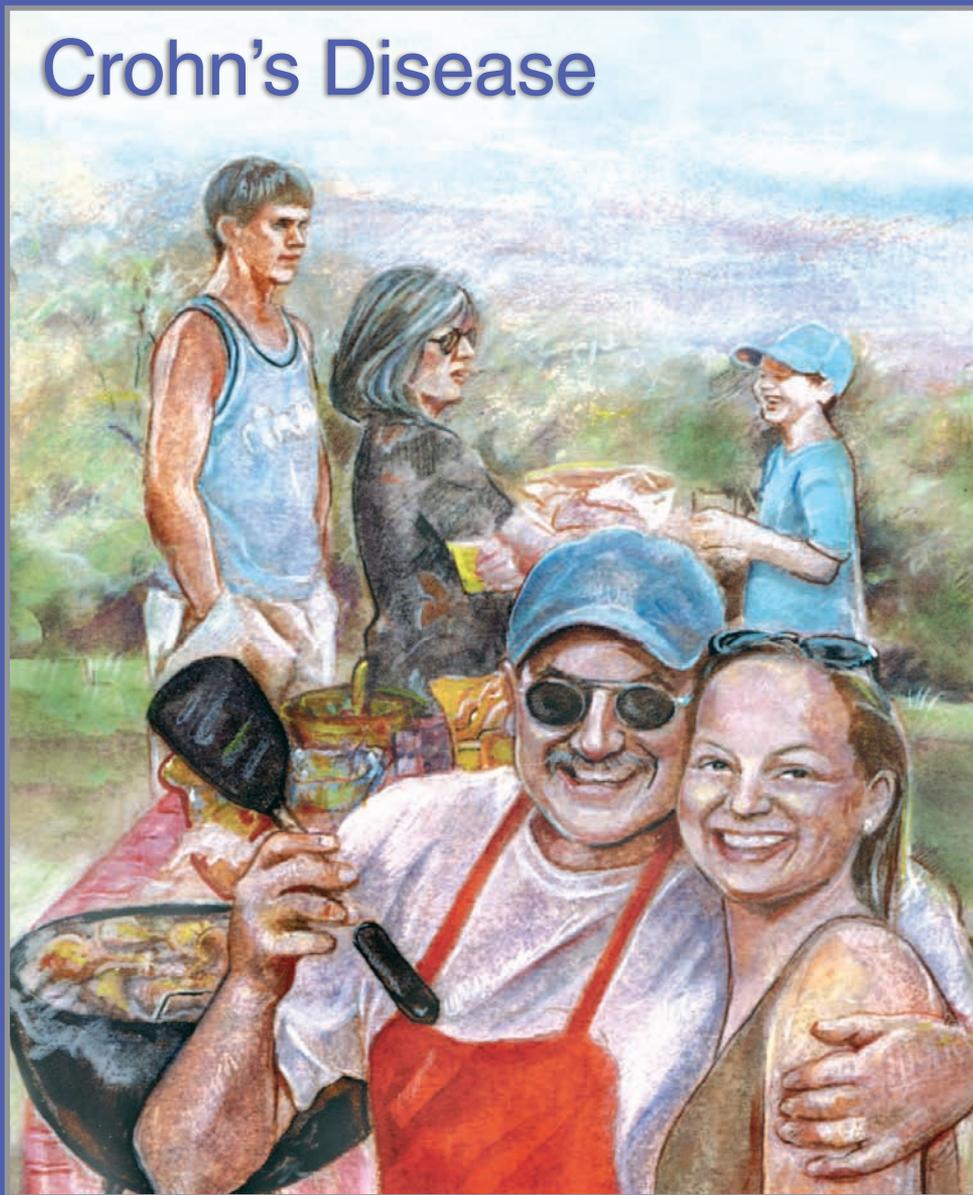


What I need to know about Crohn's Disease



U.S. Department
of Health and
Human Services

NATIONAL INSTITUTES OF HEALTH

NIDDK NATIONAL INSTITUTE OF
DIABETES AND DIGESTIVE
AND KIDNEY DISEASES

National Digestive Diseases
Information Clearinghouse

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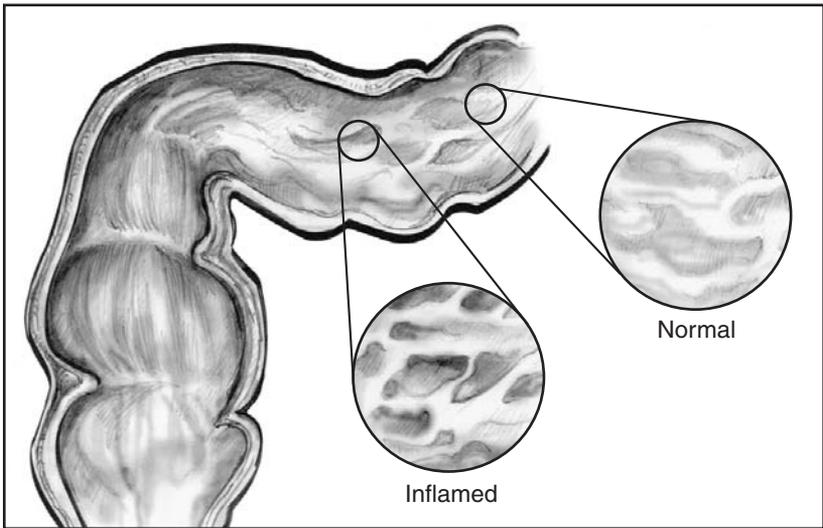
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What is Crohn's disease?

Crohn's disease is a disease that causes **inflammation**, or swelling, and irritation of any part of the digestive tract—also called the gastrointestinal (GI) tract. The part most commonly affected is the end part of the small intestine, called the ileum.

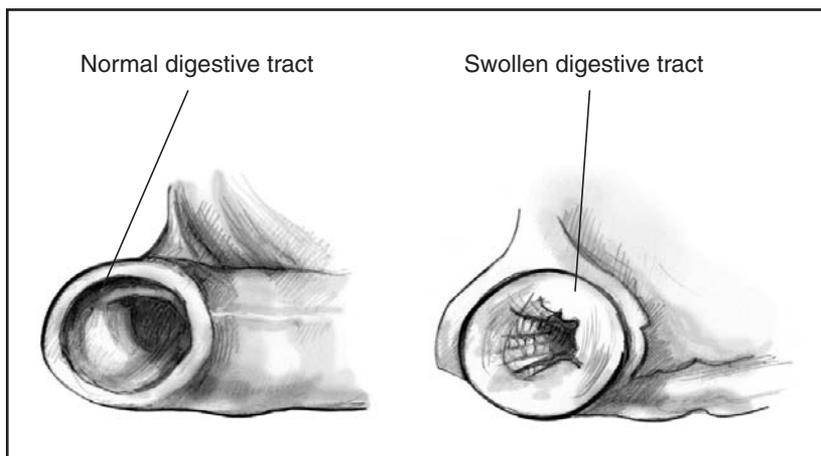


In Crohn's disease, parts of the GI tract become inflamed and scarred.

*See page 22 for tips on how to say the words in **bold** type.

Crohn's disease is one of two main forms of diseases of the GI tract named inflammatory bowel disease (IBD). The other form, called **ulcerative colitis**, affects the large intestine, which includes the colon and the rectum—the lower end of the large intestine, leading to the **anus**.

With Crohn's disease, chronic—or long lasting—inflammation may cause scar tissue to form in the lining of the intestine. When scar tissue builds up, the passage can become narrow, causing food and stool to move through the GI tract more slowly—which can lead to pain, cramps, and diarrhea.



When scar tissue builds up, the passage can become narrow.

Who gets Crohn's disease?

Both men and women can get Crohn's disease, and it can run in families. People with Crohn's disease may have a blood relative with the disease or another type of IBD. Crohn's disease most commonly starts between the ages of 13 and 30.

What causes Crohn's disease?

Researchers are studying the possible causes of Crohn's disease. Your body's natural defense system, called the immune system, protects you from infection by fighting against bacteria, viruses, and other things that can make you sick. Researchers believe that with Crohn's disease, the immune system attacks harmless bacteria and viruses. During the attack, white blood cells gather in the intestinal lining. The white blood cells cause chronic inflammation, which leads to ulcers, or sores, and damage to the intestines.

Other factors associated with Crohn's disease are

- genes—the traits passed down from your parents
- unknown triggers caused by the environment

What are the symptoms of Crohn's disease?

Crohn's disease symptoms can be different for each person. The most common symptoms of Crohn's disease are

- **abdominal** pain—often in the lower right area of the abdomen
- diarrhea
- bleeding in the rectum, which can be seen in a person's underwear, in the toilet, or in a bowel movement; rectal bleeding can be serious and may not stop without medical help
- weight loss
- fever

How is Crohn's disease diagnosed?

