Parent's and Caregiver's Guide

Supporting children with Crohn's or colitis

crohn's colitis

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Getting started

Your child or the child in your care has been diagnosed with Crohn's disease or ulcerative colitis, or perhaps an indeterminate colitis. You now know that they have a chronic illness known as inflammatory bowel disease (IBD).

Their diagnosis may bring feelings of relief and shock, and you may even be overwhelmed by the news. All these feelings are perfectly normal.

For many parents and caregivers, the big question is: ***what do I do now?***

Crohn's and Colitis Canada is here to help! This guide, along with other resources provided by us, will help you and your family better understand your child's medical condition. It will also help educate your child's teachers and school system so they can support and encourage them through any challenging moments.

IBD is *not* IBS

Crohn's and colitis are forms of IBD, not irritable bowel syndrome (IBS). Many people confuse these conditions because both have symptoms that seem comparable. However, IBD and IBS are very different.

With IBD, symptoms develop because of inflammation in the gut, leading to tissue damage. 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 both IBD and IBS.

What is IBD then? Let's begin by taking a closer look at the digestive tract.

Understanding the digestive system

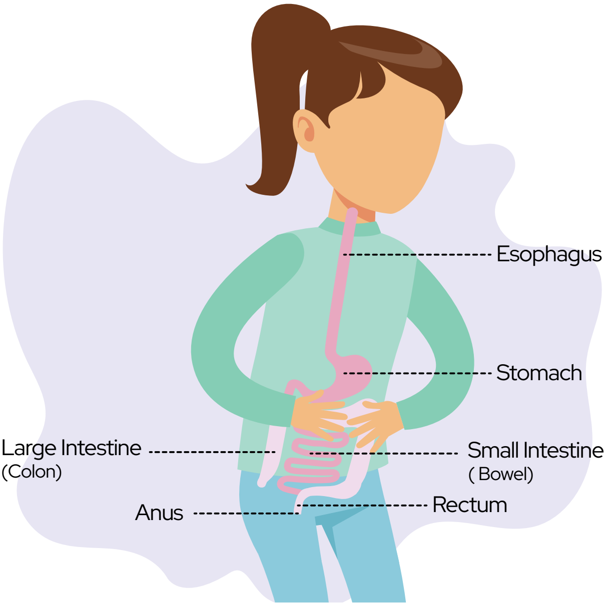
The digestive tract, or gastrointestinal (GI) tract, is essentially a tube that starts at the mouth and ends at the anus. When you eat and drink, food travels from the mouth to the stomach, small intestine (or small bowel), large intestine (or large bowel or colon), the rectum, and finally the anus. The whole system is finely balanced to help keep us healthy. The stomach is your body's "holding tank," breaking down food and passing it along to the intestines. Nutrients from food are absorbed into the body from the small intestine.

By the time what you eat or drink reaches the end of the small intestine, it's a green pea soup consistency. From there, water and some minerals are absorbed in the large bowel, and bacteria changes the colour from green to brown. In the absence of inflammation in the colon, the remnants of the digestive process, known as feces or stool, are passed to the rectum and then expelled from the body through the anus. With inflammation in the colon, this process is altered, which can result in loose, liquid-like stools (with or without blood), and, if the passage has been quick through the colon, the stool may remain green.

Crohn's and colitis

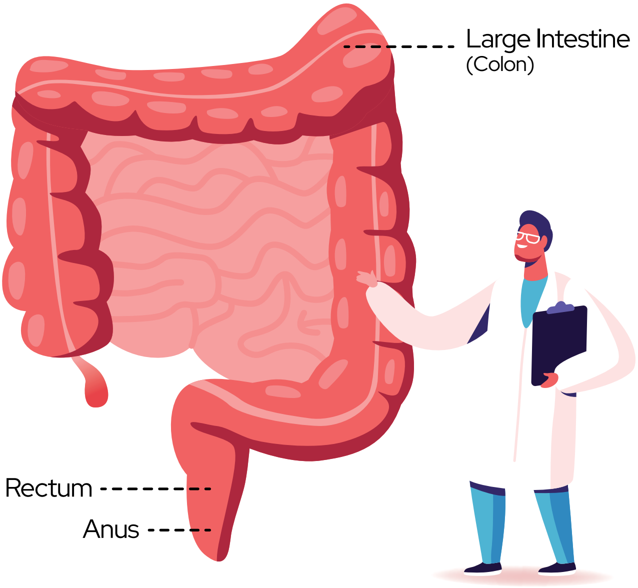
Crohn's and colitis are the two main forms of IBD. When the diagnosis is not clear, colitis may be called indeterminate colitis.

