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Gastrointestinal Society
Canadian Society of Intestinal Research



Crohn's Disease & Ulcerative Colitis

PATIENT JOURNEY

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GASTROENTEROLOGIST

Inflammatory bowel disease (IBD) is a chronic inflammatory disease that primarily involves the digestive tract. There are two main subtypes – Crohn’s disease and ulcerative colitis – which differ in the area and extent of inflammation. In Crohn’s disease, inflammation can occur in any part of the digestive tract and can penetrate all layers of tissue, whereas in ulcerative colitis it is limited to the mucosa of the large intestine. In Crohn’s disease, it can appear in multiple separate areas, but in ulcerative colitis, it always starts at the rectum and moves upward. Another less common form involves inflammation that is only visible via microscope, known as microscopic colitis, which includes collagenous colitis and lymphocytic colitis. There are other types of IBD that result from damage to the intestines: ischemic colitis, diversion colitis, and radiation enteritis.

Canada has among the highest rates of IBD in the world, with about 1 in 150 individuals, or 0.7% affected. It affects people of all ages, with many cases arising in children and young adults, although some go most of their lives without IBD only to develop it in their senior years.

IBD can be an overwhelming diagnosis because it is a lifelong disease that is often difficult to treat, and can be severe in both symptoms and its effect on overall quality of life. On top of that, the bowel symptoms of IBD add a level of embarrassment that makes it especially difficult to live with, talk about, and manage. As with many other inflammatory conditions, the IBD journey from onset to diagnosis to treatment can be lengthy and involve many appointments, tests, misdiagnoses, and frustration.

Something is Wrong

An IBD patient’s journey starts with symptoms. For some people, these start mild and either stay that way or gradually get worse. For others, symptoms come on suddenly, leaving a person who recently felt fine struggling to manage extreme pain and up to twenty bowel movements per day. The most common symptoms are diarrhea, abdominal pain, bowel urgency/incontinence, lack of appetite, weight loss, fever, fatigue, and rectal bleeding (dark stool). Some people experience nausea and vomiting, and even constipation. In severe cases of Crohn’s disease, there might also be fissures, abscesses, and/or fistulas in the rectum and anus, which can be particularly painful as well as frightening.

Some individuals have symptoms outside of the digestive tract, such as rashes, arthritis, anemia, kidney stones, and eye inflammation.

While many will seek help soon after developing symptoms, those with mild disease may not be concerned for some time, as they might attribute their symptoms to something they ate, a recent stress, or another life change. Even those who have more severe symptoms might feel embarrassed and put off going to the doctor until it gets so bad that they absolutely need care. Whatever the turning point, the next step is visiting a doctor.

Finding a Doctor

For some patients, finding a doctor presents a major roadblock. Currently, 20% of Canadians do not have a family doctor, and those who do often have to contend with wait times of weeks or even months to get an appointment.¹ This can be a time of extreme anxiety, as you go through a health scare, without knowledge of what is causing it, while you wait for a physician or try to find help at a clinic. Patients with severe symptoms, or those who just can’t get an appointment with a doctor, might end up in the emergency department.

Some patients have reported that they find it difficult to get their doctor to take them seriously. They might be told to just change their diet, increase or decrease exercise, reduce stress, lose or gain weight, etc. This can be a huge setback for patients who then struggle and suffer through these changes before returning for repeated appointments until their doctor takes them seriously, or they will have to find a new doctor who will listen to them.

Once you get in to see a physician, they will analyze your symptoms, medical history, risk factors, and family history. People with a first degree relative (parent, sibling, child) who are diagnosed with IBD are more likely to also have the disease.

Whether they suspect you have IBD, or think there might be another source for your symptoms, the next step will likely be running tests. Some general practitioners will order tests on their own, and others will refer you to a gastroenterologist. Either way, this will likely lead to more wait times. You might be fast-tracked if your disease is severe enough to warrant a hospital visit, but it could also take months to see a specialist.

Your doctor might also give you a prescription for a medication if they strongly suspect you have IBD, such

as a corticosteroid or 5-ASA, hoping these treatments will reduce symptoms in the meantime. However, if they misdiagnose you with a different disease, you might end up getting a medication that can make your symptoms worse. It is important to have proper testing as soon as possible to ensure a correct diagnosis.

