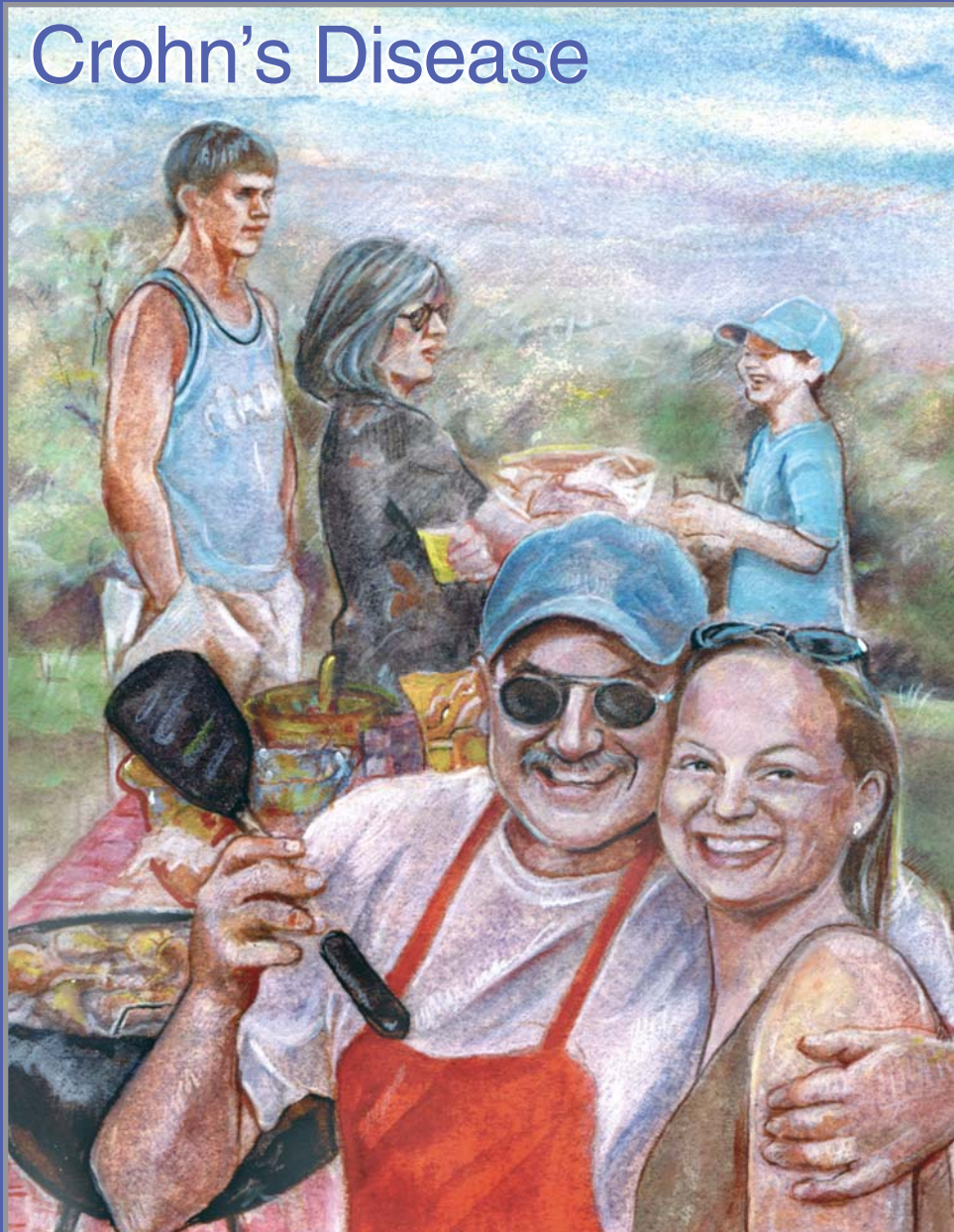


What I need to know about Crohn's Disease



NATIONAL INSTITUTES OF HEALTH
National Digestive Diseases Information Clearinghouse



