Understanding how damaging inflammation could play a role in the symptoms of Crohn’s disease and ulcerative colitis
My name is Dr. Corey Siegel and thank you for checking in with me. I am a gastroenterologist and the Director of the Inflammatory Bowel Disease Center at Dartmouth-Hitchcock and the Geisel School of Medicine. For over 10 years, I’ve helped to treat many patients living with Crohn’s disease or ulcerative colitis. And in all my years of experience, I’ve come to believe that the best patients are educated patients. That’s why I am so glad you have taken the time to download and read this Guidebook. In these pages you will be provided with a look at the ins and outs of inflammation, a roadmap to remission, and a discussion guide to share with your doctor.
If you have Crohn’s disease or ulcerative colitis, you know all too well the challenges you face on a regular basis. Sometimes those challenges are day-to-day; sometimes they are hour-to-hour. Much of your time may be spent trying to work around your symptoms. Trying to figure out ways you can manage your condition. But ignoring or pushing through your symptoms can come with a price. The inflammation that could be causing your symptoms, left unchecked, may lead to damage in your gastrointestinal (GI) tract. And that’s not something you can work around. It needs to be confronted. And it can be. This book has been designed to help.

Expert Advice is a personal guidebook to help you understand how damaging inflammation could play a role in your symptoms. This material is not meant to alarm. Rather, it’s meant to arm you with information you may need. As you will learn, even if you are taking medication, occasional symptoms need to be discussed with your doctor. They are signs of active disease and, quite possibly, damaging inflammation. Along with helping you determine why you need to talk to your doctor, we will help provide you with the information to discuss when you do.

Throughout the Guidebook, you will see this icon. It is an indicator you’ve reached an interactive section. It’s a quick and easy way to link to helpful information within the PDF.
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Living with Crohn’s disease or ulcerative colitis may mean living with symptoms at some point. And while you are certainly familiar with what your symptoms feel like, we wanted to provide some additional information and insight that may help you better understand where they come from and what they are trying to tell you. Knowing the role that inflammation plays in your symptoms could help when checking up with your doctor. Together you and your doctor can work towards controlling the inflammation, with a goal of achieving remission (few or no symptoms) and maintaining remission (keeping symptoms from returning for longer periods of time).

THIS CHAPTER IS BROKEN DOWN INTO 3 SECTIONS:

1. THE SOURCE OF YOUR SYMPTOMS
2. WHAT CAN TRIGGER YOUR SYMPTOMS
3. WHAT ACTIVE INFLAMMATION COULD LEAD TO

ALL YOU NEED TO DO IS:

CHECK IN WITH YOURSELF AND ASSESS HOW YOU’RE DOING BY COMPLETING THE DOCTOR DISCUSSION GUIDE. SIMPLY FILL OUT A FEW QUESTIONS TO GET STARTED.

CHECK UP WITH YOUR DOCTOR AFTER YOU’VE GONE THROUGH THE DOCTOR DISCUSSION GUIDE AND SHARE YOUR RESULTS WITH HIM OR HER.

Through this Guidebook and Doctor Discussion Guide, you can better understand how damaging inflammation plays a role in your Crohn’s disease or ulcerative colitis symptoms. Remember, when checking out this Guidebook, it’s always important to check up with your doctor and get his or her expert opinion on the appropriate next steps for your treatment.
Both Crohn’s disease and ulcerative colitis are ongoing inflammatory bowel diseases, also known as IBD. As the name suggests, these conditions stem from inflammation, which can be the source of your symptoms. If you have Crohn’s disease or ulcerative colitis, you may go through periods when your disease is quiet and few or no symptoms are present.

However, these periods will likely alternate with times when the disease is active and you do experience symptoms. Those symptoms may be the result of inflammation becoming active again. In people living with Crohn's disease, that inflammation can occur anywhere within the gastrointestinal (GI) tract. For those with ulcerative colitis, the inflammation takes place only in the large intestine, which includes both the colon and rectum. That's why, even if you are taking medication, occasional symptoms need to be discussed with your doctor at all of your check-ups. They may be a sign of an active disease and potentially damaging inflammation.

The symptoms of both Crohn’s disease and ulcerative colitis can be unpredictable. They may come on suddenly—without warning. They may change in severity or change altogether. You may go through long periods of remission with few or no symptoms and then, of course, have periods of flare-ups. It’s because of this unpredictability that it’s important to regularly check in on how you’re feeling and what symptoms you may be experiencing, and consistently check up with your doctor to get his or her expert opinion and insight.

### Symptoms of Crohn’s disease

Symptoms of Crohn’s disease range from mild to severe, varying widely from person to person. They include frequent diarrhea, abdominal pain or cramping, rectal bleeding, fatigue, weight loss, reduced appetite, and fever.

