



Crohn's and
Colitis Canada
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A PARENT'S GUIDE

CARING FOR A CHILD WITH
CROHN'S OR COLITIS



crohnsandcolitis.ca

WHAT NOW?

Your child has been diagnosed with Crohn's disease or ulcerative colitis, or perhaps an indeterminate colitis. You now know that your child has a chronic illness known as inflammatory bowel disease (IBD). The diagnosis may bring forth some feelings of relief, shock and even a sense of being overwhelmed by the news. All of these feelings and emotions are perfectly normal. For many parents, the big question is; what do I do now?

You can start by learning more about inflammatory bowel disease. Information will help guide you and give back a sense of control over the situation. This booklet, along with other booklets provided by Crohn's and Colitis Canada, will assist you and your family to understand your child's medical condition. It will also educate your child's teachers and the school system so they can support and encourage your child through any challenging moments.

CROHN'S & COLITIS: IBD NOT IBS



Crohn's disease and ulcerative colitis are forms of inflammatory bowel disease (IBD), NOT irritable bowel syndrome (IBS). Many people confuse these two diseases because both have symptoms that seem comparable. In reality, IBD and IBS are very different diseases.

With IBD, symptoms develop because of inflammation in the gut. IBS, on the other hand, is thought to arise because of changes to bowel function or the way the brain senses what is going on in the bowel – inflammation does not play a role. Unfortunately, and to add confusion to the situation, it is possible to have IBD and the additional symptoms of IBS.

If IBD is not IBS – what is inflammatory bowel disease? Let's begin by taking a closer look at the digestive tract.

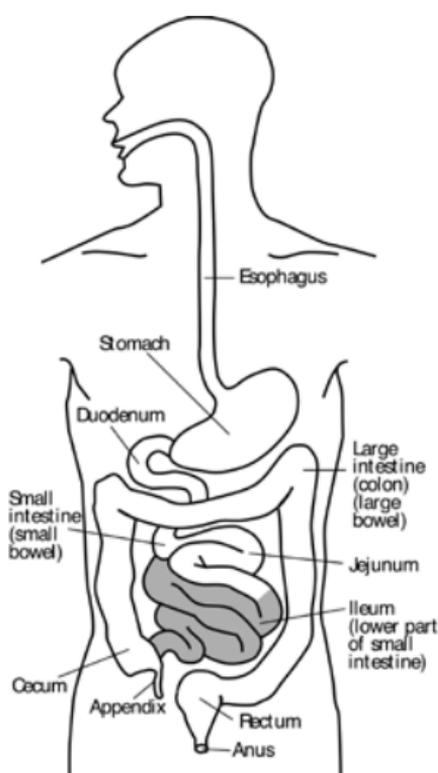
THE DIGESTIVE TRACT

The digestive tract or gastrointestinal (GI) tract is essentially a tube that starts at the mouth and ends at the anus. When you eat and drink, food travels from the mouth to the esophagus, then onward to the stomach, small intestine (or small bowel), large intestine (also known as the large bowel or colon), the rectum and finally the anus. The whole system is finely balanced to promote optimum nutrition and health.

The stomach is your body's "holding tank," initially breaking down food and passing it along to the intestines. Nutrients from food are actually absorbed into the body from the small intestine.

By the time what you eat and/or drink reaches the end of the small intestine, it is a green pea soup consistency. From there, water and some minerals are absorbed in the large bowel and bacteria

change the green to a brown colour. In the absence of inflammation in the colon, the remnants of the digestive process, known as feces, are passed to the rectum and then expelled from the body via the anus. With inflammation in the colon this process is altered, which can result in liquidy stools, with/without blood and, if the passage has been quick through the colon, the stool may be green in colour.



CROHN'S DISEASE AND ULCERATIVE COLITIS

Crohn's disease and ulcerative colitis are the two main types of inflammatory bowel disease. When the diagnosis is not clear, colitis may be called "indeterminate colitis."

Crohn's Disease

With Crohn's disease (so named after the doctor who first described it in 1932), inflammation can occur anywhere in the GI tract but it's usually present in the lower part of the small bowel and the colon.

Inflammation can occur between healthy portions of the gut and can penetrate the intestinal layers from the inner to outer lining. Treatments exist and are aimed at alleviating the symptoms of Crohn's disease but do not cure it.

