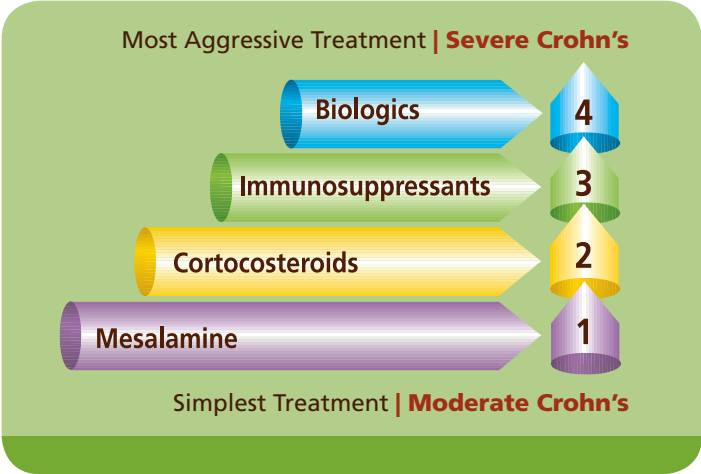
Now, let's look at the treatment options available to help you fight the disease and stay healthy. Crohn's disease is typically treated with a series of medications prescribed in a "stepped" approach. Medications you may be prescribed include mesalamine, steroids, immunosuppressants and biologics. For some people, the progression from one treatment to the next is not always direct.



Like all medications, those used to treat Crohn's disease have different potential benefits, risks, and side effects. It is important to fully understand the potential side effects of a medication and discuss them thoroughly with your physician. You need to understand what could happen and what to watch for so you can make the best decision for your body, situation and lifestyle.

The thought of taking medication on an on-going basis can be scary. It is important to understand that while medications have potential risks and side effects, **not** treating the disease can be even more dangerous. The potential risks of not treating Crohn's disease include poor growth, weight loss, development of abscesses (collections of pus), blockages of the intestine and a decreased quality of life. It is important to consider both the benefits and risks of treatment. The overall goal of treating Crohn's disease is to help you reach your full potential and participate fully in your life. This includes being well enough to grow and develop normally.

While medications have potential risks and side effects, not treating the disease can be even more dangerous.



Step 1: Mesalamine

Stop the swelling

Mesalamine

Mesalamine, also known as 5-ASAs (5-amino salicylic acid), is used to treat mild-to-moderate Crohn's disease. It reduces inflammation in the colon, controls and calms diarrhea, and helps to maintain remission. It is a very safe drug that does not contain sulfa.

Mesalamine is available in oral (capsule) or rectal (suppository or enema) forms. The different formats target specific areas of the intestines and are released into the body at different times. Your doctor will recommend which format is best for you depending upon what section of your intestine is affected and how quickly the medication needs to be released.

The delivery methods for Mesalamine medicines are:

- Oral - Pentasa® and Salofalk® is available as capsules that are taken by mouth. They have different release properties which may determine which forms your doctor chooses for you.
- Rectal – Asacol®, Salofalk®, Pentasa®, Mesavant®, and Measal®, are also available as rectal enemas or suppositories. These drugs are typically used to treat Crohn's disease located in the rectum or bottom part of the colon.

Possible side effects:

- Low appetite
- Headaches
- Joint pain
- Dizziness
- Heartburn
- Gas
- Rash
- Nausea, vomiting
- Stomach cramping
- Mild diarrhea
- Headache
- Acne
- Hair loss
- Fever

Although rare, it is also possible to experience additional side effects when taking Mesalamine which may be possible signs of liver damage. It is important to alert your health care provider if you experience any of the following symptoms: cloudy or bloody urine, dark urine, or yellowing of the skin and the whites of eyes.



Step 2: Corticosteroids

Serious about steroids!

Corticosteroids (or steroids) are used to treat moderate-to-severe Crohn's disease. These medications are not the same as "anabolic" steroids used by weightlifters and athletes to enhance performance. Delivered in tablet, liquid or suppository form, corticosteroids reduce inflammation by suppressing the immune system. They are powerful, fast-acting drugs that affect all areas of the small intestine and are used to achieve short-term remission when salicylates and 5-ASAs do not control inflammation and diarrhea. Improvement is generally felt within days to weeks of taking these drugs.

Steroids are effective wherever there is inflammation and are used to induce remission not to maintain remission. Steroid medications are effective for short-term control of a flare-up, however they are not recommended for long-term use because of their significant side-effects.