U.S. Department
of Health and
Human Services

What I need to know about Crohn's Disease



NATIONAL INSTITUTES OF HEALTH
National Digestive Diseases Information Clearinghouse

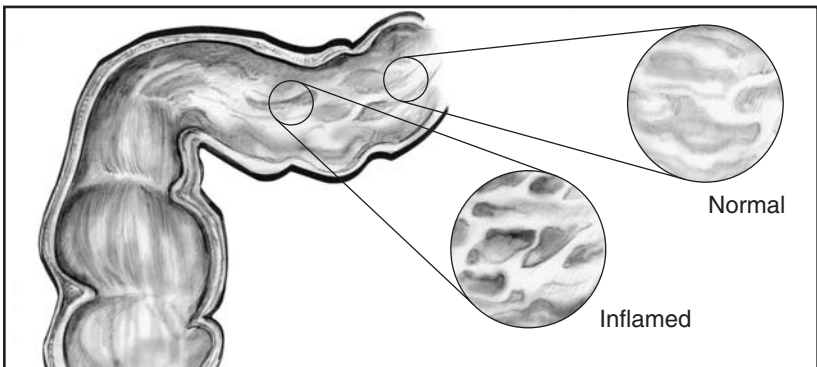
Contents

What is Crohn's disease?	1
Who gets Crohn's disease?	2
What are the symptoms of Crohn's disease?	2
What causes Crohn's disease?	3
How is Crohn's disease diagnosed?	4
What are the complications of Crohn's disease?	6
How is Crohn's disease treated?	7
Glossary	13
For More Information	14
Acknowledgments	15

What is Crohn's disease?

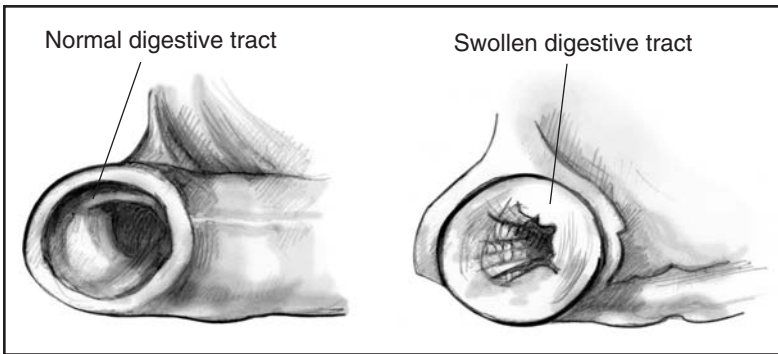
Crohn's disease causes inflammation of parts of the digestive tract. Inflammation is irritation and swelling. The inflammation, mostly caused by sores called ulcers, can cause pain and diarrhea. The digestive tract is the pathway food travels through in the body. This pathway is also called the gastrointestinal, or GI, tract. It goes from the mouth to the anus. Crohn's disease can sometimes be hard to diagnose because its symptoms are like the symptoms of other GI diseases.

Crohn's disease can affect any area of the GI tract, but it most often affects a part of the small intestine called the **ileum**.*



In Crohn's disease, portions of the digestive tract become inflamed. The diseased lining of the digestive tract becomes swollen and scarred.

*Words in **bold** type are defined in the glossary on page 13.



Swelling in the digestive tract makes the passage narrow.

Who gets Crohn's disease?

Crohn's disease can run in families. As many as 20 percent of people with Crohn's disease have a relative with Crohn's disease or another inflammatory bowel disease. It is most common in people between the ages of 20 and 30. Both men and women can have Crohn's disease.

