

# Guide to Getting Diagnosed With IBD

*Preparing for your first steps along your treatment journey*



If you're experiencing ongoing digestive symptoms and wondering whether you might have inflammatory bowel disease, you may feel overwhelmed by appointments, referrals, testing and insurance requirements. This tip sheet is designed to help you move along your treatment path efficiently while staying informed and in control.

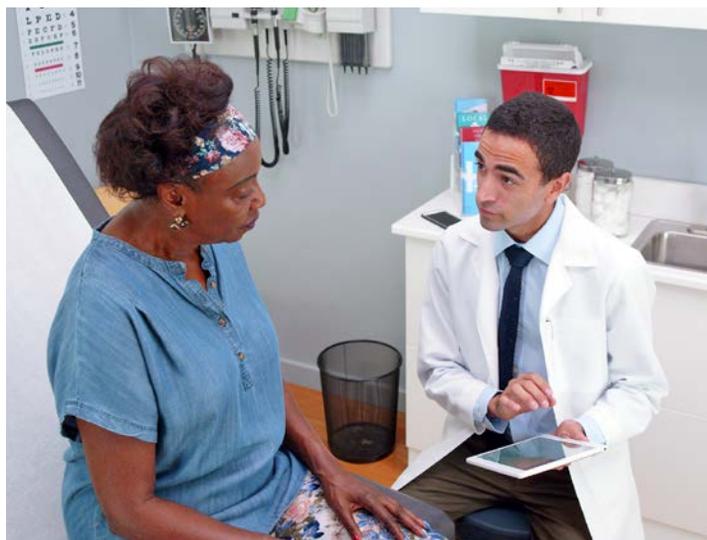
## Introduction

If you're experiencing ongoing digestive symptoms, you may be wondering what's happening and what to do next. The process of seeking answers can feel confusing, stressful and even overwhelming. This guide was created to help you prepare for the journey toward a possible diagnosis of inflammatory bowel disease, also called IBD.

***Our goal is to give you clear, practical information so you can:***

- Recognize when it's time to speak with a doctor
- Prepare for your appointment with confidence
- Understand the types of tests you may need
- Know what to expect at each step

**Remember:** You are not alone. Millions of people live with IBD every day, and through the support of their healthcare providers, they've been able to meaningfully manage their symptoms. You don't have to let your condition define you – especially when there are so many proven, effective solutions available right now.



*You are not alone.*



## What Is IBD?

Inflammatory bowel disease is a term used to describe chronic inflammatory conditions that affect the digestive tract.

The two main types are:

- **Crohn's disease**, which can affect any part of the gastrointestinal tract from mouth to anus
- **Ulcerative colitis**, or UC, which affects the colon and rectum

Both of these are what's known as autoimmune disorders, because your immune system is attacking your own cells as if they were foreign invaders. This results in inflammation that can cause pain, digestive problems and other issues. While many symptoms of Crohn's and UC can be similar, they are distinct diseases with distinct treatments.

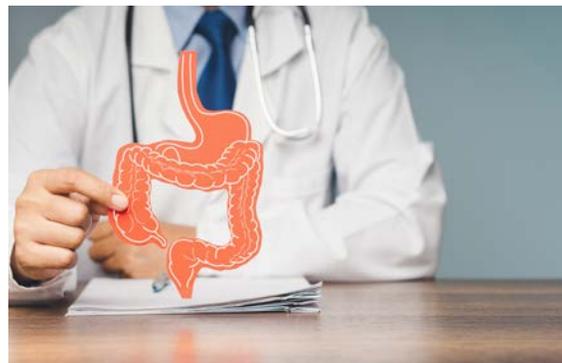
You should also keep in mind that IBD is NOT irritable bowel syndrome, or IBS. IBS does not cause inflammation or permanent damage to the digestive tract, while IBD does. Although this brochure focuses on IBD, more detailed information about IBS is available at [nafc.org/irritable-bowel-syndrome/](https://nafc.org/irritable-bowel-syndrome/).



