



# IBD warrior toolkit

Take charge and advocate for your care

IBD: inflammatory bowel disease

Endorsed by the



crohn's  colitis

abbvie

This booklet contains helpful information about:



your condition.



how to understand your test results.



how to prepare for your appointments with your healthcare provider.



the importance of agreeing on your treatment goals.

## What's inside this booklet

This booklet was designed to help you through your treatment journey. It is important to keep track of the symptoms of your condition so you and your healthcare providers can determine an appropriate treatment plan for you.

This booklet also includes a glossary for quick reference. All terms underlined throughout this resource are defined in the glossary.

Review the information in this booklet with your healthcare providers and discuss any questions you may have.

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# IBD 101

## IBD is a life-long condition

Inflammatory bowel disease is a group of autoimmune conditions that are chronic. They cause inflammation in the mucosa or lining of the gastrointestinal (GI) tract. This inflammation can disrupt the body's ability to digest, absorb nutrients, and eliminate waste properly.

Although **there are many forms of IBD**, the two most common ones are **Crohn's disease (CD)** and **ulcerative colitis (UC)**. The biggest difference between them is the location of the inflammation within the GI tract.

To better understand which areas are affected by IBD, scan to learn more about the body's anatomy.





## Educating on the differences between IBD and irritable bowel syndrome (IBS)

IBD and IBS are often misconstrued as the same condition, but they are inherently different. Although the conditions have overlapping symptoms, they are not the same. IBS is characterized as a disturbance in bowel function with no inflammation to the gut or other organs of the body. IBD, however, is a disease that causes inflammation of the intestines and can be seen using imaging testing. Addressing the misconception is a way to educate others on the differences between the two conditions.

### Here's an approach to educate people on the differences between IBD and IBS



*"I have IBS! I understand what you're going through."*



*"I am familiar with IBS. While both IBS and IBD affect the gut, they are very different. IBD is a chronic autoimmune disease that results in inflammation of the gut, and it can even affect other body systems. IBS occurs because of the way the gut functions but doesn't involve inflammation. The symptoms, complications, and treatments are mostly different for IBD and IBS."*



UNDERSTANDING THE RISKS OF UNCONTROLLED INFLAMMATION IN IBD CAN HELP YOU TAKE CHARGE OF YOUR CONDITION BY HAVING MEANINGFUL CONVERSATIONS WITH YOUR HEALTHCARE PROVIDER. SET TREATMENT GOALS WITH YOUR HEALTHCARE PROVIDER TO ADDRESS INFLAMMATION.

# IBD may extend beyond the gut

## Exploring possible complications of uncontrolled inflammation

Uncontrolled inflammation *may* result in several complications that impact the body's ability to heal the mucosa (lining of the gastrointestinal tract). This is not an exhaustive list of all the complications that may occur when living with IBD.

### Inflammation



Scarring of inflamed intestines



Narrowing and stiffening of the intestinal wall, also called strictures








Formation of tunnels, also called fistulas, that connect parts of the intestine to other organs



# IBD may extend beyond the gut (continued)

## Extraintestinal manifestations in IBD

In some cases, complications (also known as extraintestinal manifestations) may extend beyond the GI tract, affecting other parts of the body. In Europe, up to 50% of patients with IBD may develop an extraintestinal manifestation.