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 and diarrhea. Some people have bleeding in the rectum, which is the lower end of the GI tract, just before the anus. Rectal bleeding can be serious and may not stop

without medical help. Bleeding can lead to anemia, meaning the body has lost too many red blood cells. Anemia makes a person feel tired. People can also have weight loss, skin problems, and fevers. Children with Crohn's disease may develop and grow slower than most other children or they may not reach their expected full height.

What causes Crohn's disease?

Scientists have many ideas about what causes Crohn's disease. The immune system in people with Crohn's disease may mistake bacteria and foods as being "invaders." The immune system then attacks these invaders, causing white blood cells to gather in the lining of the intestines. This "gathering" leads to swelling and intestinal damage.

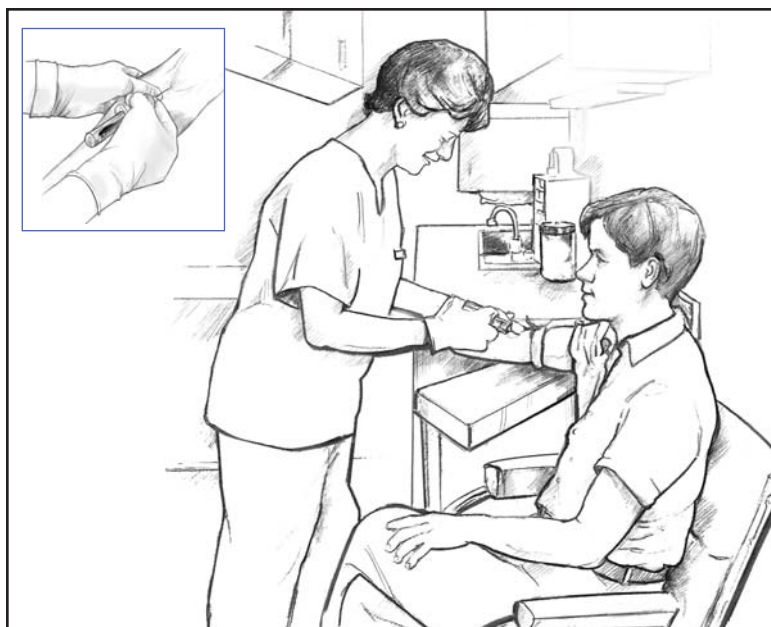
The immune system's response to these invaders may be either a cause or a result of the disease. Many things are associated with inflammation in the GI tract, such as

- a person's genes
- the immune system not being able to recognize harmless GI bacteria
- unknown triggers caused by the environment

How is Crohn's disease diagnosed?

A detailed personal history, a physical exam, and tests are needed to diagnose Crohn's disease. During your visit the doctor will ask about your symptoms and health. The doctor may run blood tests. You may also be asked for a stool sample.

Blood tests can uncover anemia. Anemia can mean you have bleeding in your intestines. Blood tests can also show a high white blood cell count, a sign of inflammation in the body. A stool sample can be used to check if you have bleeding and rule out an infection.



X rays may be needed. The doctor may also do an upper GI series and small bowel follow-through to look at your small intestine. For this test, you will drink barium, a chalky liquid. The barium looks white on x-ray film, helping the doctor see ulcers or other problems.

The doctor may also do a **sigmoidoscopy** or a **colonoscopy** to get a better look inside the intestines. For both tests, the doctor places a long tube into the anus. The tube travels through about 3 feet of the large intestine and sometimes into the very end of your small intestine. The doctor can see any inflammation, ulcers, or bleeding because the tube is linked to a TV screen that shows pictures of the intestines.

The doctor may also do a biopsy. A biopsy is when the doctor snips a bit of tissue, in this case, from the lining of the intestine. The doctor will look at the tissue with a microscope to confirm the diagnosis of Crohn's disease. You will be given medicine to make you sleepy during the procedure. You will not feel the biopsy.

What are the complications of Crohn's disease?

