



Inflammatory Bowel Disease

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1-800-994-9662

TDD: 1-888-220-5446

Q: What is inflammatory bowel disease?

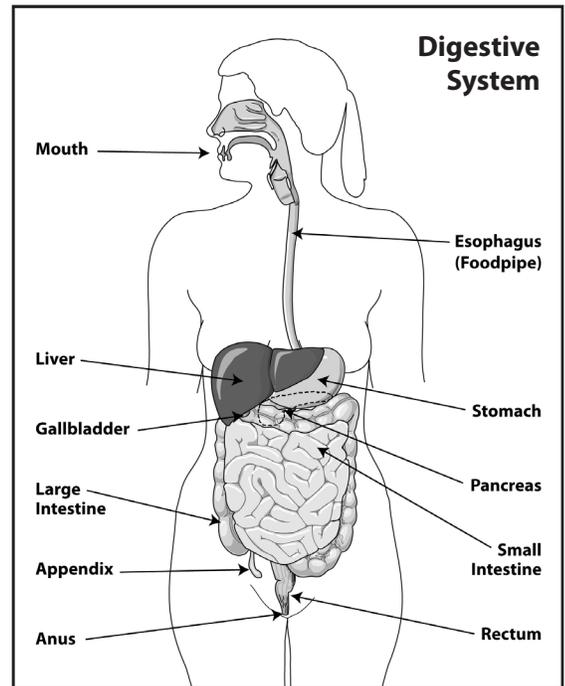
A: Inflammatory bowel disease (IBD) is the name of a group of disorders in which the intestines (small and large intestines or bowels) become inflamed (red and swollen). This inflammation causes symptoms such as:

- Severe or chronic (almost all of the time) pain in the abdomen (belly)
- Diarrhea — may be bloody
- Unexplained weight loss
- Loss of appetite
- Bleeding from the rectum
- Joint pain
- Skin problems
- Fever

Symptoms can range from mild to severe. Also, symptoms can come and go, sometimes going away for months or even years at a time. When people with IBD start to have symptoms again, they are said to be having a relapse or flare-up. When they are not having symptoms, the disease is said to have gone into remission.

The most common forms of IBD are ulcerative colitis (UHL-sur-uh-tiv koh-LEYE-tiss) and Crohn's (krohnz) disease. The diseases are very similar. In fact, doctors sometimes have a hard time figuring out which type of IBD a person has. The main difference between the two diseases is the parts of the digestive tract they affect.

Ulcerative colitis affects the top layer of the large intestine, next to where the stool is. The disease causes swelling and tiny open sores, or ulcers, to form on the surface of the lining. The ulcers can bleed and produce pus. In severe cases of ulcerative colitis, ulcers may weaken the intestinal wall so much that a hole develops. Then the contents of the large intestine, including bacteria, spill into the abdominal (belly) cavity or leak into the blood. This causes a serious infection and requires emergency surgery.



Crohn's disease can affect all layers of the intestinal wall. Areas of the intestines most often affected are the last part of the small intestine, called the ileum, and the first part of the large intestine. But Crohn's disease can affect any part of the digestive tract, from the mouth to the anus. Inflammation in Crohn's disease often occurs in patches,



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with normal areas on either side of a diseased area.

In Crohn's disease, swelling and scar tissue can thicken the intestinal wall. This narrows the passageway for food that is being digested. The area of the intestine that has narrowed is called a stricture (STRIK-choor). Also, deep ulcers may turn into tunnels, called fistulas (FISS-choo-luhss), that connect different parts of the intestine. They may also connect to nearby organs, such as the bladder or vagina, or connect to the skin. And as with ulcerative colitis, ulcers may cause a hole to develop in the wall of the intestine.

IBD is not the same as irritable bowel syndrome (IBS), although the symptoms can be similar. Unlike inflammatory bowel disease, IBS does not cause inflammation or damage in the intestines.