In addition to the physical changes brought on by steroid treatment, you may also experience emotional changes, such as sudden anxiety, depression, or restlessness which can place stress on your relationships. Try to remember that steroid treatment is used short term and that side effects will subside when the medication dose is reduced or the treatment is completed.

Steroids are effective for short-term control of a flare-up, however they are not recommended for long-term use.

It is important to discuss any emotional changes with your doctor. Techniques that help to manage changes in mood include relaxation exercises such as yoga, meditation or massage, avoiding stress, and ensuring you are getting enough rest. When sleep is disrupted, anger, anxiety and irritability are easily triggered.



Possible side effects:

- Moon face, puffy and round
- Acne (face and back)
- New growth of body hair
- Weight gain
- Muscle weakness
- Decline in growth rate in child/teen
- Delay in puberty (when used long-term)
- High blood pressure
- Night sweats
- Increased energy
- Depression/mood swings
- Insomnia

See your doctor right away if you experience the following alarm symptoms: blurred vision; shortness of breath; headaches; vomiting/nausea; or, chest pain.

When using steroid treatment:

- Schedule regular eye exams and inform your optometrist that you are taking steroids
- Wear a “Medical Alert” bracelet or necklace with the steroid name engraved
- Get your blood pressure checked at each clinic visit
- **Do not stop taking steroids on your own!** It is very important to slowly wean the body from these drugs under the direction of your physician.

Although rare, long-term steroid use may lead to more serious side effects which may include:

- Diabetes
- Osteoporosis
- Pressure in the eyes



Step 3: Immunosuppressants

Immuno – wha-a-a-t?

Immunosuppressants, or immunomodulators, were originally developed to prevent tissue rejection after an organ transplant. Now, immunosuppressants are used to maintain remission and to decrease the use of steroids in moderate-to-severe Crohn's disease.

Immunosuppressants reduce inflammation by suppressing the immune system, however, they also weaken the immune system and lower the white blood cell count which hurts the body's ability to fight off infections. Regular blood tests are recommended to monitor blood cell counts and bone marrow and liver toxicity. Immunosuppressants currently in use in Canada are outlined below.

Immunosuppressants are used to maintain remission and to decrease the use of steroids.

6-MP® (6-mercaptopurine) and Imuran® (Azathioprine)

Available in a tablet form, these drugs must be introduced to the body slowly to avoid bone marrow toxicity (decrease in your blood cell counts). It can take up to 3 months before these immunosuppressants take their full effect, therefore, they can be used in combination with steroids until the full effect is achieved. These two immunosuppressants can also help heal fistulas and abscesses.

Side effects may include:

- Nausea/vomiting
- Decrease in appetite
- Hair loss
- Joint pain
- Diarrhea
- Pancreatitis (inflammation of your pancreas)
- Hepatitis (inflammation of your liver)
- Leukemia, T cell Lymphoma, risk is higher in males
- Increased risk in developing infection to viruses and bacteria due to lower immune system



Methotrexate®

Methotrexate® is taken weekly through an injection or tablet. It is typically used to maintain remission, however, it can also be effective to induce remission for some people with Crohn's disease. Studies with methotrexate® have shown the drug to be more effective and to result in fewer digestive side effects when it is administered by injection.

Side effects may include:

- Nausea/vomiting
- Decrease in appetite, stomach upset
- Sensitivity to sunlight
- Diarrhea
- Mouth sores
- Allergic pneumonitis (rare)
- Headache
- Drowsiness/fatigue
- Hair loss
- Rash/itching

Additional potential side effects

Although rare, these symptoms may be possible signs of inflammation of the liver or lungs or bone marrow suppression. It is important to alert your health care provider if you experience any of the following symptoms: yellowing of the skin, whites of eyes and dark urine, cough, chest pain, fever, sore throat or shortness of breath.

Methotrexate® depletes the body's stores of folic acid. Folic acid (vitamin B-9) helps the body to break down and convert the food that we eat into energy and is required to produce important body cells such as amino acids and red blood cells. People receiving treatment with Methotrexate® will require a folic acid supplement. Avoid alcoholic beverages while taking Methotrexate®. Drinking alcohol while taking Methotrexate® will increase the risk of liver damage.