Ulcerative Colitis

Ulcerative colitis only affects portions of the large intestine, including the rectum and anus and typically only inflames the innermost lining of bowel tissue. It almost always starts at the rectum, extending upwards in a continuous manner through the colon. Colitis can be controlled with medication and in severe cases, can even be cured by surgically removing the entire large intestine.

Some people get confused when the term 'colitis' is used – it simply means that there is inflammation in the colon. As outlined above, this can happen in both Crohn's and colitis – so someone could have Crohn's colitis – where their Crohn's predominantly involves the colon – but it is Crohn's and not colitis.

Both Crohn's and colitis can flare-up at unpredictable times. In fact, doctors and researchers are not sure what causes a person to go into remission and what launches an acute episode. We do know that contrary to what you might think, diet and stress do not precipitate a recurrence of your child's disease, although they may aggravate his/her symptoms.

SYMPTOMS AND CHALLENGES

Unlike many other diseases, Crohn's and colitis are "invisible." In some ways, this may make it more difficult for them because their health challenges are not as obvious as someone who might be in a cast or sling.

Because these diseases inflame the lining of the GI tract, it can disrupt your child's ability to digest food, absorb nutrients and eliminate waste in a healthy manner. As a result, they may experience any of the following symptoms:

- abdominal pain
- cramping
- gas and bloating
- fatigue
- diarrhea (possibly bloody), often frequent
- slowed growth
- loss of appetite



Adults and children with Crohn's or colitis often have an urgent need to go to the bathroom. Possible diarrhea brought on by the disease and the "false urges" that sometimes accompany a flare-up may result in frequent trips to the bathroom. As you can imagine, this can be very embarrassing for your child. We will talk about strategies to cope with this later in this booklet.

During a flare-up, your child may want to avoid food because of the subsequent cramps, vomiting and diarrhea. Not surprisingly, this can lead to inadequate nutrition and add feelings of fatigue and lethargy. This can also cause difficulties with school work, concentration, chores and athletic activities. As a parent, you need to be aware that a child with Crohn's or colitis may simply not have enough energy (during a flare-up) to participate as fully in life as they usually do. Give them time and support during this time, while encouraging them to do as much as they can.

Lack of nutrients can also lead to weight loss, as well as a delay in growth and physical maturation. It is not uncommon for children with Crohn's to appear smaller and younger than their friends. However, remind yourself that your child will eventually go through puberty, and may even experience a growth spurt.

A HEALTHY APPROACH

There are a vast array of medical, nutritional, pharmaceutical and surgical options which can alleviate much of the distress caused by Crohn's or colitis. We will touch briefly on each of these areas. For more detail, please read our brochures: "Prescription for Health," "The Cutting Edge" and "Food for Thought." In addition, "Surviving and Thriving with Crohn's and Colitis" provides you with a general overview of the challenges and approaches to living with inflammatory bowel disease.

A. Medication

Be aware that all medications, prescription or otherwise, have side effects. As a result, your child's healthcare team (which includes you) must find a balance that maximizes your child's well-being while minimizing negative side-effects.

In general, medications fall into one of two very broad categories:

- drugs that are used to reduce inflammation (and may therefore reduce some of his/her symptoms); and
- drugs that are aimed only at symptom-reduction and do not affect the inflammation in his/her gut.

It's important to keep in mind that some medications and treatments may work quickly and others may be prescribed as a form of maintenance

1. Drugs for Reducing Inflammation:

Examples of the types of drugs available to combat inflammation include:

Class	Description
Sulfasalazine and 5-Aminosalicylates (5-ASA)	Limit the production of certain chemicals that trigger inflammation
Steroids	Reduce inflammation
Immunomodulators	Alter how the body mounts an inflammatory response
Biologics	Target and block molecules involved in inflammation
Antibiotics	Do not counteract inflammation directly but decrease infection that can cause, or result from, severe inflammation. Caution with overuse of antibiotics is required.