	<b>Arthritis</b>	<p>Up to 30% of IBD patients can be affected by arthritis (inflammation of the joints), including:</p> <ul style="list-style-type: none"><li>• <a href="#">Peripheral arthritis</a></li><li>• <a href="#">Ankylosing spondylitis</a></li><li>• <a href="#">Spondyloarthritis (SPA)</a></li></ul> <p>A study has shown that patients with IBD have an increased risk of <a href="#">rheumatoid arthritis</a>.</p>
	<b>Skin</b>	<p>In a single study, 29.3% of patients with IBD developed extraintestinal manifestations. Among these patients who were later diagnosed with IBD:</p> <ul style="list-style-type: none"><li>• 50% developed psoriasis</li><li>• 14.3% developed <a href="#">erythema nodosum</a></li><li>• 14.3% developed <a href="#">pyoderma gangrenosum</a></li></ul>
	<b>Bone</b>	<p>Between 30% and 60% of IBD patients have lower-than-average bone density, resulting in complications like osteoporosis.</p>
	<b>Eye</b>	<p>Approximately 10% of IBD patients experience eye problems. Below are some examples of eye complications that can occur with IBD:</p> <ul style="list-style-type: none"><li>• <a href="#">Uveitis</a></li><li>• Dry eyes</li><li>• <a href="#">Keratopathy</a></li><li>• <a href="#">Episcleritis</a></li></ul>
	<b>Anemia</b>	<p>Nearly a third of IBD patients have anemia, typically due to low levels of iron and/or other key vitamins and minerals. This can be attributed to malabsorption, blood loss, or poor intake due to symptoms.</p>

This is not an exhaustive list of extraintestinal manifestations that may occur with IBD.



BE SURE TO SPEAK TO YOUR HEALTHCARE PROVIDERS IF YOU ARE EXPERIENCING ANY SIGNS OR SYMPTOMS BEYOND THE GUT.

# Types of testing and monitoring

## What to know about testing

There are many tools and tests your healthcare providers may use to monitor your IBD. While you aren't expected to know how to interpret the results, it's important to understand what those tools are, why they matter for your treatment, and how they can help you ask better follow-up questions during your appointments.

### Blood tests



Blood tests, in combination with stool and imaging tests, are used to monitor your IBD.

Your healthcare providers will order blood tests to help rule out other potential causes for the symptoms. Usually, the healthcare providers will order a complete blood count (CBC).

These tests collect information about many types of cells in the body, including biomarkers (molecules that function as measurable indicators of the state of the body).

### Stool test or fecal calprotectin (FCP) test



A stool test is a non-invasive test that can not only help your healthcare providers confirm an IBD diagnosis (after ruling out parasites or infections) but also be used to monitor your disease activity. It measures inflammation in your gut by evaluating the levels of a protein called calprotectin. The test doesn't require any bowel preparation and can be performed at a clinic, hospital, or at home.

The healthcare providers will instruct you on how to collect the sample for testing.



**WHETHER YOU'RE NEWLY DIAGNOSED OR HAVE BEEN LIVING WITH IBD FOR YEARS, THIS INFORMATION CAN HELP YOU BECOME A MORE CONFIDENT ADVOCATE IN YOUR CARE.**

## Gastroscopy / colonoscopy assessments



Following the completion of blood and fecal calprotectin (FCP) tests, your healthcare providers will order imaging procedures ([gastroscopy](#) or [colonoscopy](#)) at regular intervals. This test provides more of a definitive view of the disease activity within the gut.

Endoscopic assessments are done using a small flexible tube with a camera at its end to check for inflammation in either your stomach ([gastroscopy](#)), small intestine, or colon ([colonoscopy](#)).

Preparation steps need to be followed carefully or else it can cause delays in scheduling your endoscopic assessment. Be mindful of the instructions given to you as preparation instructions may differ from test to test. If you need more information on how to best prepare for your appointment, ask your healthcare providers.

## Imaging test



There are also non-invasive imaging techniques that can be used to evaluate disease activity in your [mucosa](#) depending on their availability in your centre.

Abdominal ultrasounds use high-frequency sound waves to create images of the intestine; however, achieving quality images can be challenging using this approach.

Computed tomography (CT) scans use multiple x-rays to take pictures of the gut. These scans may be used with an intravenous contrast dye to paint a more complete picture.

Magnetic resonance imaging (MRI) can generate a high-quality image that shows inflamed areas and can differentiate between scar tissue.



