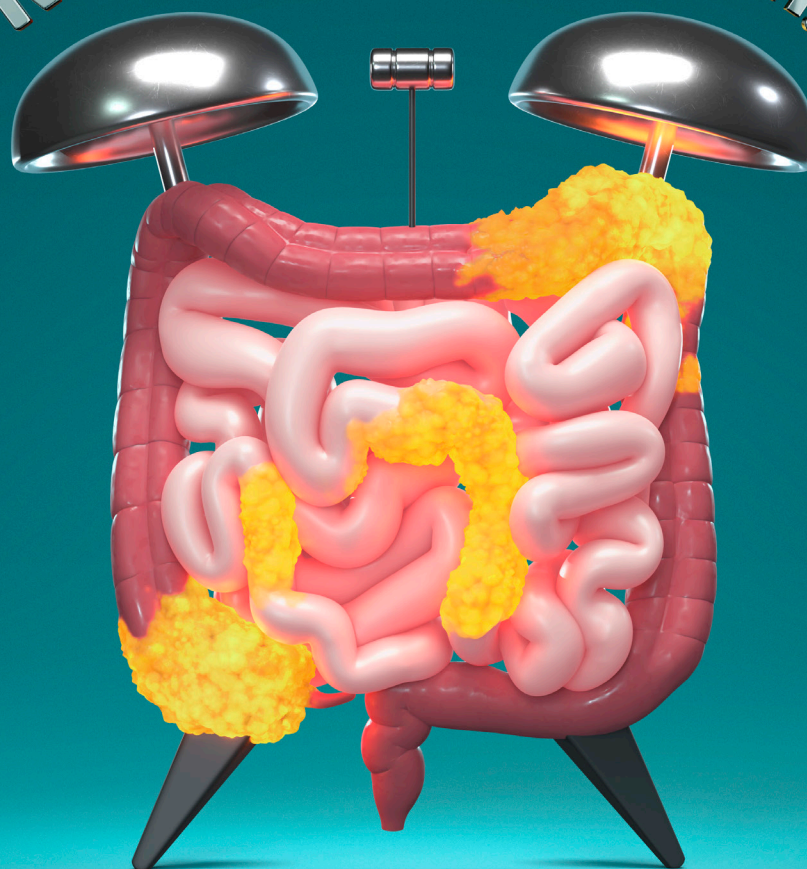


IBD STARTER **GUIDE**

MY PAIN IS
REAL!

THESE FLARES ARE
ROUGH!



Living With IBD Starts Here

Getting diagnosed with IBD can be life changing. There's a lot to take in, and some of it is pretty tough. But at least now you have an answer to what you've been experiencing, and you can start looking for help.

This guide is designed for people like you who have just been diagnosed and want to take control. Whether you're starting from zero or know a thing or two already, now is the time to learn more about your disease. Because the more you understand, the better you can advocate for yourself.

In the following pages, you'll find easy-to-understand information about your disease, ways to connect with the IBD community, and tips for getting on the same page as your doctors. Ready to jump in?



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IBD 101

Your doctor just broke the news: “You have IBD.” That can feel pretty heavy. But it also probably made you start thinking of all kinds of questions. Here are a few questions that might come to mind, and some quick answers.



FAIBDQ

[That’s “Frequently Asked IBD Questions”]

What is IBD?



IBD stands for inflammatory bowel disease. It’s a category of autoimmune diseases that mostly affect your gastrointestinal (GI) tract. The two most common types of IBD are Crohn’s disease and ulcerative colitis.

What causes IBD?



There’s no one answer, but scientists believe it’s a combination of genes, your environment, and your immune system.

What are the symptoms of IBD?



Common symptoms include diarrhea, the urgent need to use the bathroom, bloody stools, stomach pain and cramps, weight loss, and more.

How common is IBD?



About 3 million people in the United States have IBD. So you definitely aren’t alone.

Is there a cure or treatment for IBD?



To date, there are no cures, but there are treatment plans available that could help reduce your symptoms.

Good with IBD 101? Get the advanced course at LivingWithIBD.com/understanding-your-IBD

IBD Glossary

Like any disease, there's a lot of lingo to learn with IBD. Here are some of the most important words and acronyms you should know.



Autoimmune Disease

An autoimmune disease is a type of disease where your immune system attacks your body instead of protecting it. There are more than 100 types of autoimmune diseases, including IBD.

Biologics

Biologics are a type of advanced treatment made from living cells. There are different kinds of biologics that are used to treat IBD.

Clostridioides difficile

C. difficile for short, this is a germ that causes a bacterial infection that can result in symptoms that are very similar to IBD.

Colonoscopy & Endoscopy

These are diagnostic tests that use a camera to get a better look at the different parts of your GI tract.