Tests, Tests, More Tests, and a Diagnosis

Since there are so many conditions that cause similar symptoms, it might take a while for your doctor to diagnose you with IBD. In a survey we conducted in 2020,³ only 38% of respondents received an IBD diagnosis within a year of symptom onset. There is a common saying in medicine that goes, “when you hear hoofbeats, think horses, not zebras,” which means that the cause of symptoms is probably the most common ailment. Since many other conditions, such as irritable bowel syndrome, hemorrhoids, infections, and medication side effects, have symptoms that overlap those of IBD and are more common, your physician might investigate these options first, unless you have another inflammatory condition or a family member with IBD.

Testing typically begins with a simple physical examination in the doctor’s office. Then, they might order some general blood tests to check for anemia, infection, and the level of C-reactive protein, which increases when there’s inflammation in your body. Stool tests can check for biomarkers such as calprotectin and lactoferrin, and enteric pathogens such as *C. difficile* toxins or parasites. They might also test to rule out celiac disease.

The most important tool in diagnosing IBD is endoscopy. There are several types available depending on the location of the digestive tract that your physician wishes to view, but they all involve inserting a scope with a camera attached to it into your digestive system so that they can look for any visible signs of inflammation or ulcerations. A gastroscopy is for the upper gastrointestinal tract and enters via the mouth, while a sigmoidoscopy for the lower portion of the colon and a colonoscopy for the entire colon enter via the anus. During an endoscopy, your physician can also take a tissue sample to test for microscopic signs of inflammation. Another way to see what is going on in the digestive tract is imaging tests, such as computerized tomography (CT) scans and magnetic resonance imaging (MRI).

If there is inflammation in your digestive tract, you

probably have IBD. However, that isn’t the end of the testing and diagnosis process. Next, your healthcare team will establish if you have Crohn’s disease, ulcerative colitis, or another type, as well as its location and severity, and any related extra-intestinal manifestations or other comorbidities.

Crohn’s Disease vs. Ulcerative Colitis

	Crohn’s Disease	Ulcerative Colitis
Disease Location	any part, particularly terminal ileum, colon, ileocolon, and/or upper gastrointestinal	limited to colon, extent can be proctitis, left-sided colitis, or extensive colitis/pancolitis
Depth of Inflammation	can penetrate full bowel thickness	only the mucosa
Disease Severity	mild, moderate, severe, fulminant (sudden and severe)	mild, moderate, severe, fulminant (sudden and severe)

After receiving a diagnosis of IBD, you might feel overwhelmed and want to learn everything you can about it. Patient groups such as the GI Society can be great resources for medically-sound information and support groups can be a helpful way to meet others that are going through the same things as you. The Gastrointestinal Society holds a monthly support group meeting via Zoom (www.badgut.org/support-groups).

Getting Started with a Treatment Plan

Your treatment plan will be personalized depending on many factors, including which type of IBD you have, its location and severity, which symptoms you are affected by, whether or not you have any complications such as fissures/fistulas, your age, and more.

When it comes to medication, there are two main categories that your healthcare team will focus on: medications that reduce the underlying inflammation responsible for your IBD and medications that help manage individual symptoms.

Some anti-inflammatory medications include 5-aminosalicylic acid compounds, corticosteroids, immunomodulators, and biologics. You will need to take anti-inflammatory medications even when you are feeling well, as these support mucosal healing, bring you into remission, and help prevent future flares. Not all these



medications work the same in each person. Sometimes a drug can work well for years and then lose its effectiveness. More drug development research is needed to find longer-term solutions.

Symptomatic medications can include things such as analgesics for pain, anti-diarrheal medications, laxatives if you experience constipation, iron supplements if you have anemia, oral nutritional supplements if you are unable to maintain a nutritious diet, and antibiotics for infected abscesses. This isn't an exhaustive list, as there are many potential symptoms and complications, along with potential side effects from other medications, for which you might need treatment. Your physician will generally recommend these on an as-needed basis. For complete medication listings, ask for our related pamphlets on *Inflammatory Bowel Disease*, *Crohn's Disease*, and *Ulcerative Colitis*, or search for these topics on badgut.org.