# Interpreting your test results

## Understanding your blood tests

### Red blood cell (RBC) and hemoglobin count



RBCs are produced in the bone marrow and are critical to supplying the body with oxygen and nutrients. Hemoglobin is a protein found in RBCs that helps transport oxygen to the rest of the body.

With IBD, the lining of the intestines can become inflamed causing ulcers to form. These ulcers can bleed in the colon or rectum. Measuring RBCs and hemoglobin is important because low levels may suggest the presence of bleeding.

### White blood cell (WBC) count



WBCs are also made in bone marrow and consist of five different types of cells (neutrophils, lymphocytes, monocytes, eosinophils, and basophils). Each of them plays an important part in the body's immune system since they either produce and/or carry antibodies to attack foreign substances that threaten the body.

IBD is an autoimmune condition that causes the body's immune system to overreact, resulting in WBCs mistaking healthy tissue as a threat. Elevated levels of WBCs can suggest inflammation occurring in the body.

### Iron



Iron is a key component for hemoglobin in the RBCs.

Because of abnormal bleeding associated with IBD, low iron levels may suggest the presence of anemia.

## Ferritin



Ferritin levels are a measurement of how much iron is stored in the body. Low ferritin levels suggest the presence of iron deficiency, while high levels of ferritin may be a sign of chronic disease.

## C-reactive protein (CRP)



CRP is a protein made in the liver. An increase in CRP levels indicates that there is inflammation occurring elsewhere in the body.

Testing for CRP may reveal the presence of inflammation but doesn't determine the cause or location.

CRP tests are routinely performed to check for disease activity and severity.



**NO CONCLUSION CAN BE DRAWN ON THE STATUS OF YOUR IBD FROM AN INDIVIDUAL BLOOD TEST. THE RESULTS NEED TO BE CONSIDERED LIKE PUZZLE PIECES—SMALL PARTS OF A BIGGER PICTURE.**

# Interpreting your test results (continued)

## Understanding your stool tests

### Fecal calprotectin (FCP)



FCP is a highly sensitive protein (biomarker) found in WBCs. WBCs will travel to the location of inflammation in the intestines and attack it by releasing proteins, which include calprotectin.

The higher the levels of FCP found in the stool, the greater the intestinal inflammation. This test can also help your healthcare providers determine if you need to undergo alternate testing procedures like an endoscopy and/or colonoscopy.

FCP tests are routinely ordered to assess disease activity and therapeutic monitoring.

## Understanding your test results

If you would like more clarity on your test results, don't hesitate to ask your healthcare providers for your results and imaging.



*“Can you walk me through my recent test results? What do these values mean? Can you explain to me how I am trending?”*



*“My result for this appears to be within normal range. Can I do anything on my end to help manage my disease activity?”*



**REFER TO YOUR PAST TEST RESULTS TO SEE HOW YOU'RE TRENDING. THESE TESTS DO NOT TELL YOU IF YOUR CONDITION IS IMPROVING OR DECLINING BUT CAN HELP TO IDENTIFY POSSIBLE TRENDS.**

# Tracking your symptoms

## The journey ahead with IBD

Tracking is important so you can keep a pulse on your disease activity. Keep track of your IBD symptoms so you can relay them back to your healthcare providers at your next appointment. This helps your healthcare providers make proper adjustments to your medications.

Tracking your symptoms can also help you identify any triggers or stressors related to your condition. Details to consider include the date or time the symptom occurred, its severity (impact on your daily activities), and its duration.

The more you familiarize yourself with patterns related to your condition, the more you can find ways to avoid or manage triggers. Speak to your healthcare providers about your IBD symptoms to ensure that you are on track to reach your treatment goals.



**Consider some questions that your healthcare providers may ask you at your upcoming appointment**

*Have you had any changes to your diet?*

*Have there been any changes to your lifestyle, e.g. work or school?*

*Are there any new stressors in your life?*

*How many bowel movements do you have on average per day?*

*How many times do you wake up at night to go to the bathroom?*

*Are there any visible signs of blood in your stools?*

## Tracking your symptoms and how you are feeling can help you prepare for your upcoming appointment

Whether you're using smartphone apps or keeping a written journal, find a tracking method that works best for you. Alternatively, download the IBD Conversation Prep Guide to help you prepare for your upcoming appointment. This will allow your HCP to have a holistic overview of how you are doing physically, mentally, socially, and emotionally.