### Symptoms of ulcerative colitis

Symptoms of ulcerative colitis are frequent diarrhea, abdominal pain or discomfort, blood or pus in stool, weight loss, reduced appetite, tenesmus—a sudden and constant feeling that you have to move your bowels, and fever. Though not often thought of as symptoms of ulcerative colitis, fever and fatigue have been shown to occur.

Even if you are taking medication, occasional symptoms may be a sign of active disease and potentially damaging inflammation. Don’t forget to check out the Doctor Discussion Guide, the third chapter in this Guidebook, for a list of questions to ask yourself and then take with you to your next doctor check-up.
As mentioned earlier, both Crohn’s disease and ulcerative colitis are chronic (ongoing) diseases related to inflammation. There is no evidence that the following triggers can cause Crohn’s disease or ulcerative colitis. In both Crohn’s disease and ulcerative colitis, inflammation may be present even when you are not experiencing symptoms. Regardless, it’s important you try to avoid triggers that could bring about or worsen your symptoms. But remember, symptoms can also return and occur even without a specific trigger.

So, what exactly is a trigger?

If you are living with inflammation associated with Crohn’s disease or ulcerative colitis, triggers are certain factors that could aggravate your symptoms. There is no evidence that the following triggers cause Crohn’s disease or ulcerative colitis. Triggers are different for different people. That’s why it’s important to check up with your doctor, work together to understand how triggers can influence your symptoms, and develop a plan to help avoid your triggers.

**STRESS**

Stress may not be a direct trigger for Crohn’s disease or ulcerative colitis, but it certainly can make you feel worse. And while you’ll never be able to rid your life of stressful situations, it is possible to change your reaction to them so that your stressors don’t further aggravate your symptoms.
Missed Medications and Incorrect Dosing

If you have been diagnosed with Crohn’s disease or ulcerative colitis and are taking medication on a regular basis, it’s important you take your medication exactly as prescribed by your doctor, even if you’re not currently experiencing symptoms. Taking your medication can be difficult to maintain over the long term. However, missing doses can lead to a worsening of symptoms. It’s important to let your doctor know right away if you have not taken your medication as prescribed.

Smoking

Cigarette smoking not only raises the risk of actually developing Crohn’s disease, but for people who already have the disease, it can actually trigger flares. Ulcerative colitis is a bit different. It tends to occur primarily in nonsmokers and ex-smokers. In people with ulcerative colitis, smoking withdrawal can actually cause the return of symptoms. It is unclear why this is so. However, smoking carries many health risks including lung cancer and heart disease. If you do currently smoke, please ask your doctor for advice on how you can stop safely.

Nonsteroidal Anti-inflammatory and Antibiotic Drugs

Some commonly used medications may lead to flares. For example, nonsteroidal anti-inflammatory drugs (NSAIDs), which include aspirin, naproxen, and ibuprofen are possible triggers for flares. Antibiotics are good for treating bacterial infections, but they also alter the bacteria that normally live in the intestine. Changes in the balance of these bacteria could cause diarrhea or may lead to excessive growth of a specific bacteria that can cause inflammation. It’s important to let your doctor know if you notice changes in your symptoms while taking any medicine.

Food

Crohn’s disease and ulcerative colitis are not caused by eating any particular food. However, once you have the disease, your diet can certainly impact your symptoms and food triggers can vary from person to person. In general, it’s best to avoid greasy and fried foods, which can cause gas and diarrhea. For some people, foods high in fiber, such as fruits and vegetables and whole grains, can be problematic. Alcohol can also be associated with flare-ups. If a particular food causes problems, talk to your doctor or dietitian before eliminating it from your diet. And if a food does not bother you, then it’s probably okay to eat.
If you are treating your Crohn’s disease or ulcerative colitis, even occasional symptoms are signs that your disease may not be under control. And that may be a sign that you have damaging inflammation. If the inflammation continues over time, potential complications may occur.

Crohn’s disease may affect any part of the gastrointestinal (GI) tract, including the small intestine, large intestine (colon and rectum), stomach, esophagus, or mouth. Long-standing inflammation impairs the ability of these organs to properly function. It can cause the walls of the digestive tract to thicken or form scar tissue, which can lead to blockages. Inflammation in the small intestine can interfere with absorption of nutrients from the intestines into the blood stream. Ulcers can form in the inside wall of the intestines or anywhere along the digestive tract. These ulcers can extend through the entire thickness of the bowel wall and form a tunnel to another part of the intestine or another organ, such as the bladder, stomach, or vagina, or to the skin surface. These tunnels are called fistulas.