## Why Early Diagnosis Matters

Seeking medical care early can make a significant difference. An early diagnosis can:

- Help prevent complications
- Reduce long-term damage to the digestive tract
- Improve your quality of life
- Allow you to begin effective treatment sooner



Delaying care may lead to worsening symptoms and more serious health concerns. If you are unsure whether your symptoms are serious, it's always better to ask a healthcare professional.

## When Should I See a Doctor?

### Common Symptoms of IBD

IBD symptoms can vary from person to person. Some people experience mild symptoms at first, while others may have more intense or persistent issues.

#### Common symptoms include:

- Persistent diarrhea
- Abdominal pain or cramping
- Blood in the stool
- Unexplained weight loss
- Fatigue
- Urgency to have a bowel movement
- Feeling that your bowel movement is incomplete

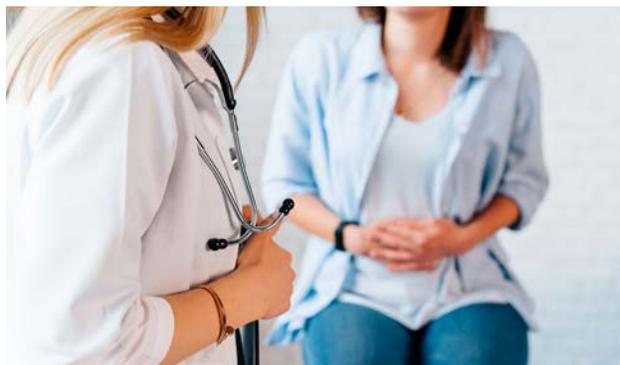
You may also experience fever, loss of appetite or joint pain. There are even some symptoms that may not seem like they're related at all – things like inflammation of the eye or skin rashes – that are actually part of your condition, so it's important that you don't ignore anything.

Also keep in mind that symptoms can come and go, which sometimes makes them harder to identify as part of a larger condition. If your symptoms last more than a few days, recur frequently or interfere with your daily life, it is time to schedule a medical appointment.

### When to Call Your Doctor Immediately

Many patients wait far too long before reaching out for treatment, but there are some symptoms that may require urgent evaluation. Seek immediate medical attention if you experience any of the following:

- Sudden, severe abdominal pain
- Increasing blood in your stool
- Weakness or dizziness
- Signs of dehydration
- High fever



# Tracking Your Symptoms

Keeping track of your symptoms before your appointment can be extremely helpful. A symptom journal allows your doctor to see patterns that may not be obvious during a short office visit.

## Some of the things you'll want to record include:

- When symptoms occur and how often
- The degree of urgency
- Possible triggers
- Stress and emotional levels

**Bring your notes to your appointment** – they can be an enormous help to your doctor in the diagnostic process. To make things as easy as possible, you can get a free, ready-to-use symptom tracker by clicking here.

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

**BOWEL URGENCY SYMPTOM TRACKER**

DATE	URGENCY	# OF EPISODES	TIME OF DAY	POSSIBLE TRIGGERS	ACCIDENT TYPE	NOTES/FEELINGS
#1						
#2						
#3						
#4						
#5						

**Severity Scale (1-10)**  
 1-3: Mild (can usually wait)  
 4-6: Moderate (must find a bathroom soon)  
 7-10: Severe (cannot delay, risk of accident)

**Weekly Reflection**  
 Most common triggers this week: \_\_\_\_\_  
 Average urgency score this week: \_\_\_\_\_  
 Impact on daily life (work, social, emotional): \_\_\_\_\_  
 Am I comfortable talking with my doctor about this? \_\_\_\_\_  
 Questions I have for my doctor: \_\_\_\_\_  
 Do I have outside support or am I on my own to deal with this? \_\_\_\_\_

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# How to Obtain a Referral to a Specialist

Depending on your insurance plan, you may need a formal referral before seeing a specialist.

## Step 1: Know Your Insurance Requirements

- Call the number on your insurance card and ask:
- Do I need a referral to see a gastroenterologist?
  - Is prior authorization required?
  - Which specialists are in-network?
  - What documentation is required from my primary care provider?