Step 4: Biologics

Biologics, a living medicine

Biologics are medications that are specifically engineered to target a known immune or genetic cause of the disease. Remember that the role of the body's immune system is to fight disease. For those with Crohn's disease, the body's immune system goes into overdrive causing inflammation and pain as it attacks the lining of your Gi tract. The role of biologics is to turn off that overactive portion of the immune system.

Remicade® and Humira® are currently the two Anti TNF alpha biologics available in Canada. Remicade® is given intravenously and Humira through self-injection. A tuberculosis (TB) skin test or blood test must be performed before biologic treatment can be approved for you.

Biologics are typically given after all other drugs have been tried and a) have not worked in managing symptoms of Crohn's disease or b) the disease is very severe. These biologics block the overproduction of special proteins made by the body called TNFa. Too much TNFa can cause inflammation and damage to healthy tissue as well as other typical symptoms of Crohn's disease such as pain, fatigue and diarrhea.



Side effects of biologic treatment may include:

- Infection (sinus, urinary tract, lung, skin)
- Headache, fatigue, nausea, rash
- Psoriasis (red scaly patch or raised red bumps under the skin)
- Reactivation of Hepatitis B if you are a carrier of the virus
- Reactivation of tuberculosis (TB) if you are a carrier of the infection
- Some people taking Remicade® may experience an infusion reaction during, or shortly after, treatment. If this happens, your doctor may need to stop or pause your treatment and give you medicines to treat the allergic reaction.
- 10% of patients taking Humira® experience an "injection site reaction" which may include redness, swelling, itching, bruising, pain and irritation.
- Additional **rare** side effects may include Lymphoma (including hepatosplenic T-cell lymphoma), skin cancer or liver injury.



Let's take a closer look at two choices for biologic treatment.

Remicade® (infliximab)

Remicade® dosage is determined by body weight, so your dose will increase as you grow bigger and gain weight. Some patients receiving Remicade® may need higher doses of medication over time to achieve the same results.

Remicade® is given intravenously (injected into a vein), which means that you will go to an outpatient hospital clinic or an infusion centre for treatment. Going to a outpatient hospital clinic or infusion clinic regularly for your Remicade® infusion can be beneficial. At a hospital or clinic, a health care professional sees you regularly in a controlled environment to monitor your health status and answer your questions. They also ensure that you continue to take the medication you need on a regular basis.

The first 3 doses of Remicade® are given within the first 6 weeks (0, 2, 6 weeks). This is known as the "induction phase" of your treatment. Following the induction phase, Remicade® treatment is typically given every 6-8 weeks, depending on how well you respond to the medication. Blood tests are performed before each infusion to ensure you are staying well.

You will be instructed to wait one hour after the infusion has finished for observation to ensure that there are no reactions or complications from the treatment. Many people respond to the treatment quickly and feel an increased sense of wellness and energy.

Reactions can happen while you are getting your Remicade® treatment or shortly afterward. Your doctor may need to stop or pause your treatment and give you medicines to treat the allergic reaction.

Remicade® is given intravenously, which means that you will go to a special clinic or a hospital for treatment.



Humira® (adalimumab)

Humira® is given subcutaneously (injected under the skin) every 1-2 weeks. You can give the injections to yourself (self-administering) or have them administered in a doctor's office or clinic. Humira® may be beneficial for patients who have lifestyles that make it difficult for them to visit an infusion clinic. With Humira®, you may not see a health care professional regularly, so it is very important to take your medication regularly and as prescribed.

Humira® is given subcutaneously every 1-2 weeks. You can give the injections to yourself.

The first 2 injections of Humira® are the highest doses and are referred to as the "induction phase" of your treatment. Following the induction phase, your dose of Humira® drops to a maintenance level and is typically given every 2 weeks. Humira® dosage is determined by your body weight. Some patients receiving Humira® may need higher doses of medication over time to achieve the same results. Many people respond to the treatment quickly and feel an increased sense of wellness and energy.

Additional potential side effects

Although rare, the symptoms listed below may be possible signs of liver, blood or nervous system problems, heart failure resulting from biologic treatment. It is important to alert your health care provider if you experience any of the following symptoms: bruising or bleeding very easily; difficulty breathing; shortness of breath; tingling/numbness/weakness in arms or legs; vision problems; yellowing of the skin or whites of eyes; dark urine; fever that does not go away; swelling of the ankles/feet; sudden, unexplained weight gain; or, chest pain.