Some drugs, known as immunosuppressants, suppress the body's immune response. This includes steroids, azathioprine, and biologics. Recent research seems to indicate that there may be a slightly increased risk of infection when given to children. In addition, there is a very small risk (in the range of 1 in 5,000 to 10,000 patients) of developing cancer of the lymph glands (lymphoma). Immunosuppressants pose the classic dilemma of risk versus benefit, where an unlikely but serious potential risk has to be weighed against an immediate and tangible benefit. Talk with your child's specialist about the pros and cons of all the medications being prescribed.

2. Drugs for Managing Symptoms:

Note that many of these drugs are available “off the shelf” in your pharmacy. You should NOT self-prescribe; **talk with your GI doctor first.**

- Bulk formers for stool: soak up water in the stool, thereby firming it up and lessening looseness as well as frequency
- Bile salt binders: prevent irritation of the gut by capturing bile salts
- Stool softeners: for softening feces to ease bowel movements if your child has hemorrhoids or anal fissures. Again, talk with your child’s doctor before trying these.
- Analgesics: for pain reduction. (Acetaminophen is safe to use)
- Acid-reducing drugs: for “heartburn”
- Vitamins and minerals: may be needed as supplements (particularly Vitamin D and calcium)
- Antidiarrheals: are very rarely given to children. This form of treatment is prescribed mostly to adults.
- Antispasmodics: similar to antidiarrheals, this form is rarely prescribed to children. It relaxes the muscles in the wall of the GI tract to reduce cramping
- **AVOID:** non-steroidal anti-inflammatory drugs (such as ibuprofen or acetylsalicylic acid (ASA): for pain control in joints.

B. Diet and Nutrition

A well-balanced diet is important for good health and healing, but you need to pay special attention to your child’s diet if they have Crohn’s disease or ulcerative colitis. As we mentioned before, your child may have a tendency to avoid eating during flare-ups because of abdominal pain, diarrhea and nausea. Malnutrition may result not only because of not eating, but also because of the difficulties their gut has in absorbing nutrients. This may lead to weight loss and fatigue, and in rare cases delays in growth and puberty.

Your child's doctor may advise you to use supplements including vitamins and minerals such as calcium, Vitamins D, B12, C, folic acid, iron, zinc and magnesium. Speak with your physician and dietitian for more information on what would be appropriate for your child, as well as the best way to administer them for maximum benefit.

It is interesting to note that current research indicates that what your child eats does not cause a flare-up, but that the flare-ups emerge simply from the underlying disease. The best thing in this case is to treat the active disease – as opposed to over restricting the diet in a growing and developing child/teen. If there is a type of food that seems to cause problems when the disease is active this may not persist once the disease has been brought into remission. An example of this would be that in some people with colitis, high fibre foods can aggravate their symptoms, but this can improve when the colitis is treated. However, it is important to note that not all people with colitis have symptoms with high fibre foods, so fibre does not necessarily need to be restricted in all patients with colitis.



Liquid Nutrition Supplements

You may find that your child may prefer a liquid nutritional supplement when regular food is unappealing to him/her. These supplements offer balanced nutrition, are easily digested and give your child's gut a chance to rest. Consult your physician or dietitian for suggestions on how and what would be appropriate.

Enteral Nutrition (for Crohn's patients)

Enteral nutrition (EN) is another strategy used by some physicians as a therapy to treat Crohn's disease or as a supplementary therapy for malnutrition and growth failure. In Canada EN is administered either orally (drinking) or by a nasogastric (NG) tube which is inserted down your child's nose into their stomach. A nutrition formula is then administered through the tube. The NG tube is used because it can be challenging to consistently drink all of the required formula on a daily basis for the period of time required to induce remission of the disease.

If your child receives EN while they sleep at night, they can remove the NG tube in the morning or disconnect it and tuck it behind their ear during the day. This therapy may sound strange at first, but be assured that children can adapt to it very quickly and it has been used successfully for many years.

EN treatments may last from one to three months if all of your child's nutritional needs are being met this way, or for months to years if they are receiving a nightly supplement for malnutrition. In that case, many children choose to have a stomach tube (gastrostomy) for nocturnal feedings, instead of an NG tube.