What is Crohn's disease?



With Crohn's (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 that can help alleviate symptoms, but there are no cures.

What is ulcerative colitis?



Colitis only affects portions of the large intestine, including the rectum and anus, and typically only inflames the innermost lining of bowel tissue. Colitis can be controlled with medication and, in severe cases, can come back or evolve into something else by surgically removing the entire large intestine.

Common symptoms and challenges

Unlike other diseases, Crohn's and colitis are "invisible." This may make it more difficult for people living with them because their health challenges aren't as obvious as someone who might be in a cast or sling.

Because these diseases inflame the lining of the GI tract, they can disrupt a person'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
- Depression and anxiety

Those living with Crohn's or colitis often have an urgent need to use the washroom. Possible diarrhea and the "false urges" that sometimes accompany a flare-up may result in frequent trips to the washroom. As you can imagine, this may make them feel misunderstood or embarrassed. We'll talk about strategies to cope with this later on.

During a flare-up, the child in your life with Crohn's or colitis may want to avoid food because of the subsequent cramps, vomiting, and diarrhea. Not surprisingly, this can lead to inadequate nutrition, and feelings of fatigue and lethargy. This can also cause difficulties with schoolwork, concentration, chores, and athletic activities. A child with Crohn's or colitis may simply not have enough energy (particularly during a flare-up) to participate as fully as they usually do. Give them patience 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 than their friends. Remind yourself that they will eventually go through puberty and may even experience a growth spurt.

Finding a healthy path forward

There are many different treatments, like medications, dietary changes, and sometimes surgery, that can help reduce symptoms and make living with Crohn's or colitis more manageable. We'll touch on each of these.

Medication

It's important to remember that all medications tend to have side effects. As a result, you and your child's healthcare team should find a balance that maximizes their 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 their symptoms)
- Drugs that are aimed only at symptom-reduction and do not affect the inflammation in their gut

Drugs for reducing inflammation

Examples of the types of drugs available to reduce 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 / Biosimilars	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.
Targeted synthetic small molecules	Small molecules that target inflammation and are created chemically.

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. Further, 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 must be weighed against an immediate and tangible benefit. Talk to their gastroenterologist about the pros and cons of all prescribed medications.

Drugs for managing symptoms

While many of these drugs are available "off the shelf" in your pharmacy, you should not self-prescribe these for your child. Speak with their gastroenterologist first.

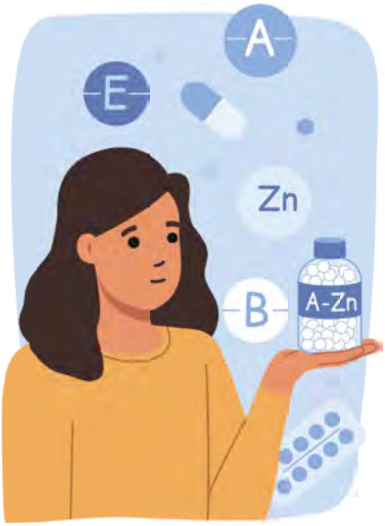
Type	Description
Bulk formers for stool	Soak up water in the stool, thereby firming it up and reducing frequency of needing to use the washroom.
Bile salt binders	Prevent irritation of the gut by capturing bile salts.
Stool softeners	Soften feces to ease bowel movements if your child has hemorrhoids or anal fissures.
Analgesics	Pain reduction (Acetaminophen is also safe to use).
Acid-reducing drugs	Help prevent heartburn.
Vitamins and minerals	May be needed as supplements (particularly Vitamin D and calcium).
Antidiarrheals	These are very rarely given to children. They are mostly prescribed to adults.
Antispasmodics	Like antidiarrheals, they are rarely prescribed to children. This drug relaxes the muscles in the wall of the GI tract to reduce cramping.

It is critical to avoid non-steroidal anti-inflammatory drugs, such as ibuprofen or acetasalicyclic acid (ASA), for pain control in joints.

Diet and nutrition

A well-balanced diet is important for good health, but be sure to pay special attention to your child's diet. As previously mentioned, they may tend to avoid eating during flare-ups because of abdominal pain, diarrhea, and nausea. This may result in malnutrition, not only due to 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.

Their doctor may advise you to use supplements including vitamins and minerals, including calcium, Vitamins D, B12, C, folic acid, iron, zinc, and magnesium. Speak with their physician and dietitian for more information on what's appropriate for their specific needs.