Antibiotics – fighting infection along the way

Antibiotics are used to treat bacterial infections, abscesses and fistulas that may occur as a side effect of immunosuppressant therapies. Antibiotics begin working quickly and are generally used as a short-term treatment. Some people who experience ongoing symptoms from Crohn's disease or recurring infections, may benefit from a regular low dosage of antibiotics.

In Canada, the following antibiotics are approved to treat bacterial infections in children and teens:

- 1) **Metronidazole (Flagyl)** is available in liquid or tablet form and is used to treat perianal Crohn's disease and fistulas
- 2) **Ciprofloxacin (Cipro)** is used to treat perianal Crohn's disease, abscesses, and fistulas. Cipro controls infection and inflammation in the intestines and can be used in combination with Flagyl.

Side effects of antibiotics may include:

- Nausea, vomiting or upset stomach
- Dry mouth or metallic taste in mouth
- Dizziness or headaches
- Drop in appetite
- Dark urine
- Sensitivity to sunlight
- Rash
- Numbness in feet (talk to your doctor if this occurs)

Crohn's Disease and Surgery

Although medications are the primary treatment options used to manage Crohn's disease, surgery may be needed if medical therapy is not successful or complications develop.

If you have been ill for some time and the inflammation or damage to your bowel cannot be controlled by medications, your specialist may recommend surgery to induce remission or to treat complications related to your Crohn's disease. The majority of patients with Crohn's disease will require at least one surgery at some point in their lives.

Surgery for Crohn's disease does not cure the illness. Medications will still be required after surgery to "maintain remission" or to keep the Crohn's disease from coming back. The most common reasons for having surgery are as follows:

Urgent surgery (surgery is needed quickly or immediately)

- Uncontrolled bleeding
- A blockage in the small bowel (bowel obstruction)
- A hole in the small bowel wall (perforation)
- Serious abscesses (collections of pus) that may be associated with fistulas

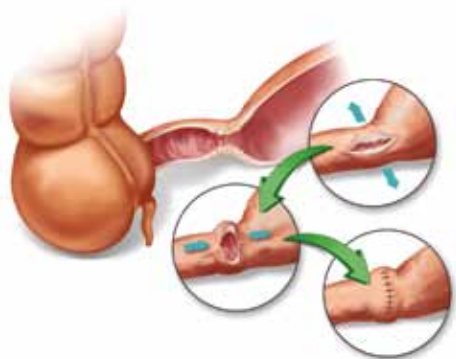
Elective surgery (when surgery needs to be performed but is somewhat flexible and arranged at an appropriate time)

- Failure of drug treatment(s) leading to a decline in health and well-being
- Strictures (narrowing in the small bowel)

Surgeries for Crohn's disease

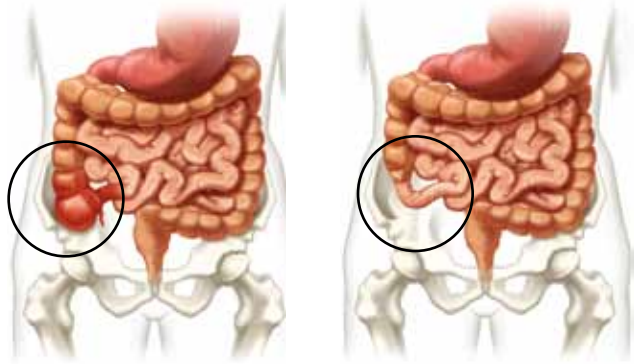
Strictureplasty

Sometimes, inflammation in the intestine can turn into scar tissue which permanently narrows the bowel causing blockages or obstructions. A strictureplasty widens these narrowed areas by cutting along the length of the bowel at the site of the stricture. The incision is then sewn up across the bowel. No bowel tissue is removed during the procedure, although the bowel does become slightly shorter in length.



Resection

A resection removes the diseased part of the bowel and joins the remaining healthy portions together. In the illustration shown near right, severe Crohn's disease affects the lower colon (red area of the illustration). In the illustration shown far right, a resection has removed the damaged lower colon and joined the remaining healthy portions of the intestine together.



Ileostomy

When Crohn's disease is active, providing bowel rest can allow the damaged colon to heal. An ileostomy procedure cuts the small bowel (ileum) near where it joins the colon. An opening is created in the abdominal wall and the end of the ileum is brought through this opening to form a stoma, usually on the lower right side of the abdomen. Feces (digestive waste) pass through the stoma and are collected into a small bag worn on the outside of the body. The bag is then emptied into the toilet when full.