C. Surgery

Surgery for Ulcerative Colitis

Removal of the large intestine and rectum (colectomy) effectively removes ulcerative colitis from your child's gut, with the result that your child is being "cured" of ulcerative colitis. Because the rectum is gone and thus the passage for feces has been removed, their surgeon may have also created an ileostomy (connection of the small bowel to the exterior of his body). An ileostomy uses a bag (otherwise known as an ostomy appliance) attached to the skin of his/her abdomen for the elimination of feces.

In some cases, surgeons can convert an ileostomy to an ileal pouch anal anastomosis (IPAA). For those people who are candidates for this surgery, the IPAA offers a high degree of satisfaction because a pouch for collecting feces is made inside the body and stool continues to be expelled through the anus rather than into an ostomy bag.

Surgery for Crohn's Disease

Because Crohn's disease can involve any part of the GI tract, surgical treatments are varied. If your child has acquired an abscess, stricture or obstruction, a resection (removal of all or part of a section of the gut) may be required to repair the problem. In some cases, a strictureplasty can be done to open up a narrowed segment of the intestine. As with ulcerative colitis, a colectomy and ileostomy are also possible surgeries.

In addition to bowel-specific surgery, patients with Crohn's can also have surgery to treat problems associated with complications of the disease. For example, if your child has developed a fistula (a tunnel formed under the bowel skin), there are procedures available to assist in reducing pain and discomfort.

Laparoscopic Surgery

Minimally invasive surgery, or laparoscopic surgery, is performed through small incisions in the abdomen with the aid of special instruments and a camera. Because of the smaller scars, younger people find the prospects of this surgery more appealing than "open surgery." In addition, healing time is faster and there is less post-operative pain.

Unfortunately, not all Crohn's and colitis patients are candidates for laparoscopic surgery, usually because of extensive scarring (adhesions) within the abdomen or because the disease is so extensive that a wider field of view is needed than that offered by the scope.

HELPING YOUR CHILD COPE

Children can be very resilient. It is true that Crohn's or colitis will bring with it some stresses, especially during flare-ups, but this should not stand in the way of living a full and rich life.

You can help your child by treating them as a child first, with their own interests, strengths and qualities, and then as a child with inflammatory bowel disease. Your parenting rules and values should remain, for the most part, the same after the diagnosis as they were before the diagnosis. It is reassuring for your child to see that although much has changed, much has also stayed the same.

Sports and Hobbies

Encourage your child to get involved in hobbies and sports. When they have a flare-up, encourage them to participate in activities that are less active in nature, but nonetheless keep them engaged and occupied. As with all children, it is important for their physical health as well as their emotional well-being.



Emotional Ups and Downs

Chronic disease may cause an emotional roller coaster for you and your child, particularly if they are older and the diagnosis comes right at the time when their body image is especially important to them. Try not to worry about brief periods of low mood or frustration. Social support from family and friends can be very helpful during times of higher stress. As long as your child is physically up for it, try to engage your child in activities that usually improve his or her mood. As simple as it sounds, getting enough sleep can also be very important in helping with stress and mood.

Sometimes, youth with Crohn's or colitis may become depressed. Depression can be a very normal reaction to difficult life events and often reflects the increased burden related to living with a chronic health condition. Be alert to signs that your child is withdrawing or having difficulties coping with school, friends and activities. If this happens, seek support from your healthcare team to reassure them and help them cope. A counsellor or child psychologist can be of enormous help; don't be afraid to ask for assistance for your child, or for you.

Children with chronic health conditions also often experience some important psychological benefits. For example, many will say that their illness helped them to learn that they had abilities and strengths that they otherwise would not have known they had. Others will say that having an illness helped them to get a different perspective on the small stresses in life, helped them to have greater empathy for others' challenges, or helped them to develop maturity and independence.

Emotional Impact on the Family

It is important for you, as a parent of a child with Crohn's or colitis, to know that the impact of having a youngster with this disease can have a significant effect on the entire family. There is no getting around it – when someone in your family is ill, the whole family can experience emotional strain as every one seeks ways to cope. This is normal; don't be too hard on yourself or on other members of the family as you work through

the challenges together. Often, parents are so focused on caring for their child that they are unable to focus on their own self-care. Self-care is important because parental coping is an important factor in a child's adjustment to a chronic illness. Also, children will learn coping strategies by watching their parents model them. So, whether you go for a walk, write in your journal, or talk to a friend, let your child know when you are making use of general stress management strategies.