### Scan to download the IBD Conversation Prep Guide!

This guide can help you communicate how you are feeling from a physical, mental, emotional, and social standpoint. This will allow for a more productive discussion with your healthcare providers about your treatment plan.



DOCUMENTING AND DISCUSSING YOUR SYMPTOMS, QUESTIONS, AND HOW YOU FEEL ABOUT THE PROGRESS, OR LACK OF PROGRESS TOWARDS YOUR TREATMENT GOALS CAN HELP IMPROVE COMMUNICATIONS BETWEEN YOU AND YOUR HEALTHCARE PROVIDERS.



# Taking part in your health discussion



## Take charge of your health discussions

Advocating for your own health means being confident about the choices you make with your healthcare providers. Be part of the discussions when it comes to determining your treatment plan.



Take time to think about your health goals and share them with your healthcare providers.



Ask yourself how you would define a good quality of life and ask your healthcare providers how you can achieve this goal.



Be open and honest about your health concerns with your healthcare providers.



If you are struggling emotionally or mentally, discuss it with your healthcare provider.



Recognize that good health also means healthy lifestyle changes, which can include diet, exercise, and rest.

# Setting and aligning treatment goals with your healthcare providers

## Treatment goals can evolve as you progress through your IBD treatment

Because IBD is a chronic disease, it is important to work with your healthcare providers to create a roadmap for your health journey. They will partner with you to set **specific goals** to manage your condition. Being transparent about **how you are feeling is important** so they can adjust your treatment plan until you reach the goals that you have aligned together. Goals like **reducing the symptoms** of your IBD can be an initial starting point when you begin your journey. As you progress, you can set and align **longer-term goals**, like **endoscopic and symptomatic remission**, in partnership with them. As you navigate through your health journey, your healthcare providers will continue to monitor your disease activity with blood and stool tests. This will allow them to **adjust your treatment plan as needed**.



Your  
health  
journey



YOU AND YOUR HEALTHCARE PROVIDERS SHOULD BE WORKING TOWARDS YOUR TREATMENT GOALS TOGETHER, WHICH IS WHY ALIGNMENT IS SO IMPORTANT.



- Reduction of symptoms of IBD
- Improving quality of life and general sense of well-being
- Reduced inflammation/flare (remission)
- Absence of ulcers altogether (mucosal healing)



## Understanding what mucosal healing means for your IBD

Mucosal healing is the healing of the inflamed lining of the intestines. Since IBD is a chronic inflammatory condition, setting goals that include addressing both the symptoms and the underlying cause (inflammation), is important.



# Setting and aligning treatment goals with your healthcare providers (continued)

## Inflammation isn't always evident through symptoms

It is important to understand the relationship between inflammation and symptoms when managing IBD because symptoms are not always reflective of the degree of inflammation. Sometimes during a flare, you might not have symptoms at all.

A flare occurs when your condition worsens due to inflammation, however flares present differently for everyone.

Symptoms are not necessarily reflective of the degree of inflammation seen in the intestine. You can experience an increase in symptoms with no presence of inflammation, just like you can present with inflammation but have no symptoms at all.

The relationship between inflammation and symptoms isn't causal, so it's important to address not only the symptoms but also the inflammation in the gut.



**BE SURE TO FOLLOW YOUR TREATMENT PLAN AND YOUR HEALTHCARE PROVIDERS' INSTRUCTIONS. LET THEM KNOW IF YOU NOTICE ANY CHANGES IN HOW YOU FEEL.**

# Navigating IBD

## Putting it all together

### Between visits

#### Daily / weekly



- Track your symptoms, including bowel movements, pain, or fatigue in a format that works for you.
- It can also help to track food intake, daily activity, sleep, and life events.
- Note if you notice new or worsening symptoms.
- Take medications as prescribed.
- Monitor your energy levels and overall well-being, noting any changes.