A doctor will perform a physical exam and tests to diagnose Crohn's disease. During your visit, the doctor will ask about your symptoms and medical history.

The doctor may order blood tests, which involve drawing blood at a health care provider's office or commercial facility and sending the sample to a lab for analysis. Blood tests can show anemia caused by bleeding. Anemia is a condition in which red blood cells are fewer or smaller than normal, which means less oxygen is carried to the body's cells. Blood tests can also show a high white blood cell count, a sign of chronic inflammation.



You may also be asked for a stool sample. A stool test is commonly used to rule out other causes of GI diseases, such as infections. The doctor will give you a container for catching and storing the stool. The sample is returned to the doctor or a commercial facility and sent to a lab for analysis. A stool sample can also be used to check if you have bleeding or inflammation.

Other tests may be needed to diagnose Crohn's disease. The following tests are all performed at a hospital or outpatient center.

- **Colonoscopy.** Colonoscopy is the most commonly used test to specifically diagnose Crohn's disease. This test is used to look inside your rectum, entire colon, and ileum. The health care provider will give you written bowel prep instructions to follow at home before the test. You may need to follow a clear liquid diet for 1 to 3 days before the test. You will need to take laxatives and enemas the evening before the test, and you will likely have one or more enemas about 2 hours before the test. A laxative is medicine that loosens stool and increases bowel movements. An enema involves flushing water, laxative, or sometimes a mild soap solution into the anus using a special squirt bottle.

For the test, you will lie on a table while the doctor inserts a flexible tube into your anus. A small camera on the tube sends a video image of the intestinal lining to a computer screen. The doctor can see inflammation, ulcers, or bleeding. The doctor may also perform a biopsy. The doctor will look at the tissue with a microscope to confirm the diagnosis of Crohn's disease. In most cases, you'll be given a light sedative, and possibly pain medicine, to help you relax. You will not feel the biopsy.

Cramping or bloating may occur during the first hour after the test. Driving is not permitted for 24 hours after the test to allow the sedative time to wear off. Before the appointment, you should make plans for a ride home. By the next day, you should fully recover and go back to your normal diet.

- **Flexible sigmoidoscopy.** This test is used to look inside the rectum and lower colon. The health care provider will give you written bowel prep instructions to follow at home before the test. You may need to follow a clear liquid diet for 1 to 3 days before the test. You may also need a laxative or enema the night before the test. And you'll have one or more enemas about 2 hours before the procedure.

For the test, you will lie on a table while the doctor inserts a flexible tube into your anus. You will not need a sedative for the test. A small camera on the tube sends a video image of the intestinal lining to a computer screen. The doctor can see inflammation, ulcers, or bleeding. The doctor may also perform a biopsy by snipping a bit of tissue from the intestinal lining. The doctor will look at the tissue with a microscope to confirm the diagnosis of Crohn's disease. You will not feel the biopsy.

You can usually go back to your normal diet after the test, though you may have cramping or bloating during the first hour after the test.

- **Computerized tomography (CT) scan.** A CT scan uses x rays and computers to create images of the inside of the body. For the test, you will lie on a table that slides into a tunnel-shaped device where the x rays are taken. The technician may give you a solution to drink and an injection of a special dye through a needle inserted into an arm vein. You will not need a sedative for the test. CT scans can be used to help diagnose Crohn's disease.
- **Upper GI series (x rays).** An upper GI series may be done to look at the small intestine. No eating or drinking is allowed for 8 hours before the procedure. You will not need a sedative for the test. During the procedure, you will stand or sit

in front of an x-ray machine and drink barium, a chalky liquid. The barium coats the small intestine, making signs of the disease show up more clearly on x rays.

After the test, you may go back to your normal diet, though you may have nausea or bloating for a short time. Traces of barium in the GI tract cause stools to be white or light colored for a few days after the test.

- **Lower GI series (x rays).** A lower GI series may be done to look at the large intestine. The health care provider will give you written bowel prep instructions to follow at home before the test. You will be asked to follow a clear liquid diet for 1 to 3 days before the test. A laxative or enema is usually used the evening before a lower GI series. Enemas are sometimes repeated the morning of the test.

For the test, you will lie on a table while the doctor inserts a flexible tube into your anus. You will not need a sedative for the test. The large intestine is filled with barium, making signs of the disease show up more clearly on x rays. After the test, you may go back to your normal diet, though you may have bloating. You also may have some soreness of the anus. Traces of barium in the GI tract cause stools to be white or light colored for a few days after the test.