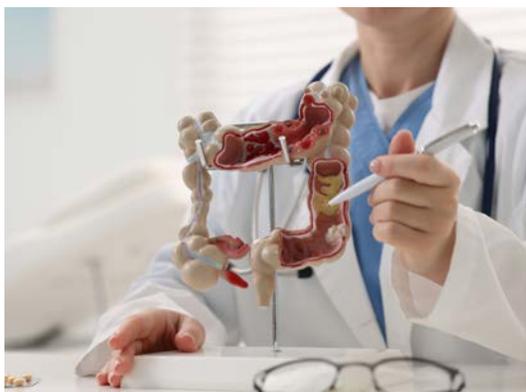
*Taking five minutes to clarify this can prevent weeks of delay.*

## Step 2: Be Direct with Your Primary Care Provider

If symptoms are ongoing or worsening, clearly communicate your concerns. You might say:

- “My symptoms have persisted despite initial treatment. I would like a referral to a gastroenterologist.”
- “Given the blood in my stool and weight loss, I am concerned about inflammatory bowel disease.”

*Advocate respectfully but firmly for specialist evaluation when appropriate.*



## Step 3: Follow Up

After your appointment:

- Confirm the referral was submitted
- Ask how long approval typically takes
- Call your insurance company to confirm receipt
- Contact the GI office to schedule as soon as approval is granted

*Do not assume the system is moving automatically. A quick follow-up call can prevent unnecessary delays.*



## Keeping Organized as Your Appointment Comes Up

A simple system can save time and frustration.

### Create a Personal Medical Folder Including:

- Referral documentation
- Insurance authorizations
- Lab and imaging reports
- Medication history
- Provider contact information

**Pro Tip:** Consider scanning documents or storing them securely in a digital folder for easy access.

### Document Everything, Including:

- Appointment dates
- Phone calls made
- Names of staff spoken to
- Instructions given

**Pro Tip:** If you're told something verbally, repeat it back to confirm understanding. Clear documentation protects you and helps prevent miscommunication.

### Understand what the IBD Diagnostic Process Typically Involves:

- Blood tests to check for inflammation and anemia
- Stool tests to rule out infection and measure inflammatory markers
- Imaging such as CT or MRI
- Colonoscopy with biopsy

**Pro Tip:** Knowing that diagnosis requires multiple steps can help set realistic expectations and reduce anxiety if the process takes time.

For more detailed information about IBD testing, visit NAFC's educational resources at [nafc.org/inflammatory-bowel-disease/](https://nafc.org/inflammatory-bowel-disease/).



## Preparing for Your Appointment

Taking time to prepare can help you feel more confident and ensure you get the most out of your visit.

### What to Bring to Your Appointment

#### Bring the following items to your appointment:

- Your symptom diary or notes.
- Your personal medical folder. If you didn't make one, be sure to have a list of the medications you take.
- A written list of questions and concerns. We suggest a few for you to consider later in this section.
- Information about your family health history. That's important because IBD can run in families. Even if relatives have different digestive conditions, share that information with your doctor.

### Questions to Ask Your Doctor

It is okay to ask direct questions. Clear communication helps you make informed decisions.

#### Consider asking:

- “What conditions might be causing my symptoms?”
- “What tests do you recommend and why?”
- “How do we rule out other causes?”
- “What should I do if my symptoms worsen before my next visit?”

Perhaps most important of all, if you don't understand anything, ask your doctor to explain it in simpler terms.

