

# ONLINE Support Group

Week 1: IBD 101



## Welcome to the Crohn's & Colitis Foundation's Online Support Group for Caregivers

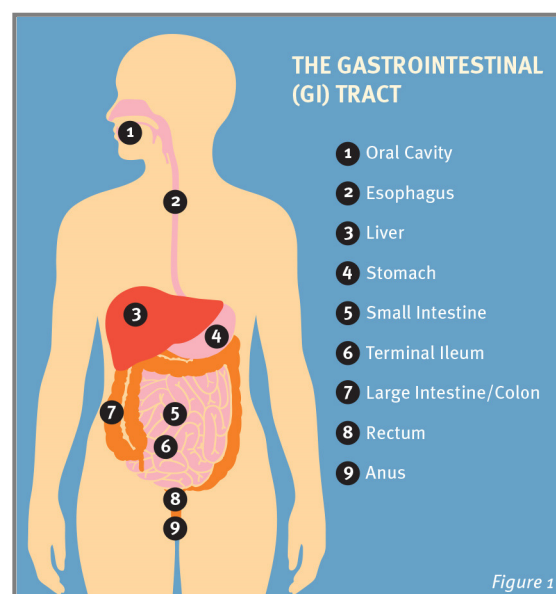
You recently learned that your loved one has Crohn's disease or ulcerative colitis. Now you're taking an important step – learning more about these conditions, as well as how they are treated and how your loved one can learn to live with Crohn's disease or ulcerative colitis from others around you. The more you know about these diseases, the better prepared you and your loved one will be to manage them.

It is important for you to know that while there is currently no cure for Crohn's disease and ulcerative colitis, there are medications available to treat them. Every day, doctors and scientists around the world are working hard to find a cure. Despite the challenges your loved one may face, he or she can lead a happy and productive life. Finding the right doctor and treatment plan as well as an effective support system can allow you and your loved one to thrive.

## What is IBD?

Let's start with the basics: Crohn's disease and ulcerative colitis are diseases that affect the digestive system. Together, they belong to a group of conditions known as inflammatory bowel diseases (IBD).

Crohn's disease and ulcerative colitis can cause parts of your gastrointestinal tract (*GI tract*) to become red and swollen (*inflamed*). The inflammation can prevent the organs in your GI tract from functioning the way they should. Although Crohn's disease and ulcerative colitis are similar, there are important differences between them.



Crohn's disease can involve any part of the GI tract, from the mouth to the anus. However, it usually affects the end of the small intestine (*ileum*) and the large intestine (*also known as the colon*). Crohn's disease may appear in "patches," affecting some areas of the GI tract while leaving other areas completely untouched. In Crohn's disease, the inflammation may extend through the entire thickness of the intestinal wall.

Ulcerative colitis only affects the colon and the rectum. In ulcerative colitis, only the innermost layer of the colon is affected —meaning it does not go through the whole wall. The inflammation usually starts in the rectum and spreads up the entire colon.

## What causes IBD?

Although no one knows what causes IBD, researchers think that it is likely an interaction between your genes, your immune system, the balance of bacteria within your intestines, and something in the environment.

Your immune system usually protects you against foreign invaders (such as viruses and other things that make their way into your body) by launching an attack, also known as an *immune response*. In people with IBD, something causes their immune system to launch an attack within the GI tract that won't shut off. Because the attack won't shut off, it causes the walls of the GI tract to become red and swollen, and the symptoms of IBD to appear.

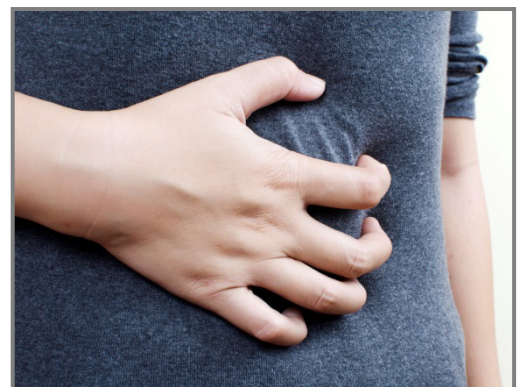


## What are the symptoms?

The symptoms of IBD vary from person to person, and may even change over time. IBD is often characterized by times of "active disease" (*also known as a flare*), when symptoms are present, and times of "remission," when little or no symptoms are present. Symptoms can range from mild to severe.

