



**HANDLING
THE HARD
QUESTIONS:**

WHAT OUR PATIENTS ARE ASKING US ABOUT CROHN'S DISEASE



THE PURPOSE OF THIS DOCUMENT

Patients with newly diagnosed Crohn’s disease often ask questions about their disease and how it can best be managed. It is important for gastroenterologists and other clinicians involved in the management of Crohn’s disease to properly and effectively communicate appropriate responses to these questions. This pocket guide includes a

brief summary of evidence surrounding some of the most common – and challenging – questions that gastroenterologists and other clinicians are likely to face from their patients with Crohn’s disease. We hope you find this guide useful for your professional development.

CONTENTS

What is Crohn’s disease, and how did I get it?	3
How do you know I have Crohn’s disease and not something else?	6
How will my Crohn’s disease be treated?	9
How will I know if I’m having a Crohn’s disease flare?	11
What are the long-term effects of Crohn’s disease?	14
Should I change my diet or lifestyle because I have Crohn’s disease?	16
Will my Crohn’s disease ever be cured?	18
How will you decide what medications I need? Will I need surgery?	19
What other doctors or specialists will help manage my Crohn’s disease?	23



WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

WHAT IS CROHN'S DISEASE, AND HOW DID I GET IT?

Crohn's disease is a lifelong condition of the digestive tract that causes inflammation. It is closely related to ulcerative colitis. Together, these conditions are referred to as **inflammatory bowel disease**.¹

Approximately 500,000 people in the United States have Crohn's disease. It is most often diagnosed in people between ages 20 and 30 years, although it can develop in patients of any age. Crohn's disease is equally as common in men and women.^{1,2}

While Crohn's disease can affect any part of the digestive tract, the small and large intestines are the most commonly affected areas. Crohn's disease can appear in patches, affecting some areas of the gastrointestinal tract but not others. For example, in some patients, an area at the end of the small bowel may be affected. Others may have

their condition affect their lower colon area.^{1,3} Although we don't know exactly what causes Crohn's disease, genetics likely plays a part. Some people with Crohn's disease have a close relative with the condition. There are other potential contributing factors as well, including your immune system (which is not "turning off" inflammation), changes in the gut microbiome, and environmental factors such as cigarette smoking.^{1,4,5} If you smoke cigarettes, our practice can connect you with resources that can help you quit.^{1,4,6}

Symptoms of Crohn's disease can vary. Often, these symptoms come and go over time. Individuals with Crohn's disease can have flares of severe symptoms. They can also have periods with no symptoms, which is called remission.^{1,3}

WHAT IS CROHN'S DISEASE, AND HOW DID I GET IT?

Possible symptoms of Crohn's disease include the following:¹⁻⁶

- Abdominal pain
- Diarrhea and/or constipation
- Blood in your stool
- Weight loss
- Fever
- Fatigue
- Poor appetite
- Mouth sores

Symptoms of Crohn's disease usually develop slowly. In fact, many patients do not recognize their symptoms as being indicative of Crohn's disease, and it may take up to a year before getting properly diagnosed. It is

important to recognize symptoms early so that your Crohn's disease does not progress to a more severe state. In some individuals, Crohn's disease can develop rapidly and may have a more challenging disease course that requires more advanced treatment compared to people with milder disease.⁴ However, this is something that is difficult to predict, so we'll need to monitor your disease as a team.

It's important to know that having Crohn's disease isn't your fault. You didn't do anything to cause this to happen. It's also important to know there are treatments to help manage your symptoms and achieve remission. Taking care of yourself and working closely with our team can help you manage your Crohn's disease over time.^{1,3,4}

WHAT IS CROHN'S DISEASE, AND HOW DID I GET IT?

WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

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WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

HOW DO YOU KNOW I HAVE CROHN'S DISEASE AND NOT SOMETHING ELSE?