Don't forget Crohn's and Colitis Canada has local chapters across the country. By joining one near you, you will meet other parents who are learning how to support a child with Crohn's or colitis, and you will have access to information locally that will enable you to help your child.

Siblings

Your other children may also be emotionally affected. Some may worry about getting the disease themselves or may worry about their brother or sister's health. Young children may worry that something they did or felt caused the illness to happen. Others may feel left out, especially at times when their brother or sister requires a lot of special attention. Parents can help by talking about these concerns, having one-on-one time with each child, and maintaining routines as much as possible. If the illness does get in the way of family life, be sure to blame "the disease" not "Alex". Just like your child with the disease, siblings of children with chronic health conditions can experience some benefits, such as increased compassion, empathy, and tolerance. Family relationships can become stronger when parents and children work together to manage challenges.

The Need for Independence

It is natural for a parent to feel very protective of a child with Crohn's or colitis; however, be careful not to overdo it. In fact, it is wise to encourage your child to assume responsibility of their medical routines as soon as they mature enough to handle it. Start early with one small task, and gradually add new tasks.

Sometimes, medication routines can become a source of conflict between parent and child, particularly if the child has reached the age where they are looking to be more independent. Just like any other issue, it is important for you to keep talking with your child. Encourage them to talk and seek support from your healthcare team. Any form of communication will help your child air out emotions or distress they may be feeling about their disease.

And remember – inflammatory bowel disease does not define your child. It may be a part of their life, but your child is so much more than this.

Friends

Friends are a very important part of a child's life. Your child may wonder what to tell their friends about their disease, or if they should say anything at all. After all, their disease is difficult to explain and the fear that some of the other children may be thoughtless and cruel may only make your child feel more vulnerable. This is an area where you, as a parent, should respect their decision and support them. If your child wants to share their diagnosis with friends, then assist them in explaining what their condition is all about.

If they prefer to keep their condition private from their friends, respect that choice. If your child does choose to keep their condition private, it may still be important to help your child to have simple explanations for things that are noticeable to other children (for example, missed time from school).

Teachers and School Administration

Even if your child prefers not to tell their friends, it is preferable that their teachers and school administrators be advised of their condition. Contact the school and let them know that your child has Crohn's or colitis, and share information about the disease. Give them a copy of this booklet. Help the staff and your child by letting them know what to expect and what they can do to ease their time at school.

Suggestions for the School Day

Talk with your child's teacher. Tell them your child may need to make frequent bathroom trips throughout the school day. Work out strategies such as placing your child at a desk close to the classroom door and allowing him/her to leave without requesting permission, to facilitate hassle-free exits that do not draw attention to them.

You may need to make arrangements with the school for medication administration throughout the day. Try to set it up so that your child can discreetly leave class, again helping reduce feelings of embarrassment.

The school may be very helpful in arranging for the use of a bathroom other than the student washrooms. Having frequent diarrhea is bad enough, but using the toilet in a public area with lots of other children around can be excruciatingly embarrassing.

It is also a good idea for your child to have a spare set of clothes tucked away at school in case they have an accident. Your child's school may be able to help out by storing them for your child and giving them a place to change if they need to.

Keep the school informed about your child's health, including when they are experiencing a flare-up. Hospitalization and absence from school are real possibilities, so make arrangements for at-home curriculum materials, tutoring and make-up tests when they are needed. Also, let the school know that even though your child is back to school after a flare-up, they may still be feeling fatigued for a while.

Crohn's and Colitis Canada also has available "A Teachers Guide" brochure. Be sure to print and share this information with your child's school.

ABOUT CROHN'S AND COLITIS CANADA

Crohn's and Colitis Canada is the only national, volunteer-based charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these diseases. We are one of the top two health charity funders of Crohn's and colitis research in the world and the largest non-governmental funder in Canada. We are transforming the lives of people affected by Crohn's and colitis (the two main forms of inflammatory bowel disease) through research, patient programs, advocacy, and awareness.

Our Crohn's & Colitis – Make it stop. For life. campaign will raise \$100 million by 2020 to advance our mission.

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For more information on Crohn's disease or ulcerative colitis visit our website **crohnsandcolitis.ca** or call 1-800-387-1479

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