

SURVIVING & THRIVING

A Guide to Living
with Crohn's Disease
or Ulcerative Colitis



**CROHN'S
& COLITIS**

Make it stop. For life.



www.crohnsandcolitis.ca

You or someone you care about has been diagnosed with Crohn's disease or ulcerative colitis (the two main forms of inflammatory bowel disease (IBD)). You may have a lot of questions, coupled with a fair degree of concern and a good dose of uncertainty.

If you find yourself asking:

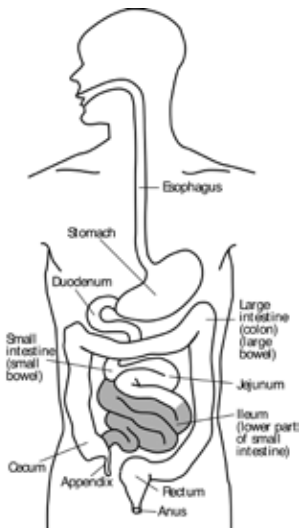
- What does this mean?
- What will happen to me?
- What caused this?
- Is there a cure?
- What can I do?

Then you are not alone. You have started a journey of discovery that will help you to cope with your disease and not just survive – but thrive. Crohn's and Colitis Canada is committed to helping you learn about your disease and providing you with ongoing sources of information that will empower you to manage your disease and become an active member of your healthcare team.

For more information, please pick up our other Crohn's and Colitis Canada booklets at www.crohnsandcolitis.ca.

Be an empowered, knowledgeable health care consumer!

THE DIGESTIVE TRACT & IBD



The digestive tract or gastrointestinal (GI) tract is a finely balanced system of tunnels that starts at your mouth and ends at your anus. When you eat and drink, food navigates through your esophagus (the tube from your mouth to your stomach), stomach, small intestine (or small bowel), large intestine (also known as the large bowel or colon), your rectum and finally your anus.

Inflammatory bowel disease inflames the lining of the GI tract and disrupts your body's ability to digest food, absorb nutrition and eliminate waste in a healthy manner. As a result, you might have any of the following symptoms: abdominal pain, cramping, gas, bloating, fatigue, diarrhea (possibly bloody) and loss of appetite.

IBD describes a group of conditions. The two main forms of IBD are Crohn's disease and ulcerative colitis. People have one disease or the other but not both. IBD also includes indeterminate colitis.



Crohn's Disease

With Crohn's disease (so named after the doctor who described it in 1932), inflammation can occur anywhere in the GI tract but is usually present in the lower part of the small bowel and the colon. Patches of inflammation occur between healthy portions of the gut, and can penetrate the intestinal layers from inner to outer lining. Medication and surgery can help to alleviate the symptoms of Crohn's disease.

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. Ulcerative colitis can be controlled with medication and, in severe cases, can even "be cured" by surgically removing the entire large intestine.

Indeterminate Colitis

Indeterminate colitis is a term used when it is unclear if the inflammation is due to Crohn's disease or ulcerative colitis.

Both Crohn's disease and ulcerative colitis can flare-up (an acute attack) at unpredictable times. In fact, doctors and researchers are not sure what causes a person to go into remission (quiet periods where your symptoms are under control) and what launches an acute episode. We do know that contrary to what you might think, diet and stress do not cause these chronic diseases or their relapses. However, both diet and stress may aggravate your gut and any symptoms that you may be experiencing. Both are also not thought to CAUSE a relapse of your disease.

IBD IS NOT IBS

You may have heard of irritable bowel syndrome (IBS) and wondered if it is the same as IBD. While often confused because their names are similar and their symptoms can seem comparable, the two are not the same.

Yes, both diseases affect the digestive tract. However, with inflammatory bowel disease, inflammation is the key characteristic. In irritable bowel syndrome it is thought that problems 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. It is possible to be diagnosed with both IBD and IBS.

WHAT CAUSES IBD?

Currently, scientists believe that a genetic tendency and a trigger in the environment combined set off inflammation in the gut. Instead of being dampened down, the immune system then continues to run amok. The chronic (life-long) process that results can manifest as either Crohn's disease or ulcerative colitis.



One thing we do know – YOU did not cause your disease by something you did or didn't do. It wasn't your diet or the stress in your life that brought this on, so free yourself (and anyone else!) from guilt over the cause of Crohn's disease or ulcerative colitis.

WHO GETS IBD?