In many people with IBD, medicines can control symptoms. But for people with severe IBD, surgery is sometimes needed. With treatment, most people with IBD lead full and active lives.

Q: What causes inflammatory bowel disease?

A: No one knows for sure what causes inflammatory bowel disease (IBD). Experts think that abnormal action of a person's immune system may trigger IBD. The immune system is made up of various cells and proteins. Normally, the immune system protects the body from infections caused by viruses or bacteria. Once the infection has cleared up, the immune system "shuts off." But in people with IBD, the immune system seems to overreact to normal bacteria in the digestive tract. And

once it starts working, the immune system fails to "shut off." This causes the inflammation, which damages the digestive tract and causes symptoms.

IBD runs in families. This suggests that inherited factors called genes play a role in causing IBD. Experts think that certain genes may cause the immune system to overreact in IBD.

Stress and eating certain foods do not cause IBD. But both can make IBD symptoms worse.

Q: Can inflammatory bowel disease cause health problems in parts of the body other than the digestive tract?

A: Yes. Inflammatory bowel disease (IBD) can cause a number of problems outside of the digestive tract.

One common problem that occurs because of loss of blood from the digestive tract is anemia (uh-NEE-mee-uh). Anemia means that the amount of healthy red blood cells, which carry oxygen to organs, is below normal. This can make a person feel very tired.

Other health problems include:

- Arthritis and joint pain
- Weak bones and bone breaks
- Inflammation in the eye and other eye problems
- Liver inflammation
- Gallstones
- Red bumps or ulcers on the skin
- Kidney stones
- Delayed puberty and growth problems (in children and teens)
- In rare cases, lung problems



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Some of these problems are caused by poor absorption of nutrients. Others are due to inflammation in parts of the body other than the digestive tract.

Some of these problems get better when the IBD is treated. Others must be treated separately.

Q: How does a healthy digestive system work?

A: A normal digestive system breaks down food into nutrients. Nutrients include proteins, carbohydrates, fats, vitamins, and minerals. The body needs nutrients for energy and to stay healthy.

The digestive tract runs from the mouth to the anus. When you eat food, it goes from your mouth, down your esophagus, and into your stomach. From there, it goes into your small intestine, where the nutrients are absorbed into your blood. Leftover water and solid waste then move down into your large intestine, where most of the water is absorbed back into the blood. Solid waste leaves the body out of the anus as a bowel movement.

Q: How does inflammatory bowel disease interfere with digestion?

A: When the small intestine becomes inflamed, as in Crohn's disease, it is less able to absorb nutrients from food. These nutrients leave the body in the bowel movement. This is one reason why people with Crohn's disease don't get enough nutrients, along with not having much appetite. Also, the undigested food that goes into the large intestine makes water absorption harder. This causes a watery bowel movement, or diarrhea.

In ulcerative colitis, the small intestine absorbs nutrients as it should. But inflammation in the large intestine keeps it from absorbing water, causing diarrhea.

Q: Who gets inflammatory bowel disease?

A: Although inflammatory bowel disease (IBD) can occur in any group of people, it is more common among:

- People who have a family member with IBD
- Jewish people of European descent
- White people
- People who live in cities
- People who live in developed countries

Smoking also seems to affect a person's risk of getting IBD. People who smoke are more likely to develop Crohn's disease but less likely to develop ulcerative colitis.

Experts think that as many as 1 million people in the United States have IBD. Most people with IBD begin to have symptoms between the ages of 15 and 30.

Q: How is inflammatory bowel disease diagnosed?

A: If you think you have inflammatory bowel disease (IBD), talk to your doctor. She or he will use your health history, a physical exam, and different tests to figure out if you have IBD and, if so, which type.