#### Monthly



- Review your symptom patterns—do you notice any triggers or trends? Is your IBD affecting your daily activities?

#### Before your next appointment



- Make a list of questions or concerns to discuss with your healthcare team.
- Gather your symptom tracking notes, e.g. fill out the IBD Conversation Prep Guide.
- Think about your treatment goals and if you feel you're meeting them.
- Complete any lab work or tests your healthcare providers have ordered.



**BE YOUR OWN HEALTH ADVOCATE AND TAKE AN ACTIVE ROLE IN YOUR IBD TREATMENT PLAN. BEING PREPARED MEANS KEEPING TRACK OF HOW YOU ARE FEELING NOT ONLY PHYSICALLY BUT ALSO EMOTIONALLY, MENTALLY, AND SOCIALLY.**

# Glossary

## **Ankylosing spondylitis or axial arthritis**

An autoimmune disease that affects the spine and the joints connecting the spine to the pelvis.

## **Autoimmune condition**

An autoimmune disease is a condition that occurs when the individual's immune system attacks its own tissues as though they were foreign substances.

## **Colonoscopy**

A procedure in which a flexible camera is inserted through the rectum, allowing visualization of the large intestine.

## **Crohn's disease**

An autoimmune condition that can cause inflammation anywhere in the GI tract from mouth to anus.

## **Endoscopy**

A procedure where a small camera is inserted via a thin, flexible tube by oral or rectal route or swallowed in a capsule, depending on the part of the gut that your medical team needs to see directly.

## **Episcleritis**

Inflammation, irritation, and reddening of the layer of clear tissue that covers the white part of your eyes.

## **Erythema nodosum**

A subcutaneous skin condition that causes tender, red bumps to form, usually on the shins, that may become purplish in colour.

## **Fistula**

A formation of tunnels that connect parts of the intestine to other organs.

## **Flare or flare-up**

An exacerbation of signs and symptoms relating to a condition.

## **Gastroscopy**

A procedure where a small camera attached to a thin, flexible tube is inserted via mouth, to view the esophagus, stomach, and the uppermost portion of the small intestine.

## **Keratopathy**

A disease affecting the cornea.

## **Mucosa**

The lining of the digestive tract.

## **Mucosal healing**

The healing of the inflamed lining of the intestines.

## **Peripheral arthritis**

A type of spondyloarthritis that occurs outside the spine, especially in the big joints in their arms or legs.

## **Pyoderma gangrenosum**

A rare condition that causes large, painful sores on the skin.

## **Rheumatoid arthritis**

An autoimmune disease that causes inflammation of the joints in the arms and legs.

## **Spondyloarthritis**

A family of inflammatory rheumatic diseases.

## **Ulcer**

A sore or lesion that occurs on the lining of the gastrointestinal tract.

## **Ulcerative colitis**

An autoimmune condition that causes inflammation in the lining of the large intestine, or colon.

## **Uveitis**

An autoimmune disease that causes inflammation of the eyes.

# Be an IBD warrior



Remember, everyone's journey is different. It is important to be your own health advocate and take an active role in your IBD treatment plan. Come prepared to your appointments with questions and be ready to share how you are feeling physically, emotionally, mentally, and socially. This will help you have more productive discussions with your healthcare providers.

**There are patient associations that share helpful information on how to cope with your condition.**

Visit the sites below to gain access to their resources and support groups.



Crohn's and Colitis Canada  
<https://crohnsandcolitis.ca/>



Gastrointestinal Society  
<https://badgut.org/>



THIS BROCHURE WAS ENTIRELY CO-CREATED WITH PEOPLE LIVING WITH IBD AND CANADIAN IBD NURSES.

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