Intestinal blockage can occur in people with Crohn's disease. Blockage occurs because the intestinal wall thickens or swells from inflammation and scar tissue. Ulcers can also cause tunnels to form through the inflamed areas of the intestine or even the healthy parts. These tunnels are called **fistulas**. Sometimes pockets of infection, called abscesses, can form in and around the fistulas. Fistulas can be treated with medicine, but sometimes surgery is needed.

People with Crohn's disease often don't get the nutrients they need. If you have Crohn's disease, you may not get enough protein, vitamins, or calories in your diet. If you aren't getting nutrients, it may be because you

- have an upset stomach that keeps you from eating enough
- may be losing protein in the intestine
- may not be able to absorb nutrients from your food

Other problems that some people with Crohn's disease suffer from are arthritis, skin problems, swelling in the eyes or mouth, kidney stones, and gallstones. Some of these problems go away during treatment. But some must be treated with additional medicines.

How is Crohn's disease treated?

Treatment for Crohn's disease depends on

- where the disease is located
- how bad the disease is
- what problems you already have from the disease
- what past treatments you have had

The goals of treatment are to

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

Treatment may include

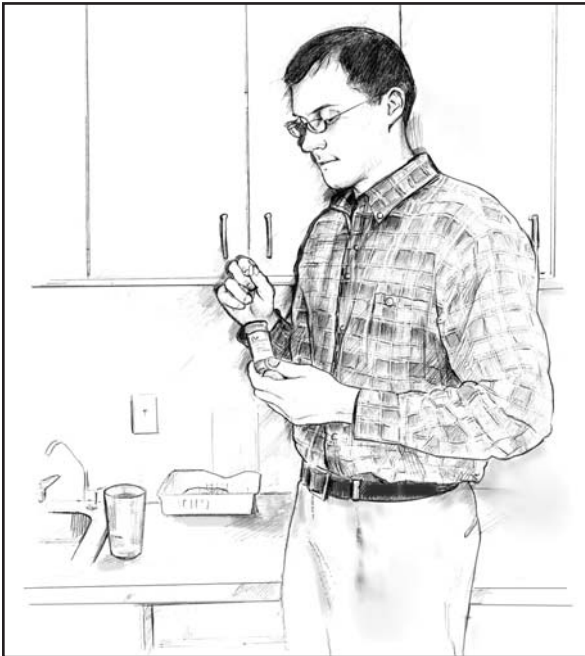
- drugs
- minerals and vitamins
- surgery
- nutritional support



Drug Treatment

The doctor may first treat your Crohn's disease with **anti-inflammatory** drugs. These drugs help stop inflammation and help relieve the pain and diarrhea. Sometimes these drugs cause side effects, so you should talk with your doctor about what to expect.

Your doctor may also need to treat you with steroids. Steroids are made from natural chemicals in the body. However, steroids are used only for a short time because long-term exposure is not good for a person.



Immune system suppressors are also used. They work by keeping your body from attacking itself. Ask your doctor about side effects.

Your doctor may also prescribe infliximab (Remicade) or adalimumab (Humira). Remicade and Humira are very strong drugs that need to be given by an injection in the vein. You can speak with your doctor and discuss if one of these drugs is right for you.

The goal for using these drugs is to avoid long-term steroid use, to get you better, and keep you better.

Diet

No foods are known to cause injury or inflammation to the bowel. But when people have Crohn's disease, hot spices, alcohol, greasy foods, and sometimes milk products may make diarrhea and abdominal pain worse. Your doctor may start you on a special diet so you get extra nutrients. High-calorie liquid supplements are often used to give you the extra calories and right amount of vitamins and minerals to keep you healthy.

Surgery

Some people with Crohn's disease may need surgery to treat blockage, fistulas, infection, and bleeding if medicines are no longer working. Surgery usually does not make a person disease-free forever. Sometimes people need to have many surgeries because the inflammation and symptoms come back.

The most common surgery for Crohn's disease is removing only the diseased section of intestine. In this operation, after the diseased piece of the intestine is cut out, the intestine is put back together.