If you have symptoms of Crohn's disease, our team may order tests to help make a definitive diagnosis. Other diseases that can have similar symptoms to Crohn's disease include the following:

- **Ulcerative colitis:** People with ulcerative colitis can also have abdominal pain, diarrhea, and blood in their stool. Imaging or colonoscopy is often needed to tell the difference between ulcerative colitis and Crohn's disease.¹
- **Irritable bowel syndrome:** People with irritable bowel syndrome (IBS) can have abdominal pain and diarrhea, but they do not usually have blood in their stool. Certain tests can help tell the difference between IBS and Crohn's disease.²

- **Celiac disease:** People with celiac disease are unable to tolerate gluten in their diet. They can present with weight loss, abdominal pain, and diarrhea. Testing is also sometimes required to tell the difference between celiac disease and Crohn's disease.³

While blood tests and imaging studies can be used to help diagnose Crohn's disease, there is no one definitive test that can determine whether or not you have the condition. Typically, a combination of testing is needed (see Table).^{4,5}

HOW DO YOU KNOW I HAVE CROHN'S DISEASE AND NOT SOMETHING ELSE?

Diagnostic Tests for Crohn's Disease⁴⁻⁸

Test	Purpose
Blood tests	A blood test may be ordered to look for signs of inflammation and infection. Blood tests can also give information about your nutritional status and determine if you have anemia.
Stool tests	Testing can be done on a stool sample to check for infection, blood, or inflammation
Imaging	You may have a CT scan or MRI of your abdomen to get a picture of your intestines and look for inflammation
Upper endoscopy	An upper endoscopy is a procedure where a camera attached to a thin tube is inserted through your mouth and used to look at your esophagus, stomach, and small intestines. Small pieces of tissue can be collected during the procedure, which is called a biopsy.
Colonoscopy	A colonoscopy is similar to an endoscopy. In this case, a small camera attached to a tube is inserted into your rectum to look at your large and small intestines. Tissue samples (biopsies) are also taken during a colonoscopy that can later be viewed under a microscope.
Transabdominal ultrasound	Transabdominal ultrasound is a newer, noninvasive procedure that can detect bowel wall thickening and inflammation. It is used to monitor transmural healing in patients with inflammatory bowel disease, including Crohn's disease.

HOW DO YOU KNOW I HAVE CROHN'S DISEASE AND NOT SOMETHING ELSE?

WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

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HOW WILL MY CROHN'S DISEASE BE TREATED?

The treatment of Crohn's disease varies from person to person based on their symptoms and severity of their condition. Here are some of the options that you may be offered.¹

Medications

There are many types of medications that are used to treat Crohn's disease. Some may be used for a short time, such as antibiotics if you have an infection. Other medications may be used for longer to treat inflammation and symptoms of Crohn's disease. Some of these medications are taken by mouth, some are given intravenously, and some are given by injection.¹⁻³

Diet

Dietary changes may be part of your Crohn's disease treatment plan, especially when you are in a flare or have narrowing in your

GI tract from scar tissue (this is called a "stricture"). In these instances, a low-residue diet (similar to a low-fiber diet) may be suggested. While many different diets have been studied to treat the inflammation found in people with Crohn's disease, none has yet been found to be consistently effective. Some people who lose weight or have poor nutritional status because of Crohn's disease may need a special diet, but this is not common.^{1,4}

Surgery

Most people with Crohn's disease will need surgery at some point in their life. This may be because they have a complication of their disease, such as an infection, stricture, or fistula, or because medical treatment doesn't work for them.^{1,5}

HOW WILL MY CROHN'S DISEASE BE TREATED?

Talking with our team about your treatment goals is an important first step in your Crohn's disease journey. We'll schedule frequent appointments, especially as you are starting treatment, to choose a personalized

regimen for you and then check on your symptoms.⁶ Remember that your treatment plan will likely need to change over time, so it is critical to let our team know if you are having any new or worsening symptoms.

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WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

HOW WILL I KNOW IF I'M HAVING A CROHN'S DISEASE FLARE?

The nature of Crohn's disease is that your symptoms will come and go throughout your lifetime. This can happen even if you are taking your medication(s) as prescribed. When your disease symptoms worsen, this is called a **flare**.¹

There is no way to predict when a flare is going to occur. We don't know what triggers a flare or why they happen. Importantly, by the time you notice your symptoms, changes may have already been taking place in your digestive tract for some time. In other words, you can't always tell what's going on in your gut by how you feel.