An ileostomy may be reversed 6 - 9 months later, although, in severe cases, the ileostomy will be permanent. Most people with permanent ileostomies find they are free from Crohn's symptoms and experience an improved quality of life.

Seton

A seton is a piece of surgical thread that is left in a fistula tract to keep the tract open. The purpose of seton surgery is to leave the tract open and allow it to drain properly so the fistula can heal while avoiding damage to the sphincter muscles (the ring of muscles that open and close the anus). Damage to the sphincter muscles can lead to bowel incontinence (where you do not have control over your bowels). Seton is also sometimes used to allow secondary tracts to heal before further surgery is done on the main tract.

Other surgeries

There are other, more complex surgical procedures used in specific, less frequent circumstances that your surgeon will discuss with you, should the need arise.

Complimentary Therapies

Probiotics

Probiotics are “good bacteria.” They are live micro-organisms that can benefit gut health when administered in proper amounts. These “friendly” bacteria are available as bacterial cultures added to foods or as dried-cell supplements.

Probiotics work mainly by promoting the development of the intestinal immune system and by displacing harmful bacteria. They can help digest food, support general wellness, prevent certain infections, and improve digestive ailments.

Recent research shows that the use of specific probiotics can aid in the reduction of intestinal inflammation in Ulcerative Colitis and pouchitis. More research is needed to gain a full understanding of the role of probiotics and Crohn's disease.

Specific digestive benefits of probiotics may include:

- Reducing the severity and duration of acute diarrhea (including diarrhea caused by antibiotics)
- Treating constipation
- Improving the symptoms of irritable bowel syndrome (IBS)
- Counteracting lactose intolerance
- Possibly reducing the risk of colon and bladder cancer
- Improving symptoms of moderate-to-severe eczema

Different types of probiotics confer different health benefits, so it is very important to select a product that addresses your specific concerns and has been proven to be effective. Always check with your physician or pharmacist to be certain that the probiotics you are consuming are appropriate.

Eating Without Eating – Supplemental Enteral Nutrition

Maintaining adequate nutrition is a common challenge for people with Crohn's disease and sometimes, you may need extra help delivering important nutrients to your body. When malnutrition is a concern, and growth and health are affected, enteral nutritional support may be helpful.

Enteral nutrition requires you to stop eating and receive all nutrition from a special, liquid diet that contains all the nutrients necessary for the body but does not tax the digestive system. Enteral nutrition (called an elemental or polymeric formula) is typically used for 6-8 weeks as a way to provide extra calories and nutrients to promote growth and development while resting the bowel so it can heal.

An enteral formulation is delivered through a small, flexible tube, called a nasogastric (NG) feeding tube. The NG tube is passed through your nose, down the esophagus, and into your stomach. The tube can be inserted before bedtime so you can receive the formula while you are sleeping and then be removed in the morning so you can carry on with your normal daily activities such as school, sports, and being with your friends and family.

There is a low risk of complications with enteral therapy and it can be used with other prescribed medications. In children, enteral nutrition can sometimes be used in the place of corticosteroids to “induce remission.”

The NG tube may cause a sore throat, sinusitis, nose bleeds or aspiration (formula entering your lungs), bloating, cramping or diarrhea. A health care professional will show you and your parents how to insert the NG tube and watch for side effects.

Note: Check with your insurance provider to see if enteral therapy is covered by your policy. Not all provinces cover the cost.

Financial Considerations and Options

Some medications for Crohn’s disease are very expensive. Biologics, in particular, are more expensive than the other medications outlined in this guide. If your doctor recommends treatment with biologics, it will be important to understand how to access these medications and to know what amount your insurance will cover. You may need to purchase extra insurance to cover the cost of these medications.

Keep in mind, there are support options available to help cover the cost of these medications if you need them. Funding supports may include:

- Drug companies that offer funding based on “compassionate grounds”
- Government applications your doctor can fill out and submit for coverage
- Organizations that may help cover the cost of treatment for a short period of time. Robbie’s Rainbow is such a charity created specifically to support children with IBD.