Some individuals will find a medication that successfully controls their IBD quickly and easily, while others might need to try many medications or combinations of medications to find a treatment regimen that enables remission. All patients with IBD will need continual monitoring to ensure that their treatment plan is working, which will involve ongoing testing.

Therapeutic drug monitoring helps measure the levels of medication in your system at a certain point in time, which provides information for your gastroenterologist to adjust your medications. Watch our video on this at www.badgut.org/tdm.

In addition to medication, your healthcare team might recommend changes to your diet or exercise routine. If you are in remission, it is important to stick to a healthy diet with plenty of nutrient-dense foods, fibre, protein,

and healthy fats. But during a flare, you might need to eat a very simple diet that is low in fibre and fats, or even a fully liquid diet, to let your bowel rest. It can be difficult to manage these drastic changes to how you eat, which is why it is vital to get help from a registered dietitian. You might find that an oral nutritional supplement can be a powerful tool in the struggle against malnutrition. Go to our website to see a review of some of these products.³

While a lot of people don't want to consider it, surgery is sometimes necessary for those with IBD. Surgical options can range from procedures to fix fistulas and fissures or drain abscesses to more complex surgeries such as bowel resection or stricturoplasty for Crohn's disease, or restorative proctocolectomy with ileal pouch-anal anastomosis (j-pouch) or proctocolectomy with end ileostomy for ulcerative colitis. These surgeries can require an ostomy. Colectomy is effective for ulcerative colitis, because inflammation is limited to the colon, so removing the colon removes the diseased tissue, but this surgery is still a last resort since it has its own complications.

The Endless Loop of Remission and Flares

Remission is the goal if you have IBD; it's what all these medications, surgeries, and other treatment methods are working toward. You might think you are in remission if your symptoms are gone and you feel well. While that is part of it, the key factor is mucosal healing, which your doctor can confirm during an endoscopy or by using other imaging tests. During remission, many patients can move on with their lives and forget about all the pain and difficulties that led them there. However, IBD is a chronic disease, which means you are never fully in the clear. This is why it is so important to keep taking your medications even when you feel great, as it can help prevent another flare.

A flare occurs when inflammation and symptoms return. At this stage, you will need to return to your healthcare team to have your treatment plan analyzed. They will consider contributing factors for the flare:

- are you taking your medications as directed?
- have you changed your diet or exercise routine?
- did you have a major stress in your life?
- have you experienced hormonal changes?
- have you been sick?

Sometimes, there are no identifiable triggers, but it is helpful to get an idea of what is going on in your life so that your doctor can help you update your management



plan. A daily journal can be a simple, effective tool for you to keep track of these factors, so that it is easy to identify any changes that could be affecting your IBD.

A few other questions to consider include:

- are your symptoms the same or different from before?
- do you have any new complications?
- do you have any new symptoms outside the gut?
- are your symptoms more severe or similar to the severity as before?

With this information, your doctor might change your medication dose, or suggest switching to a different medication or adding another medication to your current regimen. You will likely need more testing and it could take some time to get back in remission. It can be extremely frustrating and distressing to live through all of this and feel as though you are newly diagnosed again, after having experienced the freedom of having your symptoms under control.

Finding Stability: Long-Term Management

The chronic nature of IBD means that, as there is no cure at this time, you will need ongoing monitoring and care for the rest of your life. It's a daunting reality to face but, with the right support, you can live a life of thriving.

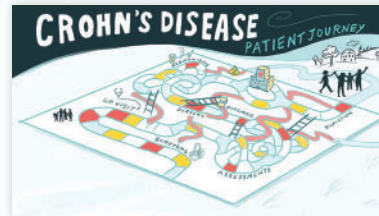
Most IBD patients need to be in regular contact with their general practitioner and their gastroenterologist, but there are so many other healthcare experts who will be part of your team from time-to-time. These can include nurses, phlebotomists, lab technicians, registered dietitians, mental health professionals, social workers, surgeons, dermatologists, kinesiologists, ophthalmologists, rheumatologists, neurologists, and more.

Regular visits with relevant experts can keep you on track and prevent any symptoms or complications from getting worse. They will likely order routine tests to monitor disease activity and medication side effects, which can include blood tests, stool tests, therapeutic drug monitoring, endoscopy, and more.