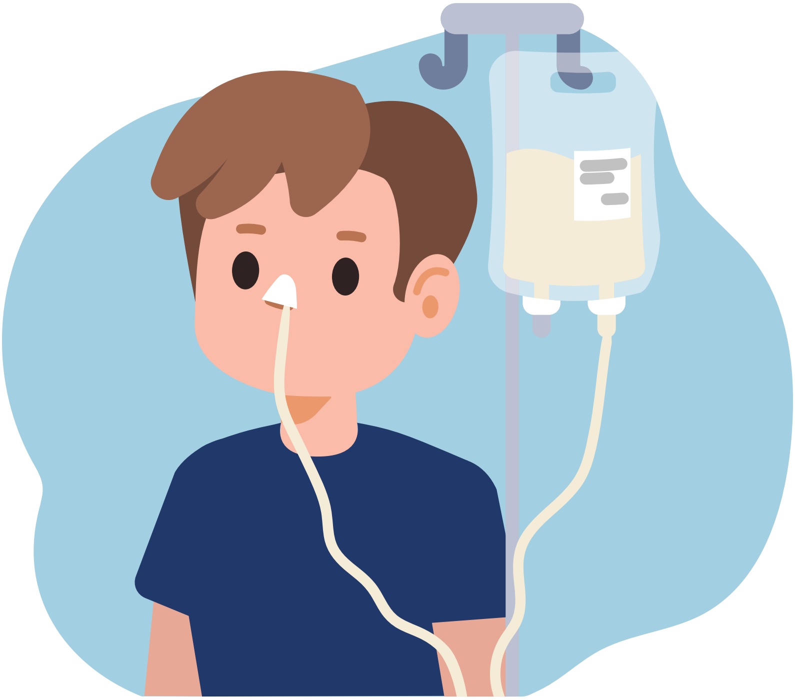


Ideally, it is best to treat the active disease rather than over-restricting their diet, particularly if they're developing. If there's a type of food that causes problems when the disease is active, this may not persist once the disease has been brought to remission. An example of this would be that in some people with colitis, high-fibre foods can aggravate their symptoms, but this can improve when the colitis is treated. However, not all people with colitis have symptoms with high-fibre foods, so fibre doesn't necessarily need to be restricted for everyone.

Using liquid nutrition supplements

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

Enteral nutrition for Crohn's



Enteral nutrition (EN) is another strategy used by some physicians as a therapy to treat Crohn's or as a supplementary therapy for malnutrition. In Canada, EN is administered either orally (drinking) or by a nasogastric (NG) tube, which is inserted down their 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 the required formula daily for the period required to induce remission.

If they receive 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 adjust to it very quickly. EN has been used successfully for many years and has been shown to replace the use of steroid treatment in Crohn's.

EN treatments may last from one to three months if all their nutritional needs are being met, or for months to years if they are receiving a nightly supplement for malnutrition. In that case, some children may choose to have a stomach tube (gastrostomy) for night-time feedings, instead of an NG tube.

Surgery

Surgery for ulcerative colitis

Removal of the large intestine and rectum (known as a colectomy) essentially removes colitis from their gut, resulting in them being "cured" of colitis. Because the rectum is gone and the passage for feces has been removed, their surgeon may create an ileostomy (connection of the small bowel to the exterior of their body). An ileostomy uses a bag (known as an ostomy appliance) attached to the skin of their abdomen for the elimination of feces.

In some cases, surgeons can convert an ileostomy to an ileal pouch anal anastomosis (IPAA). For those 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

Because Crohn's can involve any part of the GI tract, surgical treatments can vary. If they've 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 complication. In some cases, a strictureplasty can be done to open up a narrowed segment of the intestine. As with 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. 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.

Minimally invasive 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, young people may find the prospects of this surgery more appealing than "open surgery." In addition, healing time is faster and there is less postoperative 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 children cope

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

You can help your child or the child you're caring for by treating them as a child first, with their own interests, strengths and qualities, and then as a child living with IBD. Your parenting or caregiving values should remain, for the most part, the same after their diagnosis as they were before. It's reassuring for them to see that although a lot has changed, many things have also stayed the same.

Resilience grows when you model healthy coping strategies. Whether it's through humour, relaxation, or acknowledging tough days, supporting emotional health is just as important as managing physical symptoms.

Encouraging sports and hobbies

Encourage them to get involved in hobbies and sports. When they have a flare-up, it may be best for them to participate in activities that are less active in nature but can still keep them engaged and occupied. As with all children, activity is important for both their physical health and emotional well-being.