Living Positively with Crohn's Disease

Living with the unpredictability of Crohn's disease can pose physical and emotional challenges that may seem overwhelming at times. Your best approach to living with Crohn's disease is to be informed, proactive and involved in your own care. Understanding, careful planning, developing a solid partnership with your health care team, and a positive attitude can help you achieve and maintain symptom control and live a full and satisfying life. The following steps are important components of living positively with Crohn's disease:

Take medications as prescribed

Specific medication(s) has been prescribed to treat your symptoms and help keep your Crohn's disease under control. When you do not take your medication as prescribed or stop taking your medication altogether, you risk flaring your disease and putting your health and quality of life at risk.

Some medications require a slow reduction before stopping treatment. This tapering off must be done under the guidance of your doctor. If you suspect that a medication is causing side effects or discomfort, track your experiences by keeping a symptom journal that you can share with your doctor and seek his/her guidance.

See your gastroenterologist regularly

You and your gastroenterologist will see each other many times throughout your life. Good communication with your doctor will be an important part of effective management of your disease. Communicate with your gastroenterologist and your family doctor regularly, clearly, openly and with confidence.

Make good food choices

Most physicians will say food choices for those living with Crohn's disease are as individual as the people living with the disease. As a general rule, avoid foods that give you discomfort. You will need to learn what foods your body can tolerate during healthy periods and what foods to avoid during a flare. For many people living with Crohn's disease, avoiding nuts, seeds and popcorn may be beneficial, particularly when strictures are a problem.

You may need to try new foods that will benefit you nutritionally to ensure you are getting all the nutrients you need. A registered dietitian may be able to help you fine tune your dietary regimen and ensure you enjoy the foods that are fueling your body.

Managing Stress as a Family

Being diagnosed with Crohn's disease or having a child or family member diagnosed with this chronic illness can be overwhelming and can impact the family unit. This can be a scary time for everyone involved, so communication is very important.

Together, sharing each other's fears and concerns can help a family work through the stress and anxiety of this life-changing diagnosis. It's important for loved ones to know that once a child diagnosed with Crohn's disease is placed on an effective treatment, they can go on to lead a normal, healthy life.

The following tips may help to manage Crohn's as a family:

- Teach siblings about the disease
- Ensure parents have good supports in place
- Encourage open dialogue during clinic appointments
- Ask your GI team for reliable/reputable resources
- Adopt a "team mentality": involve other family members during appointments and procedures
- Encourage your child to start off the appointment so they feel they have a voice and are empowered through direct involvement in their care
- Try to restore routines to avoid feelings of isolation and to help build confidence and reassurance that although life has changed, activities that once brought joy can still do so.



When a family member is diagnosed with Crohn's disease, it can be overwhelming. Communication at this time is very important.

Questions you may want to ask at your next appointment

Taking responsibility for your health is important on your path to wellness. You have a major role to play. Make sure you are prepared for every appointment by writing down the questions you would like to ask before you see your doctor. You may want to ask some of the following :

What part of my digestive tract is affected? _____

What is my treatment plan and how long will it last? _____

What happens next if the current medication does not help me? _____

What happens if I miss taking my medication? _____

How often should I schedule appointments? _____

How can I manage my pain? _____

Should I change my diet or take supplements? _____

Can I / should I keep exercising or playing sports? _____

Can I / should I get the flu shot? _____

Are there any over-the-counter medications I should avoid? _____

Glossary

Healthcare professionals sometime seem to be speaking a different language. Don't worry, they are. It's often based on Latin terms. Understanding the terminology they use will help you better understand what is happening to your body and the treatment options that are presented to you.

Abscess: a collection of pus that forms into a pocket, usually caused by bacteria or foreign materials.

Absorption: the bloodstream gathers or soaks up nutrients from the small intestine.

Adherence: Taking medication regularly and as prescribed. This may also be referred to as compliance.

Anemia: a decrease in the number of red blood cells or less than the normal quantity of hemoglobin in the blood, caused by bleeding from the bowel.

Barium: a soft white reactive metal, mixed with water, that temporarily coats the stomach. When x-rayed, barium lights up the digestive tract.

Biopsy: a sample of tissue taken from the inside of the digestive tract during a colonoscopy/endoscopy and tested in the laboratory.

Chronic: an illness or medical condition that lasts over a long period of time and may cause long-term changes to the body.

Cobble stoning: patches of ulcerations that look like a cobblestone street, separated by areas of healthy tissue.

Colon / large intestine: Joins the small bowel to the rectum and anus. Its function is to absorb water and left over indigestible food. It is made up of four sections-ascending colon, transverse colon, descending colon, and sigmoid colon.