As many medications are costly, you will need to be in contact with government programs and/or your private insurers to make sure your medications are covered, especially where newer therapies are involved. Individuals who take biologic medications will also have access to patient support programs that will help you throughout your care, such as set up funding

Visual Learner?

We cover some of the basic information from this report in two new videos, one following the Crohn's disease journey and the other the ulcerative colitis journey. They are particularly useful to share with your friends and family so they can understand what you are going through.



<https://youtu.be/WXolKSmWZbQ>



<https://youtu.be/2X3AtaOXdkM>

by contacting insurers, finding out what is available, completing paperwork for you, and more.

While your core treatments are going to be medications and/or surgery, there are many complimentary therapies that you might want to try. Many patients find that these contribute greatly to improving quality of life.

New research is showing that there might be a benefit in treating ulcerative colitis via changes to the microbiome with either probiotics or fecal microbiota transfer (FMT), although the evidence is unclear for use in Crohn's disease.

Sitz baths, which involve soaking the rectal area in a warm, shallow bath (Epsom salts optional), can be soothing and promote healing around the rectum.

Diet and exercise are essential for good health, and this is particularly true when you have a chronic disease. A registered dietitian can work with you to develop meal plans that are balanced and take into account your symptoms, disease status, and personal preferences. They

can also test you for nutritional deficiencies, recommend dietary changes or supplements, and monitor you over time to make sure that the changes are improving your levels. A kinesiologist can help you find a safe degree of exercise and movements that work for you, especially if you have comorbid joint inflammation.

You might find yourself needing some degree of mental health care, whether in the form of self-led techniques such as meditation, yoga, or journaling, or by seeing a mental health professional for individual or family-based therapy. Support groups are helpful, as they make it easy to connect with people who are going through the same things you are.

It is important to watch out for new symptoms, extra-intestinal manifestations, and further complications. Some of these you might notice on your own, but others will be identified by your physician, such as bowel obstruction, strictures, fistulas, and abscesses if you have Crohn's disease or toxic megacolon if you have ulcerative colitis. Individuals with IBD are more likely to develop ankylosing spondylitis, rheumatoid arthritis, psoriatic arthritis, and psoriasis. It's still very rare to have any of these, but already having one inflammatory disease makes you slightly more likely to develop another.

If you have ulcerative colitis or Crohn's disease that affects your colon, you are also at a slight increased risk of developing colorectal cancer. The good news is that since your healthcare team knows you are at risk, they can provide you with more frequent screening to catch any abnormalities early enough to treat.

Having an action plan in place to manage any oncoming flares is vital and can keep you out of the hospital emergency department. Work with your healthcare team to establish what steps to take if you feel your symptoms return or worsen. This can include setting up appointments before symptoms get too bad, taking rescue medications, or starting a liquid diet. Learn more about flares and download our free Action Plan templates available at www.badgut.org/ibd-flare-video.

Hope for the Future

Living with IBD is challenging. Sometimes it feels like you can never be at peace, because even when you are in remission you might worry that a flare could be around the corner. However, as you learn more about IBD in general, your own experiences and symptom triggers, how to cope with the mental effects, how to meet new people with IBD, and that it is okay to lean on

your family, friends, and healthcare team for support, it gets easier. Researchers continue to develop medications, from new iterations of drugs we are already familiar with, to entirely novel treatment methods, so there is always hope for better symptom relief, increased quality of life, or maybe even a cure.

1 Angus-Reid Institute. Doc Deficits: Half of Canadians either can't find a doctor or can't get a timely appointment with the one they have. Available at: <https://angusreid.org/canada-health-care-family-doctors-shortage/>. Accessed 2022-11-06.

2 Survey. *The Unmet Needs of IBD 2020*. Gastrointestinal Society. Available at: <https://badgut.org/unmet-needs-of-ibd-results-2020/>. Accessed 2022-11-06.

3 Stelluti, A. *Oral Nutritional Supplements*. Gastrointestinal Society. Available at: <https://badgut.org/information-centre/health-nutrition/oral-nutritional-supplements/>

Please Note

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The Gastrointestinal Society does not intend that this report replace the knowledge or diagnosis of your physician or healthcare team, and we recommend seeking advice from a medical professional whenever a health problem arises.

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