Here are a few other important points regarding Crohn's disease flares:

- Flares may be short or long in duration, lasting from a few days to a few weeks
- You may have mild or severe symptoms during a flare

- Flares can sometimes be treated with medication at home, while some may require hospitalization, especially if you are dehydrated or develop a fever that is accompanied by infection

So how will you know if you are having a flare of your disease? Pay attention to your symptoms. If you have some or all of the symptoms that were present when you were initially diagnosed with Crohn's disease, this is a sign you are likely having a flare. Specific symptoms of a flare include the following:^{1,2}

- Diarrhea
- Fatigue
- Loss of appetite
- Weight loss
- Abdominal pain
- Fever

Although we don't know exactly what triggers a flare of Crohn's disease, there are certain factors that may increase the chances of a flare (see Table).^{3,4} Above all, the most important thing is to call a member of our

HOW WILL I KNOW IF I'M HAVING A CROHN'S DISEASE FLARE?

WHAT OUR PATIENTS ARE ASKING US ABOUT CROHN'S DISEASE

team right away if you think you are having a flare. We can perform testing to determine if you are having a flare. The sooner a flare

is identified, the faster you can be treated to help prevent further complications.

Risk Factors for a Crohn's Disease Flare

Risk Factor	Special Notes
Missing medication doses	It's critical to always take your medication exactly as prescribed. If you are having side effects or run into trouble getting your medication, let a member of our team know right away.
NSAIDs	This class of medications used to treat pain, such as aspirin and ibuprofen, may worsen Crohn's symptoms. If you need medicine for general pain symptoms, please reach out to a member of our team before taking anything.
Antibiotics	While you may sometimes need antibiotics to treat an infection, their use can also be associated with the development of a Crohn's disease flare. Again, make sure to talk to a member of our team if you need antibiotics so that we can be sure that the benefits outweigh the risks.
Smoking	Smoking cigarettes can trigger a flare in Crohn's disease. It's best to quit smoking to reduce your risk.
Stress	High levels of stress may also play a part in disease flares. Of course, no one is without stress. However, it's important for people with Crohn's disease to learn techniques for coping with stress as best as possible.
Food	While there is no special diet to cure Crohn's disease, some people find that certain foods are triggers for a disease flare. If you think this is the case for you, you can keep a food diary to record what you eat.

HOW WILL I KNOW IF I'M HAVING A CROHN'S DISEASE FLARE?

WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

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WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

WHAT ARE THE LONG-TERM EFFECTS OF CROHN'S DISEASE?

Crohn's disease is typically a chronic (ie, lifelong) disease. While symptoms of your Crohn's disease may come and go over time, there are some specific complications for which individuals with Crohn's disease are at greater risk (see Table).¹⁻³

In addition, some people also have what are called **extraintestinal complications** of Crohn's disease. These are certain diseases or conditions that happen more often in people with Crohn's disease. They sometimes get better as your Crohn's disease symptoms get better.^{4,5} These complications may include the following:

- **Anemia:** Low red blood cell count
- **Bones:** Osteoporosis
- **Eyes:** Inflammatory conditions of the eye such as uveitis
- **Joints:** Arthritis is common in patients with Crohn's disease and can affect almost any joint
- **Kidneys:** Kidney stones, inflammation, or blockage
- **Liver:** Liver inflammation and other forms of liver damage
- **Skin:** Multiple types of skin conditions can occur in individuals with Crohn's disease

Common Crohn's Disease Complications

Complication	Explanation
Abscess	Infection of the skin or in the abdomen, often requiring surgical drainage
Anal fissure	Small tear around the anus that can cause pain or infection
Blood clot	People with Crohn's disease have a higher risk of having a blood clot than people without Crohn's disease
Bowel obstruction	Crohn's disease can cause the intestines to narrow, which may cause a blockage. Surgery is required to treat a bowel obstruction.
Colon cancer	If you have Crohn's disease that affects your large intestine, you may have an increased risk for colon cancer
Fistula	A fistula is an abnormal connection that forms between your intestines and your skin, or between your intestines and another organ. These connections can become infected and require treatment.
Malnutrition	People with Crohn's disease who have diarrhea may not be able to absorb all of the nutrients they need from the foods they eat. This can lead to issues with nutrition, such as iron deficiency, that may require consumption of daily vitamins.
Medication risks	Nearly all medications have some risks associated with them. When discussing your treatment plan, we'll be sure to discuss any potential risks of any medications that are prescribed.
Ulcers	Ulcers are open sores that can happen anywhere in the digestive tract of someone with Crohn's disease

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WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

SHOULD I CHANGE MY DIET OR LIFESTYLE BECAUSE I HAVE CROHN'S DISEASE?

