

Welcome to the Crohn's & Colitis Foundation of America (CCFA) Online Support Group Chat Series.

We hope that this program will help you more easily understand the important information about inflammatory bowel diseases (IBD). The amount of information, especially if you are recently diagnosed, can sometimes be a lot to take in, but having a better understanding of the various aspects of your disease is vital to your success at living well with IBD.

But first, what is IBD?

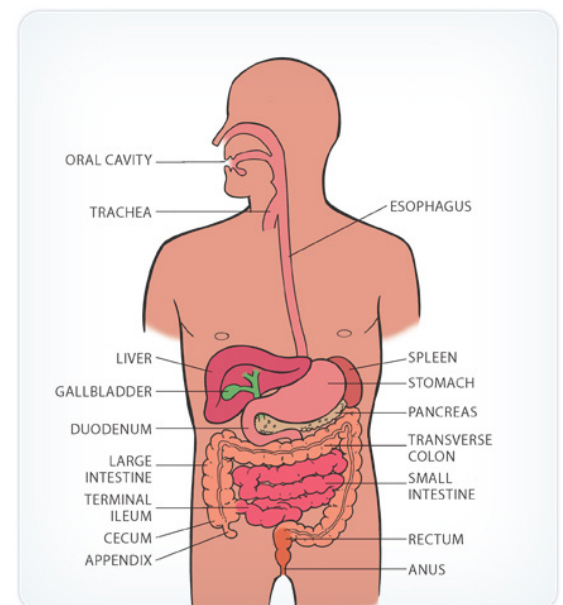
IBD, short for inflammatory bowel diseases, are a group of various inflammatory conditions of the intestines. This means that they are diseases which cause your intestines to become inflamed or red and swollen.

Two of the most common forms of IBD are Crohn's disease and ulcerative colitis. Crohn's disease and ulcerative colitis, commonly referred to as CD and UC, cause chronic or ongoing inflammation in the gastrointestinal, or GI, tract. The inflammation weakens the ability of affected GI organs to function the way they should.

There are differences between the two conditions as well as similarities. Crohn's disease can involve any

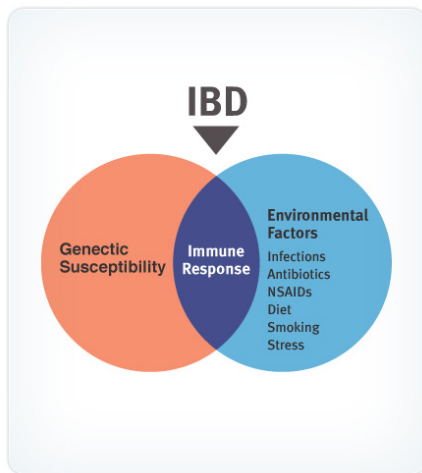
part of the GI tract, from the mouth to the anus. The condition is also characterized by patchy inflammation that may extend through the entire thickness of the wall of the affected area.

Ulcerative colitis affects only the rectum and the colon. Inflammation in the colon is found only superficially in the lining of the colon—meaning it does not go through the whole wall. The inflammation usually begins in the rectum and lower colon, but may also spread to involve the entire colon.



Let's discuss why people get UC or CD.

The exact cause of IBD is not completely understood. But it is known to involve an interaction between genes, the immune system, and environmental factors.



A healthy GI tract contains harmless bacteria, many of which aid in digestion. The immune system usually attacks and kills foreign invaders, such as bacteria, viruses, fungi, and other microorganisms by producing inflammation.

Under normal circumstances, harmless or benign bacteria in the intestines are protected from such an attack. However, researchers currently hypothesize that in people with IBD, these benign bacteria may be mistaken for harmful invaders, resulting in an immune system response of inflammation. In this situation, the inflammation does not stop, which leads to chronic inflammation, ulceration, and thickening of the intestinal wall.

According to the hypothesis, this abnormal immune system reaction occurs in people who have inherited genes that make them susceptible to IBD. Unidentified environmental factors serve as the “trigger” that initiates the harmful immune response in the intestines. These triggers create symptoms of the disease that help doctors diagnose IBD and begin treatment to control them.

The environmental factors that trigger the onset of IBD are not known, but several potential risk factors have been identified and studied.