Unlike Crohn’s disease, which can affect any part of the gastrointestinal (GI) tract, ulcerative colitis is limited to the large intestine, which includes the colon and the rectum. Long-standing inflammation in the innermost layer of the lining of the colon interferes with its ability to absorb water, resulting in loose stools (diarrhea). Inflammation can also cause small sores (ulcers) to form in the inner lining of the colon and rectum. These can bleed, resulting in bloody stools. Blood loss can eventually lead to anemia (a deficiency in healthy red blood cells) if it proceeds unchecked. These ulcers can also produce pus, which can be passed in stools. Additionally, inflammation causes the colon to empty frequently and/or urgently.
People with Crohn’s disease or ulcerative colitis may have difficulty maintaining healthy nutrition for a variety of reasons, including disease symptoms and complications. Inflammation in the small intestine of a person with Crohn’s disease can interfere with the absorption of nutrients. This is called malabsorption. The degree of malabsorption depends on how much of the small intestine is affected by Crohn’s disease, whether the disease is active, and if any portion of the intestine has been surgically removed. Patients with ulcerative colitis may experience weight loss and anemia due to severe diarrhea and blood loss.

People with Crohn’s disease and ulcerative colitis are also at a higher risk for developing colorectal cancer (CRC) than the general population, which is why it’s important to recognize its signs and symptoms—and why regular screenings and early detection are crucial.

Active inflammation can result in complications or uncontrollable symptoms that may benefit from surgery. Surgery may be performed to clear an intestinal blockage, repair a perforation (a hole in the bowel wall caused by chronic inflammation), bleeding, abscess (a pus-filled area caused by infection), damage to the intestines, or treat symptoms that have not been controlled. In some cases people may opt to undergo surgery to remove all or part of their intestine because their medications are no longer working and/or have uncontrollable and unbearable symptoms.
In the previous chapter, we provided information about how the symptoms of Crohn’s disease and ulcerative colitis may be linked to damaging inflammation. Now we’d like to offer some tips on how you and your doctor can work together to effectively take care of inflammation and treat your symptoms.

**CHAPTER 2: ROADMAP TO REMISSION**

In the previous chapter, we provided information about how the symptoms of Crohn’s disease and ulcerative colitis may be linked to damaging inflammation. Now we’d like to offer some tips on how you and your doctor can work together to effectively take care of inflammation and treat your symptoms.

**THIS CHAPTER IS BROKEN DOWN INTO 2 SECTIONS:**

1. TREATMENT GOALS
2. TREATMENT OPTIONS
When you were first diagnosed with Crohn’s disease or ulcerative colitis, perhaps you imagined a future compromised by ongoing symptoms. Now it’s weeks, months, or years later, and you’ve figured out ways to deal with your symptoms. Perhaps you believe that there’s no getting around, or avoiding, having symptoms be part of your life. We hope to change that belief by providing you with the information you need to help you and your doctor create an effective treatment plan that meets your expectations.

Whether you have Crohn’s disease or ulcerative colitis, you shouldn’t have to just cope with ongoing symptoms. **Experts believe that whether you have Crohn’s disease or ulcerative colitis, the goals for treatment are to achieve and maintain remission.**

When you are open and honest with your doctors, these goals may be within reach. It’s also important to make sure you’re seeing the right doctor. If you are looking for a doctor or thinking about changing doctors, here are a few points you should be considering:

Ideally, your gastroenterologist, or gastro, should specialize in Crohn’s disease or ulcerative colitis.

### IT IS WORTH FINDING A GASTROENTEROLOGIST WHO:

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<td>SETS GOALS FOR YOUR TREATMENT</td>
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Your doctor or gastroenterologist should be asking you for details about your symptoms. **Each patient is different and so are his or her symptoms.**

Your doctor should recognize that sometimes various symptoms are difficult to talk about; however, if your doctor doesn’t appear to recognize this, you will have to be proactive.
You should be telling your doctor or gastroenterologist the details of your symptoms. Do not hold back information and do not assume that just because your doctor is an expert, and sees a lot of patients with Crohn's disease or ulcerative colitis, that he or she is aware of what you are personally going through.

Remember, when it comes to your health, your treatment goals should be set high.
While there are no medications that cure Crohn’s disease or ulcerative colitis, there are treatments that may help you manage your symptoms. Your doctor or gastroenterologist may suggest one or a combination of the different types of treatment options if he or she believes they are right for you.

Types of treatment options

AMINOSALICYLATES (5-ASAs): Given either orally or rectally, these drugs work to decrease inflammation in the lining of the intestines.

CORTICOSTEROIDS: Given either orally or injected, rectally, or intravenously, these medications are used to help reduce inflammation by suppressing the immune system.

IMMUNE MODIFIERS (IMMUNOMODULATORS): Given orally, this class of medications suppresses the body’s immune response so that it cannot cause ongoing inflammation.

BIOLOGIC THERAPIES: Given intravenously or injected, this class of drugs suppresses the immune system to reduce inflammation by targeting a specific pathway.