Here are some quick facts:

- Inflammatory bowel disease is more common in developed countries, urban areas and temperate climates.
- Canada has the among the highest rates in the world
- Approximately 233,000 Canadians have IBD (129,000 with Crohn's disease and 104,000 with ulcerative colitis) – or 1 in every 150 Canadians.
- Over 10,200 new cases are diagnosed every year in Canada.
- Most alarming, Crohn's Disease has almost doubled in children under 10 since 1995.
- IBD can be diagnosed at any age, but people are more frequently diagnosed before the age of 30.
- Males and females are equally affected.
- IBD can affect any race or ethnic group however, people of Jewish Ashkenazi (European) descent have higher rates of IBD.

IS THERE A CURE?

Currently, there is no known cure for Crohn's or colitis. They are chronic diseases – meaning that they are long-term conditions. However, treatment with modern medications and perhaps surgery can allow you to live a full and rich quality of life.

COMPLICATIONS

You should be aware that over and above the symptoms that we have previously discussed (nausea, diarrhea, cramping and so on) occasionally people may develop complications related to Crohn's disease or ulcerative colitis that can be serious. Let's divide them into "intestinal" and "non-intestinal" categories.

Intestinal complications

While rarely seen with ulcerative colitis, strictures, abscesses and fistulas can develop in those with Crohn's disease. Strictures are a narrowing of the gut which can result in bowel obstruction (blockage). Abscesses are walled-off areas of infection that develop when inflammation penetrates the intestinal wall. Fistulas are abnormal tunnels that form between an inflamed area of the GI tract and another nearby structure (like another part of the intestine, another organ or the skin around the anus).

These are serious conditions and will usually require treatment with medication and possibly surgery.

Non-intestinal complications

In addition to the symptoms that relate to your gut, you should also be aware that you can experience "non-intestinal" related conditions such as fever, joint pain, eye inflammation, liver problems and skin disorders. These symptoms can manifest during a flare-up of your disease, or during a time when you are in remission – there is no way to predict when, or if, you might experience them. Check with your doctor if you think you might be experiencing any of these "non-intestinal" symptoms related to your disease.

WHAT ABOUT CANCER?

As we age, everyone has increasing risk of developing colorectal cancer. People with Crohn's disease or ulcerative colitis however, have a higher risk, depending upon:

- the length of time they have had CD or UC
- the location of the inflammation
- if they have a liver condition called primary sclerosing cholangitis (PSC)
- and if there is a family history of colorectal cancer

If detected early, there is a 90 per cent chance colorectal cancer can be cured – meaning colorectal cancer screening can be the difference between life and death.

ColonCancerCheck recommends that people with Crohn's disease or ulcerative colitis speak with their physicians about their risk of colorectal cancer and the need for regular screening using colonoscopy.

See Crohn's and Colitis Canada's brochure, "Let's Talk About Cancer" for more information.



TREATMENTS

Let's look at some of the ways in which your health care team will work with you to control your symptoms. Let's briefly review the medication you may be prescribed, your diet, types of surgery that might be performed if you need it and the importance of a balanced lifestyle. For more detailed information, please read our booklets on each of these topics, or go to our website. And of course, talk with your doctor, nurse, pharmacist or registered dietitian for information that is relevant to your individual situation.

1. Medication

Be aware that all medications, prescription or otherwise, have side-effects. Adjusting your medication to maximize benefits while limiting side-effects will be a balancing act that is unique to you and your condition. You and your physician must work together to find the best possible combination that optimize your health and well-being. See our brochure, "Prescription for Health" for more information.

In general, medications fall into one of two very broad categories: drugs that are used to reduce inflammation (and may therefore reduce some of your symptoms) and those that are aimed only at symptom-reduction and do not affect the inflammation in your gut.

a. Drugs for Reducing Inflammation:

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

- 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 and result from severe inflammation

This is not a comprehensive list of treatment options, please talk to your doctor about treatment options that are best for you.

b. Drugs for Managing Symptoms:

Note that many of these drugs are available “off the shelf” in your pharmacy however, you should NOT self-prescribe; talk with your doctor first before taking any of these over-the-counter medications.

- Antidiarrheals: do not take these during a flare-up as they may cause other complications! Check with your doctor
- Antispasmodics: relax muscles in the wall of the GI tract to reduce cramping
- 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 you have hemorrhoids or anal fissures; talk with your doctor before trying these!
- Analgesics: for pain reduction
- Non-steroidal anti-inflammatory drugs: for pain control in joints (but note that some people find these drugs aggravate their abdominal pain and diarrhea)
- Acid-reducing drugs: for “heartburn”
- Vitamins and minerals: may be needed as supplements



2. Diet and Nutrition

Everyone needs to have a well-balanced diet for good health, vigour and healing. People with Crohn's disease and ulcerative colitis in particular, must eat well in order to avoid problems like malnutrition and dehydration. See our booklet called, "Food for Thought" for detailed information and tips as well as Canada's Food Guide for getting information on a well-balanced diet. Talk to a registered dietitian or nutritionist for help on a food lifestyle that is best for you.