Among the potential risk factors there are:

- **Smoking**—Active smokers are more than twice as likely as nonsmokers to develop Crohn's disease.
- **Antibiotics**—These drugs may increase the risk for developing IBD.
- **Nonsteroidal anti-inflammatory drugs (aspirin, ibuprofen, naproxen)**—These drugs may increase the risk for getting IBD and may worsen the condition.
- **Appendicitis in children**—Appendectomy in childhood may increase the risk for development of Crohn's disease.

How does IBD affect you?

IBD symptoms vary from person to person, and may change over time. Symptoms can range from mild to severe. They may include persistent diarrhea, abdominal pain, cramping, rectal bleeding, and fatigue.

In 25-40% of patients, the classic signs and symptoms of IBD may be accompanied by symptoms in the eyes, joints, skin, bones, kidneys, and liver. These non-bowel symptoms are called extraintestinal manifestations or EIMs. We will talk more about EIMs later on.

What are the differences between CD and UC symptoms?

While both Crohn's disease and ulcerative colitis include symptoms of abdominal pain, diarrhea, and an urgent need to have a bowel movement, Crohn's disease may also cause a loss of appetite, fever, and weight loss. Ulcerative colitis, on the other hand, may cause small sores or ulcers that form in the colon and rectum. These can bleed, resulting in bloody stools.

? What symptoms have you experienced? Do you find any symptoms difficult to control?

Disease severity

Chronic conditions are ongoing situations. They can be controlled with treatment, but not cured. This means that the disease is a long-term condition. In fact, many medical illnesses such as diabetes, high blood pressure, and heart disease are successfully treated but not cured. Occasionally, people may develop serious complications—such as colorectal cancer—but this occurs in a very small number of people afflicted with IBD. Studies show that people with IBD usually

have the same life expectancy as people without IBD. It is important to remember that most people who have Crohn's disease or ulcerative colitis lead full, happy, and productive lives.

However, you need to pay attention to your symptoms and if they should increase, you should contact your doctor. You may need to have your medication changed or the amount altered.

Flares

A *flare* is the reappearance of the characteristic symptoms of Crohn's disease or ulcerative colitis. People with Crohn's disease and ulcerative colitis go through periods when the disease is quiet alternating with times when it is active. Medical treatment for IBD is aimed at bringing these conditions into a state of remission (no active disease or symptoms) and keeping it that way for as long as possible.

Symptoms related to inflammation of the GI tract:

- Diarrhea
- Abdominal cramps and pain
- Rectal bleeding
- Urgent need to move bowels
- Sensation of incomplete evacuation
- Constipation

General symptoms that may also be associated with IBD:

- Fever
- Loss of appetite
- Weight loss
- Fatigue
- Night sweats
- Loss of normal menstrual cycle



Medications control the inflammation, which relieves diarrhea and pain, and must be continued to maintain the remission. There is always the possibility, though, that the disease may flare up. Some possible reasons for a flare to initiate:

- Stress
- Lapse in taking medications
- Not taking the correct dose
- Use of certain medications, such as nonsteroidal anti-inflammatory (NSAIDs)
- Antibiotics
- Smoking in Crohn's disease
- Eating certain foods
- Travel-related changes (e.g. food, drinking water, stress)



Have you noticed any possible triggers for a flare that you have experienced?

Potential complications

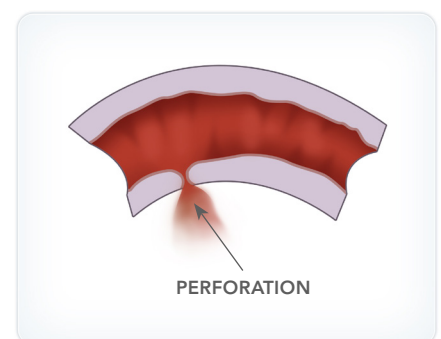
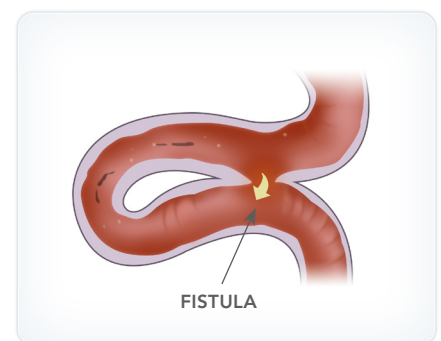
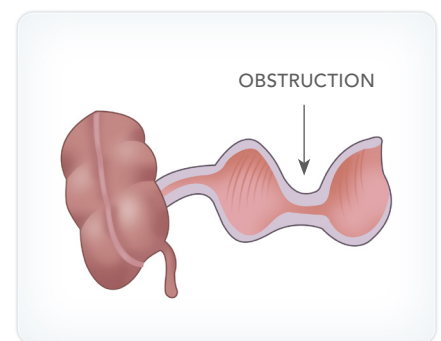
Complications are by no means inevitable or even frequent—especially in appropriately treated patients. But they are common enough, and cover such a wide range, that it is important to be acquainted with them.