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Tests used to diagnose IBD include:

- **Blood tests.** A sample of blood is studied in a lab to find signs of inflammation and anemia.
- **Stool sample.** A sample of a bowel movement is tested for blood. It is also tested for signs of an infection that can trigger a flare-up of IBD.
- **Colonoscopy or Sigmoidoscopy.** For both of these tests, a long, thin tube with a lighted camera inside the tip is inserted into the anus. The image appears on a television screen. A sigmoidoscopy (SIG-moi-DOSS-kuh-pee) allows the doctor to see the lining of the lower part of the large intestine. A colonoscopy (koh-lon-OSS-koh-pee) allows the doctor to see the lining of the entire large intestine and often the last part of the small intestines. The doctor will then be able to see any inflammation, bleeding, or ulcers. During the exam, the doctor may do a biopsy (BY-op-see). This involves taking a sample of tissue from the lining of the digestive tract to view with a microscope.
- **X-rays with barium:** In this procedure, a thick, chalky liquid called barium is used to coat the lining of the digestive tract. Then x-rays are taken. Areas coated with barium show up white on x-ray film. This allows the doctor to check for signs of IBD. The barium can be drunk or given as an enema.
- **Computerized axial tomography (CT or CAT scan):** A CT scan takes x-rays from several different angles around the body. The doctor studies the images with a computer to look for signs of ulcerative colitis.

- **Capsule endoscopy.** Regular endoscopies and colonoscopies cannot get to your small intestine. But doctors can examine the small intestine through a capsule endoscopy (en-DAHS-kuh-pee). A capsule endoscopy is a small, pill shaped camera. You swallow the pill, which then travels through your digestive system. It records video of the small intestine and sends the video to a monitor where your doctor can watch it. Capsule endoscopies can't be used if there is any narrowing of the digestive system.

It often takes awhile for doctors to diagnose IBD. This is because IBD symptoms vary and are similar to those of many other problems.

Q: Can I do anything to avoid getting inflammatory bowel disease?

A: Since doctors don't know what causes inflammatory bowel disease, there is no proven way to prevent it.

Q: How is inflammatory bowel disease treated?

A: Treatments for inflammatory bowel disease (IBD) may include:

- Medicines
- Surgery
- Changes in the foods you eat — some people find following specific diets helps ease their symptoms.
- Nutritional supplements
- Reducing stress and getting enough rest



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If you have IBD, your treatment will depend on:

- Your symptoms and how severe they are
- Which part of your digestive tract is affected
- If you have health problems outside the digestive tract

Most people with IBD take medicine to control their symptoms. If medicines cannot control their disease, some people will need surgery.

Q: What medicines are used to treat inflammatory bowel disease?

A: Medicines for treating inflammatory bowel disease (IBD) reduce the inflammation, relieve symptoms, and prevent flare-ups. Every patient is different. What may work for one person with IBD may not work for another. You may need to try several different medicines before you find one or more that work best for you. You should keep track of how well the drugs are working, any side effects, and report all details to your doctor. The following kinds of medicines are used to treat IBD:

Aminosalicylates

Most people with mild to moderate cases of IBD are first treated with medicines called aminosalicylates (uh-MEE-noh-suh-LISS-uh-layts). They are given as pills, through an enema, or in a suppository, depending on which part of the digestive tract is inflamed. Possible side effects include nausea, vomiting, heartburn, diarrhea, and headache.

Corticosteroids

Corticosteroids (KOR-tih-koh-STEER-oids) are powerful and fast-acting drugs that suppress the immune system. They are given for short periods of time to treat IBD flare-ups. They are not given long-term because of possible serious side-effects. Side effects may include increased risk of infection, bone loss, diabetes, and high blood pressure. Corticosteroids are usually taken as pills. But for people who do not respond to the pills, they may be given through an enema, in a suppository, or injected into the blood.