For now, you should know that your diet does not cause a flare-up, but it may exacerbate (increase) your symptoms if you eat "trigger" foods. Trigger foods are those which aggravate your gut and are individual to you. Identifying those foods which are triggers for YOU is an important part of your day-to-day strategy in living well with Crohn's disease or ulcerative colitis.

Conversely, you should also identify what are your "safe" foods. These are foods which are unique to you and do not appear to bother your digestive tract. Examples of foods that appear to be "safe" for many people include white rice, white bread, bananas, chicken (white meat) and toast.

3. Surgery

Approximately 47% of people with Crohn's and 16% of those with colitis will require surgery at some point in their lives. Surgery should not be regarded as a last resort in the treatment of Crohn's disease or ulcerative colitis, nor is it a sign that you or your treatment program have failed. In reality, surgery should be regarded as just another treatment option for the management of Crohn's and colitis. See our brochure, "The Cutting Edge" for more details.

Surgery for Ulcerative Colitis

Removal of the large intestine and rectum (colectomy) effectively removes ulcerative colitis from your body with the result that you are "cured" of colitis. Because the rectum is gone and thus the passage for feces has been removed, your surgeon may have also created an ileostomy (connection of the small bowel to the exterior of your body). An ileostomy uses a bag (otherwise known as an ostomy appliance) attached to the skin of your 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 eligible for this surgery, the IPAA offers a high degree of satisfaction because a pouch for collecting feces is made inside your 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 can be many and varied. If you have 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 possible surgeries.

The IPAA is not usually performed on patients with Crohn's disease because unlike ulcerative colitis, the disease can recur after the procedure is done. This necessitates further surgery and potentially the removal of the internal pouch.

In addition to bowel-specific surgery, patients with Crohn's disease can also have surgery to treat problems associated with complications of the disease.

For example, if you have developed a fistula, there are procedures available to reduce the pain and pus.

Laparoscopic surgery is performed through small incisions in your abdomen with the aid of special instruments and a camera. This surgery has been used for intestinal surgery. Advocates for this specialized surgery have found that it is less invasive for the patient and speeds up healing time while decreasing post-operative pain. However, some patients do not do well with laparoscopic surgery due to the amount of internal scarring (adhesions) inside the abdomen or because the disease is so extensive that a wider field of view is needed than that offered by the scope.

LEADING A BALANCED LIFESTYLE

At the end of the day, you are the person who must deal with your disease and you are the one in charge of your body and your attitude. Leading a balanced lifestyle is vitally important for success in surviving and thriving with Crohn's disease or ulcerative colitis.

Exercise

Crohn's disease or ulcerative colitis can drain energy and the temptation to give up exercise is very strong. Instead of doing high energy, high demanding activities, try some gentle things like walking, swimming, yoga or tai chi. The point is – keep moving. When you are in remission, you can go back to your previous activities, making sure you approach them sensibly; stay aware and mindful of your body and be kind to yourself.

Emotional overload

Sometimes the psychological impact of your disease gets to be too much. On top of the physical symptoms, feelings of uncertainty, embarrassment, aversion to being dependent on others, guilt and self-doubt can weigh you down. Be aware of how you are feeling and how these emotions are affecting your quality of life. If depression seems to have taken up residence in your emotional house, seek the help of your physician as there are treatments available to help you through it. Seek the support of family and friends – let them be there for you just as you would be for them.

And remember – YOU are not your disease. YOU are not your diagnosis, you are so much more than that.

Stress

Stress does not cause Crohn's or colitis, but for some, it does appear to aggravate symptoms. This is not true for everyone however, once again, it depends on you. If you do find that stress bothers your gut, some of the tips below will help you to cope. Try things like meditation, relaxation techniques, and avoiding caffeine.



ABOUT CROHN'S & COLITIS CANADA

Crohn's and Colitis Canada is a volunteer-based charity dedicated to finding the cures for Crohn's disease and ulcerative colitis and to improving the lives of children and adults affected by these chronic diseases. As Canada's leading non-governmental funder of inflammatory bowel disease (IBD) research, we have invested over \$88 million to foster advances in research, education, awareness and advocacy. By working together we can help advance the understanding of Crohn's and colitis; fund the programs that result in a better life for those living with these diseases and ultimately find the cures.

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For more information on Crohn's disease
or ulcerative colitis visit our website
www.crohnsandcolitis.ca or call
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