Some common symptoms include:

- Diarrhea
- Rectal bleeding
- Urgent need to go to the bathroom
- Abdominal cramps and pain
- Fever
- Loss of appetite
- Weight loss
- Fatigue
- Night sweats
- Loss of normal menstrual cycle



While these symptoms are the same in children and adults, children may experience a delay in growth and puberty. Active IBD can slow down bone growth and prevent the GI tract from absorbing the vitamins and nutrients your child needs to form healthy bones and muscles. Taking steroids (like prednisone) for more than 3 months can also affect bone formation and growth. Be sure to talk to your doctor about getting your child's bone mass tested.



- What symptoms has your loved one experienced?
- Do you or your loved one find any symptoms difficult to control?
- Have you or your loved one discussed these symptoms with the doctor?
- For parents: Has your child's bone mass been tested?

## What to do if symptoms appear?

If your loved one experiences any of the symptoms listed above, let the doctor know.

Although symptoms do not always mean that inflammation is present, they often suggest that inflammation has returned or is becoming severe. You or your loved one will need to follow up with the doctor to figure out what is causing the symptoms and if the medication needs to be adjusted or changed.



Patients and caregivers often ask how to tell the difference between a disease flare and an emergency. If your loved one experiences any of the following, they should be evaluated by the doctor immediately:

- Fever (above 100.5 degrees Fahrenheit)
- Severe difficulty eating or drinking, causing symptoms such as nausea, vomiting, or pain
- Abdominal pain that is constant and cannot be tolerated
- Large amounts of diarrhea leading to dehydration, causing symptoms such as dry mouth, extreme thirst, dizziness, or decreased urine production
- Heavy bleeding from the anus

These are only a few of the possible emergency conditions. Other severe situations may also require immediate attention.

## Possible complications

Disease complications do not occur frequently – especially in those whose IBD is being appropriately treated – but they do occur. Therefore, you should become familiar with them and their symptoms.

### Complications of Crohn's disease:

- **Stricture:** A stricture is a narrowing of the intestine. This happens when inflammation causes the intestine to swell and develop scar tissue. The scar tissue can cause the intestine to become very narrow, making it hard for food to pass through. It can even become completely blocked. Common symptoms include crampy pain, nausea, vomiting, and loss of appetite.
- **Ulcers:** When IBD is active, it can cause sores (*ulcers*) along the intestine.
- **Fistula:** Sometimes an ulcer can get so bad that it extends through the wall of the intestine, forming a hole, and creates a fistula – an unnatural channel that forms between the intestine and another organ, like the skin, bladder, or vagina. A fistula can even form between the intestine and another part of the intestine. When the connection forms, digestive juices from the intestine can leak into the other organ and cause problems, like a bladder or urinary tract infection. Sometimes a fistula can form between the intestines and the outside of the body. This usually occurs around the anus, and can be painful. If this happens, it is possible for pus and waste to leak from the area.
- **Abscess:** Sometimes a hole in the intestines can turn into an abscess (collection of puss). These abscesses may be responsible for fever, fatigue, and abdominal pain.

### Complications of ulcerative colitis:

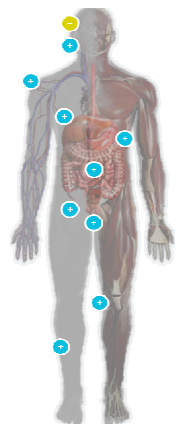
- **Anemia:** Anemia may occur due to blood loss.
- **Perforations:** Although it is not common in ulcerative colitis, ulcers can weaken the intestinal wall and cause holes (*perforations*). This can lead to a serious infection called *peritonitis*.

Surgery may be needed if a fistula develops, the intestine becomes completely blocked, or the intestine is extremely damaged. Surgery will be discussed in more detail during next week's session.