Complications of Crohn's disease:

- The most common complication of CD is **obstruction** or blockage of the intestine. This occurs when inflammation causes the bowel to swell shut and, as a result, scar tissue may develop and create a stricture at that point.
- **Stricture** or narrowing of the intestines is a common complication of CD and is frequently responsible for obstructive symptoms, such as crampy pain, nausea, vomiting and loss of appetite.
- Sometimes, a perforation or hole turns into an **abscess** (collection of pus). These abscesses may be responsible for fever, chronic fatigue, and abdominal pain.
- The inflammation in the bowel wall or in an abscess may develop into a **fistula**. A fistula occurs when a hollow organ, such as the bowel, breaks through and leaks into another area, such as the skin, bladder, vagina or colon.

Complications of ulcerative colitis:

- **Anemia** may occur due to blood loss.
- Free **perforations**, or holes, are not common in UC but do occur as a result of chronic inflammation and ulceration weakening the intestinal wall to such an extent that a hole forms. This can lead to a serious infection called peritonitis.



Extraintestinal complications

Not all complications of IBD are confined to the GI tract. For reasons that are not entirely understood, some people develop symptoms that affect other parts of the body.

These extraintestinal complications may be evident in the:

- Joints (arthritis) or muscle pain
- Eyes (redness, pain, and itchiness)
- Mouth (sores)
- Skin (tender bumps, painful ulcerations, and other sores/rashes)
- Bones (osteoporosis)
- Kidney (stones)
- Liver (fatty liver and rarely hepatitis and cirrhosis)

Long-term complications

About 5% of people with IBD develop serious diseases including:

- **Primary sclerosing cholangitis (PSC)**, a severe inflammation and scarring that develops in the bile ducts and that may ultimately require a liver transplant;
- **Toxic megacolon**, when the colon loses its ability to contract properly and which requires immediate attention and possible surgery;
- **Colorectal cancer**, about 5% to 8% of those people with ulcerative colitis will develop colorectal cancer within 20 years after diagnosis of having IBD; the risk increases with the duration and severity of the disease. As a comparison, the risk of colorectal cancer is between 3% and 6% for the general population. A link between colorectal cancer and Crohn's disease is less strong, but is a risk factor for those whose disease affects the colon.

Early recognition often means more effective treatment so be sure to speak with your healthcare team about possible symptoms. To learn more, visit the CCFA Resources page at www.ccfa.org/resources/.

We hope this introduction to IBD has been informative. In preparation for this week's live online support group session, consider the following:

- What did you learn from this presentation?
- What do you still want to learn?
- Do you have any fears or concerns regarding your disease?

We will address Medical Management of IBD, including treatments, surgery, and complementary and alternative therapies, in next week's material.

Additional Resources

CCFA offers many resources and services to provide you with accurate, current, disease-related information. Check out the resources below for more information on living well with IBD.

CCFA's Information Resource

Center (IRC) is a support line for patients and caregivers living with IBD. We can help guide you in the right direction—whether you need to locate a doctor, find financial resources, or have questions about your disease. Specialists are available Monday-Friday, 9 AM to 5 PM Eastern time. Call 1-888-MYGUTPAIN (1-888-694-8872) or email info@ccfa.org.

CCFA's website (www.ccfa.org)

is a great place to continue your research on IBD and connect with your local chapter to learn more about programs in your area. Additionally, you can:

- View free educational webcasts on a variety of topics at www.ccfa.org/resources/webcasts.html.
- Visit www.IBDetermined.org to learn more about IBD through videos, interactive quizzes, and more!
- Download pertinent brochures at www.ccfa.org/resources/, including:
 - Living With Crohn's Disease or Ulcerative Colitis
 - Diagnosing and Managing IBD
 - Managing Flares and other IBD Symptoms