Colonoscopy: a camera on a flexible tube is inserted through the anus to the colon; provides a visual diagnosis and the opportunity to biopsy tissue/lesions.

Contrast: a reactive solution made from compounds from iodine or barium (depending on the scan). Contrast is used to light up or improve the visibility inside the body using scans such as CTs or X-rays.

Compliance: Taking medication regularly and as prescribed. This may also referred to as adherence.

Digestive system: the system that breaks down the food we eat, so our bodies can use it as energy to survive and thrive. It runs from "gum to bum."

Endoscopy: a camera on a flexible tube that examines the interior of the body, typically throat to stomach.

Enema: the insertion of a liquid into the bowels via the rectum as a treatment, especially for constipation, or as an aid to diagnosis.

Fistula: a tunnel or passageway between tissue, vessels or organs that do not normally connect.

Flare: a period when the disease is active and causing very significant symptoms.

Gastroenterologist: A doctor with special training and experience in managing digestive diseases.

Gastroscopy: A test used to examine the stomach using a camera on a flexible tube with a light that is passed through the mouth and down the esophagus into the stomach.

Ileum: the last section of the small intestine.

Immune system: a system that protects against disease by recognizing and killing invaders and tumor cells to protect healthy cells and tissues.

Induction phase: The introduction of a new medication into the body.

Inflammation: The body's immune system responds to injury, disease and/or infection causing pain, swelling, heat and redness.

Maintenance: Keeping the disease inactive through medication.

Malnutrition: when symptoms of Crohn's such as ulcerations, prevent the body from absorbing needed calories, proteins and nutrients, so the body can maintain and grow at a healthy rate.

Nutrients: carbohydrates, proteins, fats, vitamins and minerals found in the foods we eat. They help our bodies perform its daily activities and function.

Perianal fistula: Common fistula that is found around the anus. Anal fistulas may arise from an infection in the glands around the anal opening. Fistulas can be very uncomfortable.

Remission: the complete absence of disease activity.

Slow taper: reducing the number of tablets taken slowly over a determined period of time.

Small bowel / small intestine: Found after the stomach and before the colon / large intestine. In the small bowel, much of the digestion and absorption of food takes place.

Stoma: a temporary or permanent opening made by a surgeon to bring part of the intestinal tract out through the abdominal wall.

Strictures: narrow sections of the intestine caused by swelling or scar tissue built up over time from previous inflammation.

Ulcerations: Red, swollen sores in the inner intestinal lining, which causes abdominal pain and possible intestinal bleeding.

Probiotics: living microscopic organisms (microorganisms) that research has found are beneficial to health. Products must contain live or active bacteria to qualify as probiotics.



Our Appreciation

Guiding Your Gut is the result of collaboration between the Canadian Digestive Health Foundation and Robbie's Rainbow with contributions from gastroenterologists from the Canadian Association of Gastroenterology, The Hospital for Sick Children (Toronto), Mr. John Bradley and Dr. Karen Kroeker.

About the CDHF

Over 20 million Canadians suffer from digestive disorders every year. The Canadian Digestive Health Foundation believes this is unnecessary and unacceptable. The CDHF reduces suffering and improves quality of life. As the Foundation of the Canadian Association of Gastroenterology, we work directly with leading physicians, scientists, and other health care professionals to help Canadians understand and take control of their digestive health with confidence and optimism by developing trusted, unbiased, science-based information and programs.

Through education and research, the CDHF strives to:



REDUCE

the incidence
and prevalence of
digestive disorders



IMPROVE

understanding
of digestive
health issues



SUPPORT

those suffering
from digestive
disorders



ENHANCE

quality of life for
those living with
digestive disorders

CDHF Resources

NEW for Kids!

Solving the Mystery of Endoscopy

This fun and interactive on-line game helps ease anxiety and educate young patients undergoing endoscopy.

Join Robbie and Whitney for a tour of an endoscopy suite and your digestive tract.
www.CDHF.ca



www.CDHF.ca

The CDHF website is your 24/7 resource centre. With illustrations, fact sheets, videos, personal stories and more. You can quickly learn from gastroenterologists and other people living with Crohn's disease how to take control of your digestive health with confidence and optimism.



Crohn's On-Line Seminars

Join Crohn's Warrior Jeff Sheckter and CDHF President, Dr. Richard Fedorak for an hour on-line of learning. This duo provides an honest and informed introduction to Living Positively with Crohn's Disease from both patient and physician perspectives. New seminars are being added regularly, so visit www.CDHF.ca often.