What are the problems of Crohn's disease?

Intestinal blockage can occur in people with Crohn's disease when scar tissue blocks the intestinal passage. A narrow intestinal passage is called a **stricture**. When the passage blocks completely, food and stool stop moving, causing abdominal cramps and vomiting. If you have these symptoms, you should see a health care provider right away.

Ulcers from Crohn's disease can cause tunnels to form through the inflamed areas, or even the healthy parts, of the intestine. These tunnels are called **fistulas**. Fistulas are seen most often in the areas around the rectum and anus. Sometimes a pocket of infection, called an abscess, can form in and around the fistulas. Most fistulas can be treated with medicines, but sometimes surgery is needed.

People with Crohn's disease often have anemia, which can be caused by the disease itself or by iron deficiency. Anemia may make a person feel tired.

People with Crohn’s disease, particularly if they have been treated with steroid medicines, may have weakness of their bones—called **osteoporosis** or **osteomalacia**.

People with Crohn’s disease may also have arthritis, skin problems, swelling in the eyes or mouth, kidney stones, gallstones, and liver problems. Some people with Crohn’s disease may have restless legs syndrome—extreme leg discomfort the person feels while sitting or lying down. These problems may go away during treatment, but some must be treated with medicines.

People who have Crohn’s disease may not get enough nutrition, such as protein, vitamins, or calories, because they

- have an upset stomach that keeps them from eating enough calories
- may not be able to absorb nutrients in the intestine

Children with Crohn’s disease may fail to grow normally and may have low height for their age.

How is Crohn's disease treated?

Treatment for Crohn's disease depends on

- where the disease is located in the GI tract
- what problems you already have from the disease
- what past treatments you have had for the disease

The goals of treatment are to

- decrease the inflammation
- relieve symptoms such as abdominal pain, diarrhea, and rectal bleeding
- correct nutritional problems

Treatment may include

- medicines
- surgery
- eating, diet. and nutrition



Medicines

One or more of the following medicines may be used to treat Crohn's disease:

- **Anti-inflammation medicines** may be used first to treat your Crohn's disease. These medicines help lower inflammation in the intestine and relieve the pain and diarrhea. Sometimes anti-inflammation medicines cause side effects, so you should talk with your health care provider about what to expect.
- **Steroids** also help lower inflammation. Steroids are similar to natural chemicals in the body. However, steroids are used only for a short time because long-term use can lead to serious side effects.
- **Immune system suppressors.** Azathioprine and 6-mercaptopurine work by keeping your immune system from attacking harmless foreign substances. Immune system suppressors also cause side effects, so you should talk with your health care provider about what to expect.

- **Biological therapies.** Biological therapies are medicines that are given by an injection in the vein, infliximab (Remicade), or an injection in the skin, adalimumab (HUMIRA). Your health care provider may treat you with these medicines if others are not helping to decrease inflammation, or if you have fistulas with abscesses. The goals for using these medicines are to get you better, keep you better, and avoid long-term steroid use.
- **Antibiotics.** Antibiotics are used to treat bacterial overgrowth in the small intestine caused by stricture, fistulas, or surgery. For this common problem, the doctor may prescribe one or more of the following antibiotics: ampicillin, sulfonamide, cephalosporin, tetracycline, or metronidazole.



- **Anti-diarrheal medicines and fluid replacements.** Diarrhea and abdominal cramps are often relieved when the inflammation improves, but more medicine may be needed. Anti-diarrheal medicines include diphenoxylate, loperamide, and codeine. People with diarrhea should drink plenty of fluids to prevent **dehydration**—loss of fluids from the body. If diarrhea does not improve, the person should see the doctor promptly for possible treatment with fluids given through a small tube inserted into an arm vein.

Surgery

Some people with Crohn's disease need surgery if medicines are no longer working to control blockage, fistulas, abscesses, and bleeding. A surgeon performs the procedure in a hospital, where you will receive medicine to make you sleep during the surgery.

One or more of the following surgeries may be needed:

- **Intestinal resection.** The surgeon removes the diseased section of intestine and puts the ends of the intestine back together.

- **Proctocolectomy.** Proctocolectomy is surgery to remove the rectum and part or all of the colon. An ileostomy is performed with a proctocolectomy.
- **Ileostomy.** Ileostomy is an operation to create an opening—called a stoma—for the stool to exit the body when the ends of the intestine cannot be put back together. To create a stoma, an end of the intestine is brought out through a small opening made on the lower right part of the abdomen near the beltline. The stoma is about the size of a quarter. An ostomy pouch is worn outside the body over the stoma to collect waste, and it is emptied several times a day. Your health care provider may refer you to an ostomy nurse—a specialist who cares for people with an ostomy pouch.