Crohn's Disease

Crohn's disease is one of the two main types of IBD. It can affect your entire GI tract, from your mouth to your anus.

Fistula

Fistulas are a potential complication of Crohn's disease. They are abnormal connections between two parts of your gut that can sometimes open externally.

Flare

IBD symptoms can come and go. When your symptoms are acting up, that's called a flare.

Gastroenterologist

A gastroenterologist, or GI, is a type of doctor who focuses on the digestive system and diseases like ulcerative colitis and Crohn's disease. For more info on GIs, go to [page 10](#).

GI Tract

Your gastrointestinal tract is your digestive system, including your mouth, esophagus, stomach, intestines, rectum, and anus.

IBS

IBS, or irritable bowel syndrome, is a different condition from IBD, but it can have similar symptoms.

Immune System

Your immune system is designed to protect your body from threats like bacteria and viruses. In people with IBD, your immune system mistakenly attacks cells in your GI tract.

Infusion & Injection

IBD treatments come in a few different forms, including oral medication, infusions, when the drug is administered by a healthcare provider into a vein, and injections, when the drug is administered via a small shot at home.

Remission

Although IBD can't be cured, remission is a term for the period of time in-between flares when you experience few to no symptoms.

Steroids

Corticosteroids (often shortened to just "steroids") can be used to treat IBD symptoms by decreasing inflammation.

Ulcerative Colitis

Ulcerative colitis, or UC, is the other main type of IBD. It only affects your colon and rectum.

Learn more lingo at LivingWithIBD.com/understanding-your-IBD

What Are Your Goals?

It's important to make sure your goals are all about you—your body, your environment, your life. This worksheet can help you figure out what your individual goals are so you can bring them up with your doctor when talking about treatment options.

Select the goals that are important to you.

Make sure to bring this sheet with you to your next appointment.

Physical Goals

- ☐ Reduce symptoms such as:
 - ☐ Abdominal pain ☐ Cramping
 - ☐ Diarrhea ☐ Lots of trips to the bathroom
 - ☐ Other: _____
- ☐ Have fewer, less intense flares
- ☐ Reduce use of over-the-counter drugs
- ☐ Other: _____

Medical Goals

- ☐ See improvement in my lab work
- ☐ Reduce inflammation in my gut
- ☐ Other: _____

Life Goals

- ☐ Explore your travel options
- ☐ Miss fewer life/work events
- ☐ Feel more comfortable meeting new friends or romantic partners
- ☐ Other: _____

Mental Health Goals

- ☐ Decrease stress and anxiety
- ☐ Focus more on the things that matter most to you
- ☐ Other: _____



Ready to work through your goals with your care team?
Our Doctor Discussion Guide can help: LivingWithIBD.com/ddg

Support Is All Around You

Feeling isolated and looking for support? Your personal relationships can be the foundation of a strong support system. Here are some tips for finding the support you need from the people in your life.



Your family and friends can support you, but only when you're honest about your condition. Tell them when you're in pain, and ask for help when you need it.



If you're feeling particularly down, seek the help of a **therapist or mental health professional**. They can help you develop ways to overcome negative emotions.



Your **healthcare team**, with a **GI** leading the way, is available to help when you are feeling overwhelmed or anxious.



If you find your IBD is affecting your work life, chat with your **HR representative**. They may be able to help you find workarounds or support. Your boss and coworkers may be able to help as well, if you're comfortable talking to them.



In the event of a medical emergency, have 911 on speed dial, set up emergency contacts, and have your physicians information on hand.

Ready to work through your goals with your care team?
Explore more resources to help you find support at LivingWithIBD.com/resources

Community Organizations

Your individualized support network has two key components: people in your personal life that you can count on and community organizations designed to help you navigate your disease.

Select the organization that sounds like it could be a good fit for you.

Different organizations offer different resources, but they are all dedicated to helping people living with IBD get the support they need. Check the one(s) you're interested in.

General Support Organizations



Bezzzy IBD

A one-stop-shop for blog content and peer-to-peer discussions.



Connecting to Cure Crohn's & Colitis

Online support groups for patients and caregivers.



My Crohn's and Colitis Team

Great for those who want to get in touch with other people living with IBD.



The Crohn's and Colitis Foundation

An organization devoted to improving the quality of life for people with IBD.



The IBD Support Foundation

Offers psychosocial support and education to IBD patients and their families.

Specialist Support Organizations



Color of Crohn's & Chronic Illness

An organization dedicated to equity for people of color with IBD.



Girls with Guts

A community of women looking to empower other women with IBD.



IBD Moms

A safe space for mothers affected by IBD to share their journeys with each other.



South Asian IBD Alliance

Resources and education for members of South Asian community with IBD.