Immunomodulators

Like corticosteroids, immunomodulators (ih-myuh-noh-MAH-juh-lay-turs) suppress the immune system. They can take a long time to work (as much as 6 months for full effect). But, unlike corticosteroids, they can be taken long-term to prevent relapse. They are often given along with corticosteroids. As the disease is brought under control and the immunomodulator starts working, the corticosteroid dose is slowly reduced. Like corticosteroids, these medicines may raise the risk of infection. Other side effects are uncommon but may include nausea, vomiting, and headache. Immunomodulators are usually taken as pills, but some are injected.

Biologic Therapies

Biologic therapies are proteins that block substances in the body that help cause inflammation. Biologics used to treat IBD block a substance called tumor necrosis factor alpha (TNF-alpha). Anti-TNF-alpha therapies have been used for years to treat Crohn's disease and are now being used for ulcerative colitis. Blocking TNF-alpha can reduce inflammation, which can



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improve the symptoms of IBD. Anti-TNF-alpha therapies like infliximab (in-FLIK-sih-mab), adalimumab (A-duh-LIM-uh-mab), and certolizumab (SER-toe-LIZ-oo-mab) are used to treat people with moderate to severe IBD when other therapies don't work. Infliximab has also been used to treat people with Crohn's disease who have open, draining fistulas.

Infliximab is given intravenously (into the vein) by a doctor or nurse. But adalimumab and certolizumab can be taken at home by injecting under the skin.

These therapies may lower your body's ability to fight diseases. This can raise your chances of having a serious, or even life-threatening infection. Other side effects may include stomach pain, rash, and nausea.

Antibiotics

Antibiotics are used to treat people with Crohn's disease but are usually not given to people with ulcerative colitis. Antibiotics can reduce bacterial growth in the small intestine caused by stricture, fistulas, or surgery. Experts think that antibiotics may also help by suppressing the immune system.

Antibiotics are usually taken as pills. Side effects may include nausea, vomiting, and diarrhea. Long-term use of one type of antibiotic can cause tingling of the hands and feet. If you develop this side effect, tell your doctor right away. The medicine should be stopped and not restarted.

Other treatments

Drugs that relieve diarrhea and pain are sometimes used to treat IBD symptoms. But it is important to talk with your doctor before taking any over-the-counter drugs. Some can make your symptoms worse.

Patients who are dehydrated because of diarrhea may be treated with fluids and minerals. People with Crohn's disease are sometimes given nutritional supplements.

Q: What types of surgery are used to treat inflammatory bowel disease?

A: Sometimes severe inflammatory bowel disease (IBD) does not get better with medicine. In these cases, doctors may suggest surgery to fix or remove damaged parts of the intestine. There are different types of surgery used to treat IBD.

Surgery for ulcerative colitis

About 25 to 40 percent of people with ulcerative colitis need surgery at some point in their lives. Surgery that removes the entire large intestine can completely cure ulcerative colitis. After the large intestine is removed, surgeons perform one of two types of operations to allow the body to get rid of food waste:

- In one procedure, a small opening is made in the front of the abdominal wall. Then the end of the ileum is brought through the hole. This allows waste to drain out of the body. An external pouch is worn over the opening to collect the waste, and the patient empties the pouch several times a day.
- In another procedure, the surgeon attaches the ileum to the inside of the anus where the rectum was, creating an internal pouch. Waste is stored in the pouch and passes out of the anus in the usual manner.



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Surgery for Crohn's disease

About 65 to 75 percent of people with Crohn's disease need surgery at some point in their lives. Surgery can relieve symptoms and correct problems like strictures, fistulae, or bleeding in the intestine. Surgery can help relieve Crohn's disease symptoms. But, since Crohn's disease occurs in patches, surgery cannot cure the disease. If a part of the small or large intestine is removed, the inflammation may then affect the part next to the section that was removed.

Types of surgery for Crohn's disease include:

Strictureplasty (STRIK-chur-PLASS-tee). In this surgery, the doctor widens the strictured, or narrowed, area without removing any part of the small intestine.

Bowel resection. In this surgery, the damaged part of the small or large intestine is removed and the two healthy ends are sewn back together.

Removal of the large intestine.