On rare occasions the surgeon cannot put the two ends back together and needs to create an outlet, or stoma, also called an ostomy. To create a stoma, an end of the small intestine that was not connected is brought out through a small opening made on the lower abdominal wall. The stoma is about the size of a quarter. A small bag is worn over the opening to collect waste, and the person empties the bag as needed.

People who have Crohn's disease involving all or part of the large intestine may need to have their entire colon removed in an operation called a **colectomy**. If the whole colon is removed, a stoma is usually needed.

Because people can have symptoms even after surgery, they should talk with their doctor and other patients before making a choice. People should know what to expect from surgery and decide what drugs, if any, would work best afterwards to try to stop the disease from coming back. Groups for people with Crohn's disease can help a person find support.

People with Crohn's disease may feel well and be symptom-free for a long time. They may need to take drugs for long periods of time, but most are able to hold jobs, raise families, and live fulfilling lives.

Glossary

anti-inflammatory (AN-tee-in-FLAM-uh-toh-ree): preventing or reducing inflammation.

colectomy (koh-LEK-toh-mee): an operation to remove all or part of the colon.

colonoscopy (KOH-lon-OSS-kuh-pee): a test to look into the rectum and colon. The doctor uses a long, flexible, narrow tube with a light and tiny lens on the end. This tube is called a colonoscope.

fistulas (FISS-tyoo-luhs): an abnormal passage between two organs or between an organ and the outside of the body. Caused when damaged tissues come into contact with each other and join together while healing.

ileum (IL-ee-uhm): the lower end of the small intestine.

sigmoidoscopy (SIG-moy-DOSS-kuh-pee): looking into the sigmoid colon and rectum with a flexible or rigid tube, called a sigmoidoscope.

For More Information

Crohn's & Colitis Foundation of America

386 Park Avenue South, 17th Floor

New York, NY 10016-8804

Phone: 1-800-932-2423

Email: info@ccfa.org

Internet: www.ccfa.org

Reach Out for Youth with Ileitis and Colitis, Inc.

84 Northgate Circle

Melville, NY 11747

Phone: 631-293-3102

Email: reachoutforyouth@reachoutforyouth.org

Internet: www.reachoutforyouth.org

United Ostomy Associations of America, Inc.

P.O. Box 66

Fairview, TN 37062

Phone: 1-800-826-0826

Email: info@uoaa.org

Internet: www.uoaa.org

Acknowledgments

The National Digestive Diseases Information Clearinghouse (NDDIC) would like to thank the following individual for assisting with the scientific and editorial review of this publication:

Marla Dubinsky, M.D.
Cedars-Sinai Medical Center
Los Angeles, CA

Thanks also to Jyl Pomeroy, B.S., R.N., at the Arlington Free Clinic, Arlington, VA, for facilitating field-testing of this publication.

The U.S. Government does not endorse or favor any specific commercial product or company. Trade, proprietary, or company names appearing in this document are used only because they are considered necessary in the context of the information provided. If a product is not mentioned, the omission does not mean or imply that the product is unsatisfactory.

National Digestive Diseases Information Clearinghouse

2 Information Way
Bethesda, MD 20892-3570
Phone: 1-800-891-5389
Fax: 703-738-4929
Email: nddic@info.niddk.nih.gov
Internet: www.digestive.niddk.nih.gov

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health of the U.S. Department of Health and Human Services. Established in 1980, the Clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. The NDDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases.

Publications produced by the Clearinghouse are carefully reviewed by both NIDDK scientists and outside experts.

This publication is not copyrighted. The Clearinghouse encourages users of this booklet to duplicate and distribute as many copies as desired.

This booklet is also available at www.digestive.niddk.nih.gov.



U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
National Institutes of Health



National Institute of Diabetes and
Digestive and Kidney Diseases

NIH Publication No. 07-5774
May 2007