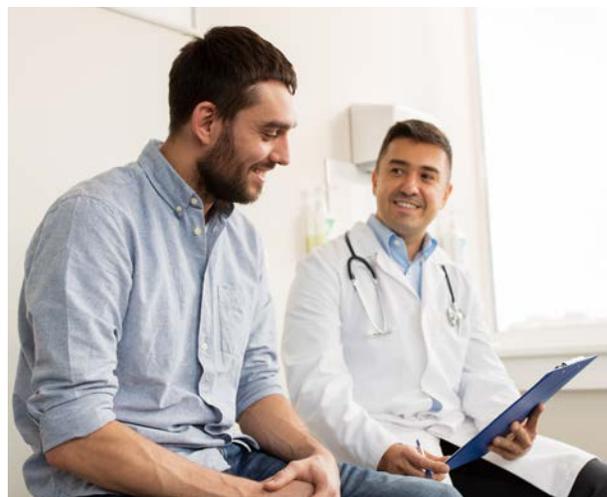
### Tips to Reduce Anxiety

Medical appointments can feel intimidating, especially if you're worried about the results.

To reduce stress:

- Bring a trusted friend or family member for support.
- Write down your questions in advance.
- Ask your doctor to summarize the visit.
- Take notes during the discussion.

*Remember: Your healthcare provider's role is to help you understand your condition and guide your care.*



# What to Expect at the First Doctor Visit

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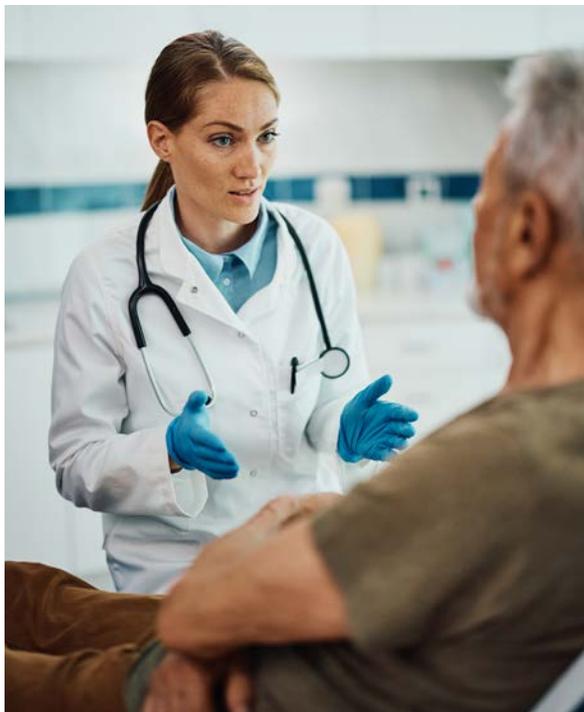
Your first visit will likely focus on gathering information, including:

## Medical History Review

Your doctor will ask detailed questions about:

- Your symptoms
- How long they have been occurring
- Your diet and lifestyle
- Recent travel
- Family medical history

*Be honest and thorough. Even details that seem minor may be helpful.*



## Physical Exam

A physical exam may include:

- An abdominal exam to check for tenderness, bloating or masses
- Listening to bowel sounds
- A rectal exam if needed

*These exams are routine and help your doctor better understand what is happening.*

## Discussion of Possible Next Steps

Your doctor may discuss IBD as a possibility, but they will also consider other conditions such as:

- Irritable bowel syndrome
- Bacterial or viral infections
- Celiac disease
- Food intolerances

*Diagnosing IBD requires multiple steps and careful evaluation.*

# The Diagnostic Process

Diagnosing IBD often takes time. There is no single test that confirms it immediately. Instead, doctors use a combination of blood tests, stool tests, imaging and endoscopic procedures.

## Blood Tests

Blood tests may check for:

- Markers of inflammation such as C-reactive protein and ESR
- Anemia
- Signs of infection

*These tests help rule out other causes and support a possible IBD diagnosis.*

## Stool Tests

Stool samples may be analyzed for:

- Infection such as C. difficile or parasites
- Inflammation markers such as calprotectin and lactoferrin

*These tests help distinguish IBD from infections or other digestive disorders.*

## Imaging Tests

Imaging may include:

- Ultrasound or CT scans to identify inflammation or blockages
- MRI enterography to provide detailed images of the small intestine

*These tests allow doctors to see areas that cannot be viewed during a physical exam.*