Since Crohn's disease affects your digestive tract, you may wonder if you should change your diet or lifestyle to help your symptoms. Despite considerable research, it is unfortunately not a question with a simple answer. Nonetheless, here are some diet and lifestyle considerations we can explore and discuss.

Diet

The issue of what to eat when you have Crohn's disease is something researchers have been studying for a long time. The bottom line is that no one has found a diet that is best for everyone with Crohn's disease. However, there are *some* diets that work for *some* people. For instance, if you are in a flare or have a stricture, a low-residue diet (similar to a low-fiber diet) may be suggested. There are also ongoing studies about diet and Crohn's disease that may lead to more answers in the future. Since different people with Crohn's disease have different dietary needs, we'll talk about any dietary adjustments that might be right

for you. Our team might also refer you to a dietician for more information.^{1,2}

One important note: Obesity can be associated with having worse Crohn's disease symptoms, so one goal for patients with Crohn's disease should be to maintain a healthy weight.³

Smoking

Since smoking can trigger a Crohn's disease flare, it's best to quit smoking. Our team can help, perhaps by prescribing nicotine patches or gum, or by directing you to other resources.^{3,4}

Exercise

Exercise is safe for most patients with Crohn's disease. It may even decrease your risk of having a flare, so keeping up your exercise routine or starting a new one is a good idea. However, when adjusting or starting a new routine, check with a member of our team first to make sure your plan is safe for you.³

SHOULD I CHANGE MY DIET OR LIFESTYLE BECAUSE I HAVE CROHN'S DISEASE?

Sleep

Poor sleep is a risk factor for a Crohn's disease flare. It's important to get at least 7 hours of sleep per night. Going to bed and waking up at the same time every day may help you get into a regular routine. Talk with a member of our team if you are having trouble sleeping.³

Stress

It is not well understood how much stress plays a role in Crohn's disease symptoms. However, people with Crohn's disease report more stress than those without the disease. Managing stress is important for everyone, and we may recommend that you work with a therapist to develop techniques for coping with stress.³

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WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

WILL MY CROHN'S DISEASE EVER BE CURED?

Crohn's disease is a lifelong condition, meaning that while there are medical and surgical ways to treat the symptoms, it cannot currently be cured. You can, however, experience periods of no symptoms and achieve disease remission. It's important to know that people with Crohn's disease are able to live long lives and participate in the same activities as people without Crohn's disease.^{1,2}

One way you can help make living with Crohn's disease easier is to take good care of yourself. Eat a healthy diet, exercise, and get enough sleep. It is especially important to make sure you take any medications your doctor has prescribed exactly as instructed.

Missing doses can lead to a flare. If you are having trouble getting your medication, let a member of our team know as soon as possible.^{1,2}

It is also important to talk to our team about your treatment goals. We'll work together using shared decision-making techniques to choose a personalized treatment option that best meets your needs.³

The good news is that there is a lot of ongoing research about new treatments for Crohn's disease. Many new treatments have been discovered in recent years, and hopefully even more will become available in the near future.⁴

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HOW WILL YOU DECIDE WHAT MEDICATIONS I NEED? WILL I NEED SURGERY?

The choice of medication for your Crohn's disease depends on many factors. These can include the severity of your disease, your treatment goals, your medication history, and other components. Regardless of the treatment regimen we agree upon, the main goals of treatment for Crohn's disease are to get your disease into remission and keep it there.¹

It is likely that you will need different medications over the course of your life to treat your Crohn's disease. You may also need more than one medication at a time. Medications for Crohn's disease can come in oral, intravenous, injection, or rectal forms.

The following types of medications are most commonly used to treat Crohn's disease:¹⁻⁵

Aminosalicylates: These drugs reduce inflammation, but do not act on the immune system.

Antibiotics: People with Crohn's disease may develop certain types of infections in their digestive tract that need to be treated with antibiotics.

Antidiarrheal medications: When you are experiencing diarrhea, we may recommend an antidiarrheal medication to help.

Biologics: Biologics are a category of medication that work by calming down the response of your immune system, which is overactive in people with Crohn's disease (see Table).⁶⁻¹²

Corticosteroids: Corticosteroids such as prednisone work quickly in acute situations to calm inflammation and get your disease under control. They are typically used only for short-term treatment because of their side effects.

HOW WILL YOU DECIDE WHAT MEDICATIONS I NEED? WILL I NEED SURGERY?

WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

Immunomodulators: Similar to biologics, immunomodulators also work by calming down the response of the immune system. Even when taken regularly as prescribed, immunomodulators can take 3 to 6 months or longer to improve symptoms.

In addition to these medical interventions, patients with Crohn's disease may also sometimes need surgery. Urgent procedures are necessary if you develop a serious complication such as a bowel obstruction. Surgery may also be an option to treat your Crohn's disease if medication does not work and/or your quality of life is poor. The choice whether to have surgery (or not) will be a shared decision

between you, members of our team, and your surgeon.^{2,4}

While all of these medications may cause side effects, we can reduce your risk with proper pre-treatment, testing, and vaccinations, as well as ongoing monitoring. Many of the medications we use to treat Crohn's disease are also approved to treat other autoimmune diseases such as psoriasis and psoriatic arthritis, so we have a long track record of knowing what the specific medication risks might be. It is important to recognize that your greatest health risk is not properly treating your Crohn's disease.

**HOW
WILL YOU
DECIDE WHAT
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WILL I NEED
SURGERY?**

Biologic Treatment Options for Crohn's Disease

Medication	Indication(s)
Adalimumab	Treatment of moderately to severely active Crohn's disease in adult patients
Certolizumab	Reducing signs and symptoms of Crohn's disease and maintaining clinical response in adult patients with moderately to severely active Crohn's disease who have had an inadequate response to conventional therapy
Infliximab	<ol style="list-style-type: none"> 1. Reducing signs and symptoms and inducing and maintaining clinical remission in adult patients with moderately to severely active Crohn's disease who have had an inadequate response to conventional therapy 2. Reducing the number of draining enterocutaneous and rectovaginal fistulas and maintaining fistula closure in adult patients with fistulizing disease
Natalizumab	Inducing and maintaining clinical response and remission in adult patients with moderately to severely active Crohn's disease with evidence of inflammation who have had an inadequate response to, or are unable to tolerate, conventional Crohn's disease therapies and inhibitors of TNF- α
Risankizumab	Moderately to severely active Crohn's disease in adults
Ustekinumab	Moderately to severely active Crohn's disease in adults
Vedolizumab	Moderately to severely active Crohn's disease in adults

HOW WILL YOU DECIDE WHAT MEDICATIONS I NEED? WILL I NEED SURGERY?

WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

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WHAT OUR PATIENTS
ARE ASKING US ABOUT
CROHN'S DISEASE

WHAT DOCTORS OR SPECIALISTS WILL HELP MANAGE MY CROHN'S DISEASE?

Getting the best care for your Crohn's disease may mean that you need to see a few different specialists over the years. These can include the following:

Gastroenterologist: Crohn's disease is usually mainly managed by a gastroenterologist. This is a doctor who specializes in diseases of the digestive tract. Sometimes they are also called "GI doctors." You will have regular appointments with your gastroenterologist to help guide medical treatment for your Crohn's disease. Gastroenterologists may also have nurses, nurse practitioners, and physician associates who work with them to help care for you.¹

Surgeon: Since many people with Crohn's disease will need surgery at some point, a surgeon may eventually be part of your care team.²

Primary care doctor: Even though you will have specialized clinicians to treat your Crohn's disease, it's important to still see

your primary care clinician. You will need vaccines and other screening tests that only your primary care clinician can prescribe.²

Dietician: Since treating your Crohn's disease may involve some changes to your diet, you may need to meet with a dietician. Registered dietitians have special training to help you choose the best diet for your needs.²

Psychiatrist: It's common for people with Crohn's disease to develop anxiety or depression. If this happens to you, it's important to let our team know. We may refer you to a psychiatrist for treatment.³

Therapist or counselor: Dealing with Crohn's disease can be stressful, and talking to a trained therapist or counselor can help. Therapists can work with you to develop coping techniques and also help with symptoms of anxiety or depression.³

You may also need to see other types of specialists depending on your specific

WHAT DOCTORS OR SPECIALISTS WILL HELP MANAGE MY CROHN'S DISEASE?

Crohn's disease symptoms. For example, if you have arthritis, you may need to see a rheumatologist.²

Some people with Crohn's disease also find it helpful to join a patient support group.

This allows you to meet other people with Crohn's disease, share your experiences with each other, and offer each other support. The Crohn's and Colitis Foundation is a good place to find a local support group.

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