## Complications outside the GI tract

For reasons that are not entirely understood, those with IBD may also experience symptoms in other parts of the body (*extra-intestinal manifestations*), including:

- Joints (swelling and pain)
- Eyes (redness, pain, and itchiness)
- Mouth (sores)
- Skin (tender bumps, painful ulcerations, and other sores/rashes)
- Bones (osteoporosis)
- Kidney (stones)
- Liver (primary sclerosing cholangitis, hepatitis, and cirrhosis)



## Long-term complications

A very small percentage of those diagnosed with IBD develop serious diseases including:

- **Primary sclerosing cholangitis (PSC):** PSC is a severe inflammation and scarring that develops in the bile ducts.
- **Toxic megacolon:** Toxic megacolon is a rare, life-threatening condition that causes the large intestine to malfunction. This condition requires immediate attention and possible surgery.
- **Colon cancer:** Longstanding inflammation of the colon can damage the intestinal lining over time, increasing the risk for colorectal cancer. However, it is important to note that the vast majority of those diagnosed with Crohn's disease and ulcerative colitis will never develop colorectal cancer. It is also important to note that it is highly treatable when caught early. Therefore, it is recommended that those with ulcerative colitis or Crohn's disease involving the colon get a colonoscopy every one to two years, which should begin after 8 to 10 years of IBD symptoms.

One of the most important things that someone with IBD can do to reduce their risk for complications is to take their medication as prescribed.

## Common tests

Once your loved one is diagnosed and begins treatment, there will be regular follow-up appointments to monitor their disease as well as the medications that they are taking.

Blood tests may be used to:

- Check medication levels
- Check for signs of inflammation
- Check for infection
- Check for anemia

Stool tests may be used to:

- Check for infection
- Check for signs of inflammation



## Common procedures

The following procedures may be used to monitor your loved one's disease and to look out for possible complications.

- **Endoscopy:** Endoscopy refers to procedures where a thin, flexible tube attached to a camera (*scope*) is used to look at the inside of the digestive tract by entering through the mouth (*upper endoscopy*) or through the anus into the colon (*colonoscopy*). The scope also has other tools that may be used for additional purposes, including collection of tissue samples and biopsies.

During these procedures, your loved one may be given medications that allow them to fall sleep (*sedation*).

A new form of endoscopy, called the pill endoscopy, may also be used. With this procedure, your loved one swallows a small pill-shaped camera, which takes pictures as it travels through the intestines. The images are captured on a device worn by the patient. The camera naturally leaves the body when your loved one goes to the bathroom.

- **Magnetic resonance imaging (MRI):** MRIs use magnetic waves to create detailed images of internal organs, such as your intestines. This allows your doctor to see what is going on inside the body. MRIs do not use radiation.
  - **Barium studies:** During this procedure, your loved one drinks a chalky liquid that coats the upper portion of the digestive tract. A series of X-rays are then taken while the patient is moved around on a table. This allows the doctor to see how the chalky liquid flows through the digestive tract.
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## This week's online support group

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

- What did you learn from this information?
- What do you still want to learn?
- Do you have any fears or concerns regarding your loved one's disease?

In next week's materials, we will address *Medical Management of IBD*, including treatments, surgery, and complementary and alternative therapies.

To join this week's support group, visit: <http://ccfacommunity.org/chatseries.aspx>

## Crohn's & Colitis Foundation Resources

The Crohn's & Colitis Foundation offers many resources and services to provide you with accurate and current disease-related information. Check out the resources below for more information on living well with IBD:

- The Foundation's **IBD Help Center** is a support line for IBD patients and caregivers. We can help guide you in the right direction—whether you need to locate a doctor, find financial resources, or have questions about the disease. Specialists are available Monday-Friday, 9 AM to 5 PM Eastern Standard Time (EST). Call 1-888-MY-GUT-PAIN (1-888-694-8872) or email [info@ccfa.org](mailto:info@ccfa.org).

- The Foundation's **Website** ([www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)) is a great place to continue your research on IBD. Additionally, you can:
  - View free educational videos and webcasts
  - Download free brochures and fact sheets
  - Connect with your local chapter
  - Find ways to get involved