## Endoscopic Procedures

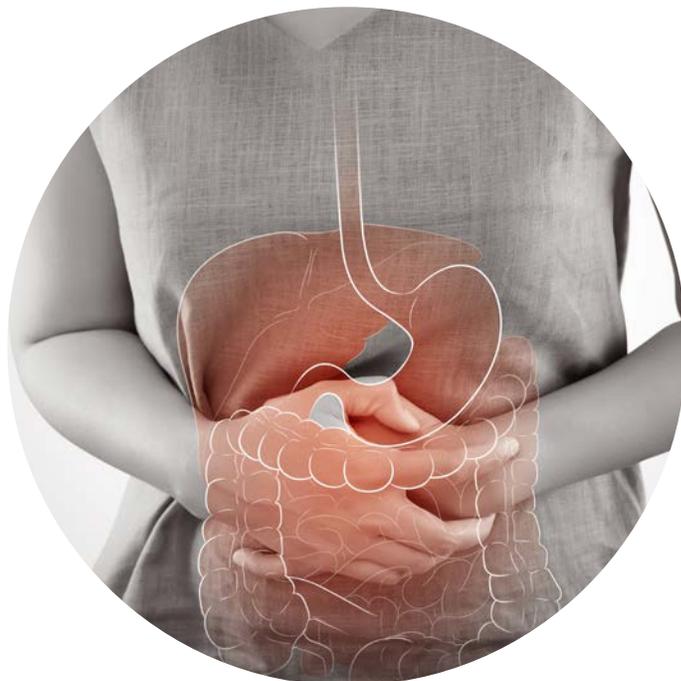
Endoscopy allows doctors to look directly at the digestive tract.

Common procedures include:

- Colonoscopy to examine the colon and take biopsies
- Upper endoscopy if upper gastrointestinal symptoms are present

## Biopsy

During a colonoscopy or endoscopy, small tissue samples may be taken. These biopsies are examined under a microscope to confirm inflammation and help distinguish between Crohn's disease and ulcerative colitis.



## Endoscopic Preparation Tips

Before a colonoscopy, you will need to complete a bowel prep. This involves drinking a prescribed solution that cleans out your colon. Although the process can be uncomfortable, it is essential for clear results.

Most endoscopic procedures involve sedation. You will need someone to drive you home afterward. Recovery is usually quick, and many people resume normal activities the next day. A full list of diagnostic tests can be found at [nafc.org/inflammatory-bowel-disease/](https://nafc.org/inflammatory-bowel-disease/).

## Understanding Your Diagnosis

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### After Test Results

Once testing is complete, your doctor will review the findings with you. This discussion should include:

- What the results mean
- Whether a diagnosis has been confirmed
- What treatment options are available

*Do not hesitate to ask follow-up questions. You deserve to understand your condition fully.*

### Possible Diagnoses

You may be diagnosed with:

- Crohn's disease
- Ulcerative colitis
- Indeterminate colitis, when features overlap

*Each condition has its own treatment approach, but many management strategies are similar.*



## Follow-Up and Treatment Planning

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### What Comes Next

After diagnosis, your care team will discuss:

- Additional testing if needed
- Medication options
- Lifestyle adjustments
- Long-term monitoring plans

*Treatment goals often include reducing inflammation, managing symptoms and preventing complications.*

### Questions to Ask

At this stage, consider asking:

- “What are my treatment options?”
- “How will we monitor my condition over time?”
- “What lifestyle changes should I consider?”