This procedure is the same as that done for ulcerative colitis. But, people with Crohn's can't have an internal pouch for waste because it can become inflamed. Instead, surgeons use the external pouch procedure.

Q: I have inflammatory bowel disease and my doctor says that I should have surgery. Did I fail at managing my disease?

A: No. If medicines can no longer control your symptoms, you should consider surgery. Surgery can give lasting relief from symptoms and may reduce or even get rid of the need for medicine. Not every type of surgery is right for every

person. People faced with the decision to have surgery should get as much information as they can from their doctors, nurses, and other patients.

Q: Can changing the foods I eat help control inflammatory bowel disease?

A: No special eating plan has been proven effective for treating inflammatory bowel disease (IBD). But for some people, changing the foods they eat may help control the symptoms of IBD.

There are no blanket food rules.

Changes that help one person with IBD may not relieve symptoms in another. Talk to your doctor and maybe a dietitian about which foods you should and should not be eating. Their suggestions will depend on the part of your intestine that is affected and which disease you have.

Your doctor may suggest some of the following changes:

- Taking specific nutritional supplements, including possibly vitamin and mineral supplements
- Avoiding greasy or fried foods
- Avoiding cream sauces and meat products
- Avoiding spicy foods
- Avoiding foods high in fiber, such as nuts and raw fruits and vegetables
- Eating smaller, more frequent meals

Even though you may have to limit certain foods, you should still aim to eat meals that give you all the nutrients you need.



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Q: Can stress make inflammatory bowel disease worse?

A: Although stress does not cause inflammatory bowel disease (IBD), some people find that stress can bring on a flare-up in their disease. If you think this is happening to you, try using relaxation techniques, such as slow breathing. Also, be sure to get enough sleep.

Q: What new treatments for inflammatory bowel disease are being studied?

A: Researchers are studying many new treatments for inflammatory bowel disease (IBD). These include new medicines, such as new biologic therapies. Researchers are also studying whether fish or flaxseed oils can help fight the inflammation in IBD. Some evidence supports using probiotics to treat some types of diarrhea and a form of IBD called pouchitis. Probiotics are “good” bacteria that may improve the balance of bacteria in your digestive system. Some researchers are hoping to develop new therapies by studying probiotics.

If you are interested in participating in a clinical study on IBD, visit the clinical trials web site of the U.S. National Institutes of Health: <http://www.clinicaltrials.gov>.

Q: With inflammatory bowel disease, do I have a higher chance of getting colon cancer?

A: Yes. Inflammatory bowel disease (IBD) can increase your chances of getting cancer of the colon, or large intestine. Even so, more than 90 percent of people with IBD do NOT get colon cancer.

What we know about colon cancer and inflammatory bowel disease (IBD) comes mostly from studying people with ulcerative colitis. Less is known about the link between Crohn's disease and cancer. But research suggests that Crohn's patients have an increased risk as well. For both diseases, the risk of colon cancer depends on:

- How long you have had IBD
- How much of your colon is affected by IBD

Also, people who have family members with colon cancer may have an even higher chance of getting the cancer.

For people with ulcerative colitis, the risk of colon cancer does not start to increase until they have had the disease for 8 to 10 years. People whose disease affects the entire colon have the highest risk of colon cancer. People whose disease affects only the rectum have the lowest risk.

People with inflammatory bowel disease (IBD) should talk to their doctors about when to begin checking for colon cancer, what tests to get, and how often to have them. Your doctor's suggestions will depend on how long you have had IBD and how severe it is.

In people who have had IBD for 8 to 10 years, most doctors recommend a colonoscopy with biopsies every 1 to 2 years. This test checks for early warning signs of cancer in the cells of the colon lining. When cancer is found early, it is easier to cure and treat.



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Q: Can my inflammatory bowel disease make it harder for me to get pregnant?