Navigating emotional ups and downs

Living with a chronic disease may cause an emotional roller coaster for you and your child, particularly if they're older and the diagnosis comes right at a time when they're sensitive about their appearance. Try not to worry about brief periods of frustration. Social support from family and friends can be very helpful during times of higher stress. If they are physically up for it, try to encourage them to engage in activities that improve their 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 they're 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 support.

Supporting the whole family

It's important for you, as a parent or caregiver of a child with Crohn's or colitis, to know that their disease can have an impact on the entire family. When someone in your family is ill, the whole family can experience emotional strain as everyone seeks ways to cope. This is normal. Don't be too hard on yourself or on other members of your family as you work through the challenges together.

Often, parents or caregivers are so focused on caring for their child that they're unable to focus on caring for themselves. 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, talk to a friend, or seek help from a counsellor or support group, let them know you're making use of stress management strategies.

Don't forget Crohn's and Colitis Canada offers online support. By joining a Caregiver Peer Connect event, you'll meet other parents or caregivers who are learning how to support a child with Crohn's or colitis. You can also join Crohn's and Colitis Connect (crohnsandcolitisconnect.ca), a free online group for caregivers and people living with Crohn's or colitis.

Supporting siblings or other children in your care

Other children in the family may also experience emotional effects. Some may worry about being diagnosed with IBD themselves, or about their sibling's health.

Young children may worry that something they did or felt caused the disease to happen. Others may feel left out, especially at times when their sibling requires a lot of special attention.

Parents or caregivers can help by talking about these concerns, having one-on-one time with each child, and maintaining routines as much as possible. If their illness does get in the way of family life, be sure to blame "the disease" and not them.

Family relationships can become stronger when parents or caregivers and children work together to tackle challenges.

Fostering independence

It's 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's not a bad idea to encourage them to assume responsibility for their medical routines as soon as they are mature enough to handle it. Start early with one small task and gradually add new tasks.

Sometimes, routines around treatment can become a source of conflict between a parent or caregiver and child, particularly if they've reached the age where they're looking to be more independent. Just like any other issue, it's important to maintain communication.

Encourage them to seek support from their healthcare team. Any form of communication will help your child air out emotions or distress they may be feeling about their disease.

And remember: IBD does not define your child. It may be a part of their life, but they are so much more than their disease.

Talking to friends

Friends are an important part of a child's life. They may wonder what to tell their friends about their disease, or if they should say anything at all. Their situation may be difficult to explain, and the fear that other children may be thoughtless or cruel may only make them feel more vulnerable.

This is an area where you, as a parent or caregiver, should respect their decisions and support them. If they want to share their diagnosis with friends, then assist them in explaining their condition.

If they'd prefer to keep it private, respect that choice. If they do choose to keep it private, it may still be helpful to come up with simple explanations for things that may be noticeable to other children (for example, missed time from school).

Working with teachers and schools

Even if they'd prefer not to tell their friends, it's important that their teachers and school be advised of their condition. We encourage you to contact their school to let them know that your child has been diagnosed with Crohn's or colitis and share information about the disease. Help school staff by letting them know what to expect and what they can do to support.

Crohn's and Colitis Canada also offers a **Teacher's Guide**. Be sure to share it with their school, along with our **Letter to School** which will help explain your child's diagnosis and what school administrators can expect.

Tips for a supportive school day

Talk with their teacher. Tell them that they may need to make frequent trips to the washroom throughout the school day. Work out strategies that allow them to leave the classroom as needed without drawing attention.

You may need to plan with their school for medication administration throughout the day. Try to set it up so that they can discreetly leave class, helping reduce feelings of embarrassment.

Their school may be very helpful in arranging for the use of a washroom separate from other students. Having frequent diarrhea is challenging enough, but using the washroom with others around can be embarrassing.

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

Keep their school informed about their health, including when they're experiencing a flare-up. Hospitalization and absence from school are real possibilities, so plan for at-home curriculum materials, tutoring and make-up tests if needed. Let their school know that even though they may be back to school after a flare-up, they could still feel fatigued for a while.

About Crohn's and Colitis Canada

Crohn's and Colitis Canada's Promise is to find the cures for Crohn's disease and ulcerative colitis and to improve the quality of life of everyone affected by these diseases. Crohn's and colitis are the two main forms of inflammatory bowel disease (IBD).

We are one of the top two health charity funders of Crohn's and colitis research in the world, investing over $150 million in research since 1974. With the support of our donor community, we are on a relentless journey to transform the lives of people affected by Crohn's and colitis through research, patient programs, advocacy, and awareness.

Stay connected with Crohn's and Colitis Canada by subscribing to our Talk About Guts newsletter for the latest updates. To learn more about our work or to find support, visit **crohnsandcolitis.ca**.

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