Surgery usually does not cure Crohn’s disease forever. Sometimes you need to have more than one surgery because the disease returns next to where the intestine was removed. Because Crohn’s disease can return after surgery, you can talk with your health care provider and other patients to get as much information as possible before having surgery.

Eating, Diet, and Nutrition

Your health care provider may start you on a special diet, so you get extra nutrition and calories. High-calorie liquid supplements are often used to give you the extra calories and right amount of vitamins and minerals to keep you healthy. During acute phases of the disease, you may need to receive intravenous nutrition to give the intestine a rest.

No foods are known to cause injury or inflammation to the intestine. But foods such as hot spices, alcohol, greasy foods, and milk products may make diarrhea and cramping worse. You should eat a healthy diet and avoid foods that make symptoms worse. Your health care provider may refer you to a dietitian to help you with meal planning.

Can smoking make Crohn's disease worse?

People with Crohn's disease who smoke may have worse symptoms and more problems from the disease. If you smoke, you're more likely to need surgery than a person with Crohn's disease who does not smoke. Quitting smoking can help make your Crohn's disease less severe. Ask your health care provider if you need help quitting smoking.

Can stress make Crohn's disease worse?

People with Crohn's disease sometimes feel more stress in their lives, which can make symptoms worse. Eating well, getting enough rest, and learning to relax may help you through stressful times. Support groups may help lower stress for people with Crohn's disease. Ask your health care provider for help finding support groups.

Even though you may need medicines and other treatments, you may feel well and be symptom-free for long periods of time. Most people with Crohn's disease are able to work, raise families, and live full lives.

Is pregnancy safe for women with Crohn's disease?

Many women with Crohn's disease can become pregnant and have a baby. However, if you are a woman with Crohn's disease, you should talk with your health care provider before getting pregnant.

Points to Remember

- Crohn's disease is a disease that causes inflammation, or swelling, and irritation of any part of the digestive tract—also called the gastrointestinal (GI) tract.
- People with Crohn's disease may have a blood relative with the disease or another type of inflammatory bowel disease (IBD).
- Symptoms of Crohn's disease include abdominal pain, diarrhea, bleeding, weight loss, and fever.
- A physical exam, blood tests, stool tests, and other tests are needed to diagnose Crohn's disease.
- Problems of Crohn's disease include intestinal blockage, fistulas, abscesses, anemia, and slower growth in children.

- Doctors treat Crohn's disease with medicines, surgery, diet, and nutrition.
- People with Crohn's disease should eat a healthy diet and avoid foods that make symptoms worse.
- Quitting smoking can help make Crohn's disease less severe. Ask your health care provider if you need help quitting smoking.
- Support groups may help lower stress for people with Crohn's disease.
- Most people with Crohn's disease are able to work, raise families, and live full lives.
- Many women with Crohn's disease can become pregnant and have a baby. You should talk with your health care provider before getting pregnant.

Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK's) Division of Digestive Diseases and Nutrition supports research into digestive conditions, including Crohn's disease. Researchers are working to better understand genes and Crohn's disease. They are also studying new medicines and ways to deliver medicines that might be more effective than current treatments.

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. For information about current studies, visit www.ClinicalTrials.gov.

Pronunciation Guide

abdominal (ab-DOM-ih-nul)

anus (AY-nuhss)

colonoscopy (KOH-lon-OSS-kuh-pee)

dehydration (DEE-hy-DRAY-shuhn)

fistulas (FISS-tyoo-luhs)

ileostomy (IL-ee-OSS-tuh-mee)

inflammation (IN-fluh-MAY-shuhn)

intestinal resection (in-TESS-tih-nuhl)
(ree-SEK-shuhn)

osteomalacia (OSS-tee-oh-muh-LAY-shee-uh)

osteoporosis (OSS-tee-oh-poh-ROH-siss)

proctocolectomy (PROK-toh-koh-LEK-tuh-mee)

sigmoidoscopy (SIG-moy-DOSS-kuh-pee)

stricture (STRIK-choor)

ulcerative colitis (UHL-sur-uh-tiv) (koh-LY-tiss)

For More Information

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Reach Out for Youth with Ileitis and Colitis, Inc.

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