A: If you have ulcerative colitis, you can get pregnant as easily as other women. The same is true of Crohn's disease, if your disease is in remission. But if you are having a flare-up of Crohn's disease, you may have trouble getting pregnant.

Q: I have inflammatory bowel disease. Is pregnancy safe for me?

A: You should talk with your doctor before getting pregnant. If you think you might be pregnant, call your doctor right away. Some of the medicines used to treat inflammatory bowel disease (IBD) can harm the growing fetus.

If possible, your disease should be in remission for 6 months before becoming pregnant. It is also best if you have not started a new treatment or are taking corticosteroids. If you are already pregnant, you should continue taking your medicines as your doctor has told you to take them. If you stop taking your medicines and your disease flares, it may be hard to get it back under control.

In some cases, IBD gets better during pregnancy. This is because of changes in the immune system and hormone levels that occur during pregnancy. Even so, you shouldn't get pregnant as a way of treating your IBD. That is better done with medicines and perhaps surgery.

Q: Can my inflammatory bowel disease harm the fetus or affect delivery?

A: If you have ulcerative colitis, your chances of having a normal delivery and a healthy baby are the same as for women who do not have inflammatory

bowel disease. If you have a flare-up of Crohn's disease during pregnancy, you have a slightly higher risk of miscarriage, preterm birth, and stillbirth.

Q: Can inflammatory bowel disease affect my monthly period?

A: Yes. Some women with inflammatory bowel disease (IBD) feel worse right before and during their menstrual periods than at other times. Diarrhea, abdominal pain, and other symptoms can be more severe during these times. Women with IBD and their doctors should keep track of these monthly changes in symptoms. This will prevent overtreating the disease.

If you have not been eating well and have lost a lot of weight, your menstrual cycles can become irregular or even stop entirely.

Q: Can inflammatory bowel disease affect my sex life?

A: Yes, but there are steps you can take to have a healthy sex life.

Inflammatory bowel disease, as well as the surgery and medicines used to treat it, can all affect your sex life. Sometimes, you may just feel too tired to have sex. You may also have emotional issues related to the disease. For instance, you may not feel as confident about your body as you did before you got the disease. Even though it may be embarrassing, it is important to talk to your doctor if you are having sexual problems. She or he may have treatments that can help. For instance, if you are having pain during sex, your doctor may prescribe a hormonal cream or suppository for your vagina.



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If you have an external pouch, here are some tips:

- Empty the pouch before sex.
- Use deodorizers — one in the pouch and perhaps a pill or liquid you take by mouth (ask your doctor about them).
- Make sure the pouch is secure.
- If the pouch is in the way or causes pain during sex, experiment with different positions.

- Cover up your pouch with a pouch cover or by wearing a short slip or nightie.

Talking with your partner about how having inflammatory bowel disease is affecting your sex life can help build intimacy and clear up misunderstandings. Talking with a counselor or therapist may also help you find ways to deal with your emotional issues. ■

For more information

For more information on inflammatory bowel disease, please call [womenshealth.gov](http://www.womenshealth.gov) at 1-800-994-9662 or contact the following organizations:

National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK)

Internet Address: <http://digestive.niddk.nih.gov>

National Digestive Diseases Information Clearinghouse

2 Information Way Bethesda, MD 20892-3570

E-mail: nddic@info.niddk.nih.gov

Crohn's & Colitis Foundation of America, Inc.

Phone Number(s): (800) 932-2433 or (212) 685-3440

Internet Address: <http://www.cdfa.org>

The American College of Gastroenterology

Phone Number(s): (703) 820-7400

Internet Address: <http://www.acg.gi.org>

American Gastroenterological Association

Phone Number(s): (301) 654-2055

Internet Address: <http://www.gastro.org>

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

Phone Number(s): (215) 233-0808

Internet Address: <http://www.naspghan.org>

Social Security Administration Information on Disability Benefits

Phone Number(s): (800) 772-1213

Internet Address: <http://www.ssa.gov>

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