Gi BodyGuard – Smart Phone Aps

The CDHF has developed a smart phone app for iPhone and Android called **Gi BodyGuard** to help you quickly, easily and privately track and share your digestive symptoms with your physician. **Gi BodyGuard** has a built-in symptom tracker (stool, pain, blood), food, fitness and medication trackers, a health history form and appointment/medication reminders.

Gi BodyGuard lets you produce comprehensive reports so you can share important information with your physician during your next appointment. You can download Gi BodyGuard for free at: <http://www.cdhf.ca/resources/GIbodyguard.shtml>





About Robbie's Rainbow

Today, Robbie is a young boy living with severe Crohn's disease. He calls himself a Crohn's warrior! Robbie has undergone a multitude of tests, scans and treatments with great courage. Robbie was diagnosed shortly after

his 6th birthday but responded poorly to traditional drug treatments. He began Remicade® 6 months after diagnosis at the age of nine and is now enjoying great health.

Robbie has witnessed children denied access to biologics due to the high cost of this drug treatment and lack of coverage through private insurance. In an effort to provide access to much-needed medications for Crohn's disease, Robbie, his family, and supporters created "Robbie's Rainbow." This organization, run entirely by volunteers, raises funds through capital fundraising campaigns to bring treatment to at-risk children living with Crohn's disease.



In addition to providing critical medicines for children in need, Robbie's Rainbow raises awareness of Crohn's, shares how the disease impacts the lives of young children, and empowers families by providing information on the various treatments available for their children.

As parents, we want our children to lead lives that are as normal as possible. We also want them to learn to take charge of their healthcare when they transition from pediatric to adult patients.

We hope you find the contents of this guide helpful and use it often as a quick reference tool. We encourage you to visit our website www.robbiesrainbow.ca and welcome your questions and comments.

About Kate Murray

Kate is a compassionate and energetic mother of three, member of the Board of Directors for the Canadian Digestive Health Foundation, and co-founder of the national charity, Robbie's Rainbow. Kate and her eldest son, Robbie, founded the charity in 2010, shortly after Robbie was diagnosed with Crohn's disease. Their mission is to provide access to treatment for all children and raise awareness about the growing number of paediatric IBD cases. Kate serves as a mentor, supports education events, speaks publicly, advocates for children with IBD and supports programs at hospitals caring for children with Inflammatory Bowel Disease.

About The Hospital for Sick Children (Sick Kids, Toronto), Department of Gastroenterology

A dedicated team of 12 full-time staff, the goal of this department is to provide high-quality clinical care using an evidence-based approach whenever possible. Their devotion to healthy children extends further than the physical. By developing programs and resources, the Sick Kids GI team educates children on how to best manage and live positively with their disease. It is the GI staff's holistic approach to care that underscores a clear investment into the long-term success of their pediatric patients.

About John Bradley

We would like to thank John Bradley for contributing his insights, experience and writing talents to *Guiding Your Gut*. John is the author of "The Foul Bowel," a humorous and personal perspective on living life with Crohn's disease. In his book, John shares important lessons learned, and his advice in managing Crohn's as a patient, parent, and employee. John lent us a strong patient perspective for clear and relevant information for those living with Crohn's disease.

About Dr. Karen Kroeker

Dr. Karen Kroeker is an Assistant Professor at the University of Alberta in Edmonton. She is an adult IBD specialist who has a special interest in transition care. Dr. Kroeker has recently completed her Masters looking at the impact of having a pediatric diagnosis of IBD. She is passionate about helping young adults with inflammatory bowel disease to become independent in managing their illness.

Recommended Links



Canadian Digestive Health Foundation
www.CDHF.ca



Robbie's Rainbow
www.RobbiesRainbow.ca

Fighting Crohn's Disease.
One **child** at a time.

The Foul Bowel
www.FoulBowel.com

Crohn's & Colitis Foundation of America
www.cafa.org

Crohn's & Colitis Foundation of Canada
www.ccfc.ca

The development of *Guiding Your Gut* was made possible through an unrestricted education grant from Janssen Inc. The views herein do not necessarily reflect those of Janssen Inc.



The Canadian Digestive Health Foundation is the foundation of the Canadian Association of Gastroenterology. As such, we are uniquely positioned to empower Canadians with trusted, current, science-based information so they can take charge of their digestive health with confidence and optimism.