Want to explore even more community organizations? Visit LivingWithIBD.com/resources

Speaking With Friends & Family



We get it. Talking about this kind of stuff with your family and friends can be a little awkward. But it's important that they understand what you're going through so they can support you. These conversation cards can help you practice these tricky conversations and make sure everyone is on the same page about your disease.

What Is IBD?



IBD, or inflammatory bowel disease, is a lifelong condition that involves inflammation of the digestive system. There are two main types of IBD: ulcerative colitis and Crohn's disease. I have [ulcerative colitis/Crohn's].

What are the symptoms?



Everyone has different symptoms, but mine are

- ☐ Diarrhea
- ☐ More trips to the bathroom
- ☐ Cramps
- ☐ Abdominal pain
- ☐ Fatigue
- ☐ And _____

What causes IBD?



Doctors aren't 100% sure, but it's most likely a combination of my genes, my environment, and my immune system. One thing doctors are sure of, though, is that I cannot spread IBD or my symptoms to anyone else.

Is IBD the same as IBS?



No, IBS is irritable bowel syndrome and is a different condition. However, they do share some common symptoms.

Can it be treated?



Yes, there are several types of treatments for IBD. I'll be working with my doctor to find the treatment plan that's right for me.

Would it help to [change your diet, exercise more, meditate, try this supplement, etc.]?



It might! I am working with my doctor to create a treatment plan that works for me which could include lifestyle changes.

See more conversation cards on the next page.

Speaking With Friends & Family

Will you miss work/school/events?



Sometimes, when my symptoms are acting up. But my doctor and I are working to find a treatment plan to help reduce those symptoms.

How can I help?



The best thing you can do is listen to what I'm feeling and support me as I manage my disease.

Will you have to be on medication forever?



Maybe. IBD is a lifelong disease with no known cure. My doctor and I are taking things one step at a time.



“My condition is usually one of the first things I bring up whenever I talk to new people because I didn’t realize how many people are affected by it until after I was diagnosed.”

– Danielle, Living with Crohn’s and Ulcerative Colitis

**Want to talk to someone who knows what it’s like to live with IBD?
Sign up to have a phone conversation with one of our mentors at ibdmentorprogram.com**

What Does a GI Do?

When you have a disease like IBD, you need a specialist on your side. That's where a GI, or gastroenterologist, comes in.



GIs know your GI tract inside and out

GIs are specifically trained to manage diseases in the [gastrointestinal tract](#), meaning they are experts on ulcerative colitis and Crohn's disease. They can diagnose your disease and help you find a treatment plan that works for you.

Your GI is an important part of your care team and is almost like your co-pilot as you navigate living with IBD. It's vital to stay in touch with your GI regularly. These check-ins can help them understand if a treatment plan is working for you or if it's time to try something new.

Your IBD care team may also include nurse practitioners, physician assistants, nutritionists, and even your primary care provider. They each have a unique role to play in your treatment journey.



"I would encourage everyone who is dealing with a chronic disease to find the right doctor and the right treatment plan for you."

– Dave, Living With Ulcerative Colitis

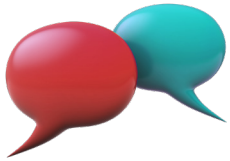
Ready to team up with a GI? Find one near you at FindAGIURL.com

4 Tips for Teaming Up With Your GI

“A great doctor listens to you and is a partner with you in regard to your healthcare.”

—Dave, Living With Ulcerative Colitis

Building a strong relationship with your GI can help you make the most of your time with them. Here are some tips to help make sure you're getting the care you need.



1. Be Specific

It's perfectly normal to feel awkward talking about your symptoms. But the more direct you can be about what you're experiencing physically (and how often), the better your doctor can help you. Consider [tracking your symptoms](#) ahead of your appointment so you don't have to rely on memory alone.



2. Come Prepared

You might only have a few minutes with your GI, so a little preparation can go a long way. Write down your concerns and questions, or try out our [Doctor Discussion Guide](#) for a customized printout you can bring with you.



3. Set Your Goals

What does success look like to you? Making sure you and your GI are on the same page about your treatment goals can help you both evaluate if a treatment plan is working well for you. Get started with our [goals worksheet](#).



4. Bring a Wing-Person

Bring someone from your support network to be an extra set of ears, or just for moral support. However, if you feel more comfortable going alone, you can always ask to record your discussion on your phone or get a printed record of your visit.

To make the most of your partnership, ask your GI what is the best way to get in touch with them. This could be a call to the office, text/email, or an appointment.

Learn about the types of treatments your GI might prescribe to you at LivingWithIBD.com/managing-your-IBD



All done with the IBD Starter Guide?
Take the next step to learn more
at **LivingWithIBD.com**