*Understanding your treatment plan helps you stay engaged in your care.*



## Next Steps

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### Know When to Escalate

Contact your healthcare provider immediately if you experience:

- Severe abdominal pain
- Increasing blood in your stool
- Signs of dehydration
- High fever
- Dizziness or weakness

*If symptoms are severe, go to the emergency room.*

### Build a Support System

Navigating the healthcare system is easier with support – not to mention the fact that support reduces stress and helps you make informed decisions. Consider:

- Bringing a trusted person to appointments
- Joining a patient advocacy group
- Connecting with [NAFC.org](https://www.nafc.org) for educational tools
- Sharing with and learning from other patients in the NAFC message boards ([sign up here](#))

### Advocate for Yourself

You are the most important member of your healthcare team. It's always appropriate to:

- Ask questions
- Request clarification
- Seek specialist care
- Pursue a second opinion
- Follow up when delays occur

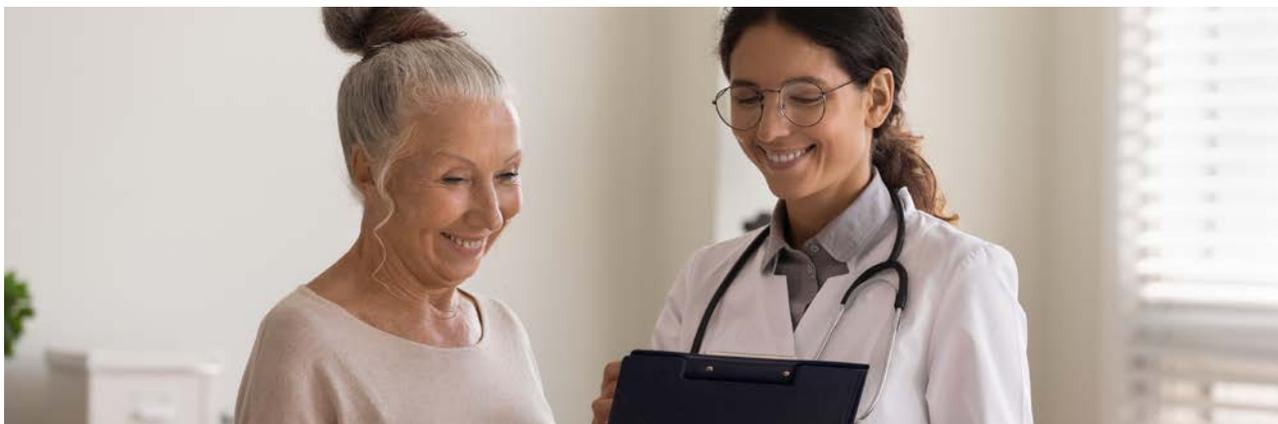
Confidence does not mean confrontation. It means being informed, organized and proactive.

## Final Reminder

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The path to an IBD diagnosis may take time, but persistence and preparation can help reduce unnecessary delays. Stay organized, communicate clearly and use trusted resources such as NAFC to guide you along the way.

For free educational tools, symptom trackers and other resources, visit [NAFC.org/bowelurgency](https://www.nafc.org/bowelurgency) today.



## Patient Support and Resources

### Support Systems

Living with IBD can be challenging. Support makes a difference. Consider connecting with:

- Patient advocacy organizations like NAFC
- The online community of patients on NAFC's message boards ([click here](#))
- Local support groups

*Speaking with others who understand your experience can reduce feelings of isolation.*

### Educational Resources

Reliable information is essential. Use trusted websites such as NAFC for:

- Educational articles
- Downloadable symptom trackers
- Meal planning tools
- Updates on treatment advances

*Avoid relying solely on social media or unverified sources.*

### Symptom Tracking

Keeping tabs on your symptoms isn't only helpful leading up to your diagnosis – it can also help you understand how you respond to treatment. For your free downloadable symptom tracker, [click here](#).

### Doctor Discussion Guide

It's not always easy to remember what you wanted to talk with your doctor about in your appointment, so NAFC has prepared a free downloadable discussion guide to ensure that your next visit is as productive as possible. [Click here](#) for yours now.

### You Are Not Alone

Seeking a diagnosis can feel uncertain, but taking the first step is empowering. Early action, informed conversations and trusted resources can help you move forward with clarity and confidence.

For more information, free resources and patient-centered support, visit [nafc.org](https://nafc.org).

Visit [NAFC.org/inflammatory-bowel-disease/](https://nafc.org/inflammatory-bowel-disease/) today for access to all of these and more.



**Find relief.  
Take Control.  
Start here.** 