SURGERY: Even though a person may be taking medication, in some instances, people with active Crohn’s disease or ulcerative colitis may benefit from surgery. Surgery may also be performed to clear an intestinal blockage, repair a perforation (a hole in the bowel wall caused by chronic inflammation), bleeding, abscess (a pus-filled area caused by infection), damage to the intestines, or treat symptoms that have not been controlled. In some cases people may opt to undergo surgery to remove all or part of their intestine because their medications are no longer working and/or have uncontrollable and unbearable symptoms.

ANTIBIOTICS: Metronidazole, ciprofloxacin, and other antibiotics may be used when infections occur or to treat complications of Inflammatory Bowel Disease (IBD).

OVER-THE-COUNTER MEDICATIONS: Antidiarrheals, pain relievers, and nutritional supplements are occasionally used as supplemental therapies along with your regular prescription medications.

If you are taking any of these medications or following any of these courses of action, and are still experiencing even occasional symptoms, you may have damaging inflammation and it may be a sign that you and your doctor need to discuss a different treatment plan. It is also very important to keep in mind that your condition may change over time. What works at one point during your treatment may not be effective during another stage. It’s important to talk to your doctor so he or she can assess which course of therapy is best—bearing in mind that a combination of therapies may be the optimal treatment plan.
The goal of this chapter is to help you evaluate your condition and your coping mechanisms, and then to share that information with your doctor. You should be discussing everything from seemingly minor symptoms to whether or not damaging inflammation is something you should be concerned about. Also, the lengths you go to manage your symptoms—what you’re sacrificing, for instance—is information that will be helpful to your doctor.

There might be things you’re uncomfortable—or even embarrassed—to talk about. Try not to let your feelings hold you back. **You owe it to yourself to make sure your doctor has all the information he or she needs to help you.** The questions below should be answered openly and honestly and then shared with your doctor at your next visit.

Simply answer the questions below and take these results with you to your next gastroenterologist check-up, to help you have well-informed conversations about your condition and what your next treatment steps could be.

1. To get started, please select the condition you have been diagnosed with: (circle)
   - Crohn’s Disease
   - Ulcerative Colitis

2. How many liquid or very soft stools have you had over the past 7 days?
   Your number: _______________

3. Over the past 7 days, how often did you take any prescription or over-the-counter medicine, such as Imodium® or Lomotil®, to stop diarrhea? (circle)
   - Never
   - A few times
   - Most days
   - Every day

4. Have you noticed any blood in your stool in the past week? (circle)
   - Yes
   - No

5. Are you currently experiencing abdominal pain related to Crohn's disease or ulcerative colitis? (circle)
   - Yes
   - No
   **If No, skip to question 8.**

6. Choose the area(s) where you are experiencing abdominal pain. (circle areas)

7. On a scale of 1-10, how severe is your abdominal pain? (Scale 1-10: 1 = Not severe; 10 = Very severe)
   Your number: _______________

8. Have you recently experienced a change in your weight? (circle)
   - Yes
   - No
   **If No, skip the next question.**
9. Approximately how much weight have you lost or gained, compared with the weight that is normal for you? (circle and fill in) Lost Gained _______ lbs.

10. Over the past week, how many nights did you wake up because of urgent symptoms to move your bowels? (circle) 1-2 nights 3-4 nights 5-7 nights

11. During the past month, how many times have you changed your plans because of your symptoms? Your number: ________________

12. Are there events or activities you prefer not to attend because of your symptoms? (circle) Yes No

13. In the past 6 months, your disease has been: (check all that apply)
   - Constantly active—giving you symptoms every day
   - Often active—giving you symptoms most days
   - Sometimes active—giving you symptoms on some days (for instance 1-2 days per week)
   - Occasionally active—giving you symptoms 1-2 days per month
   - Rarely active—giving you symptoms on a few days in the past 6 months
   - You have been well in the past 6 months—what you consider a remission or absence of symptoms

14. Have you experienced any fevers recently? (circle) Yes No

15. In general, how do you feel? (circle) Good Fair Poor

16. How does your condition make you feel? (check all that apply)
   - No different than normal
   - Sad
   - Anxious/Nervous
   - Afraid/Frightened
   - I don’t know how I feel

17. Have your symptoms increased or worsened since your last doctor visit? (circle) Yes No

18. Which statement best describes your overall feelings about treatment? (check)
   - I don’t have any concerns right now—my treatment is fine
   - I wonder if there are other treatments available for me
   - I have symptoms, but I want to do as little as possible to make them subside
   - I just want to feel better—and I’m willing to do whatever it takes
   - I don’t know how I feel about treatment

Now that you have answered these questions, please share this checklist with your doctor at your next visit. Understanding your symptoms and the impact they have on your life will help your doctor develop a treatment plan that’s right for you.