



About Crohn's Disease

When you first learn that you have Crohn's disease, you will probably feel overwhelmed. You may not even have heard of Crohn's disease until now. And even if you are familiar with the disorder, the information you have may be pretty limited. That's all about to change. Clearly, you will have many questions about how this disease will affect you -- both now and down the road. For example, you'll want to know:

- Will I be able to work, travel, and exercise?
- Should I be on a special diet?
- How will other people react to my illness?
- Could my medications have side effects?
- How will Crohn's disease change my life?

Learning all you can is an important step toward taking charge of your illness -- and your life. The following is an overview of Crohn's disease. It is designed to help you understand more about the diagnosis and treatment of this illness, and its impact on the day-to-day lives of patients and their families. The better informed you are about Crohn's disease, the more equipped you'll be to participate as an active member of your healthcare team.

What is Crohn's Disease?

Crohn's disease is a chronic (ongoing) disorder that causes inflammation of the digestive or gastrointestinal (GI) tract. Although it can involve any area of the GI tract from the mouth to the anus, it most commonly affects the small intestine and/or colon. The disease is named after Dr. Burrill B. Crohn. In 1932, Dr. Crohn and two colleagues, Dr. Leon Ginzburg and Dr. Gordon D. Oppenheimer, published a landmark paper describing the features of what is known

today as Crohn's disease. Crohn's and a related disease, ulcerative colitis, are the two main disease categories that belong to a larger group of illnesses called inflammatory bowel disease (IBD).

Because the symptoms of these two illnesses are so similar, it is sometimes difficult to establish the diagnosis definitively. In fact, approximately 10 percent of colitis cases are unable to be pinpointed as either ulcerative colitis or Crohn's disease and are called indeterminate colitis.

Both illnesses do have one strong feature in common. They are marked by an abnormal response by the body's immune system. The immune system is composed of various cells and proteins. Normally, these protect the body from infection. In people with Crohn's disease, however, the immune system reacts inappropriately. Researchers believe that the immune system mistakes microbes, such as bacteria that is normally found in the intestines, for foreign or invading substances, and launches an attack. In the process, the body sends white blood cells into the lining of the intestines, where they produce chronic inflammation. These cells then generate harmful products that ultimately lead to ulcerations and bowel injury. When this happens, the patient experiences the symptoms of IBD.

Although Crohn's disease most commonly affects the end of the small intestine (the ileum) and the beginning of the large intestine (the colon), it may involve any part of the GI tract. In ulcerative colitis, on the other hand, the GI involvement is limited to the colon. In Crohn's disease, all layers of the intestine may be involved, and there can be normal healthy bowel in between patches of diseased bowel. In contrast, ulcerative colitis affects only the superficial layers (the mucosa) of the colon in a more even and continuous distribution, which starts at the level of the anus.

What Causes Crohn's Disease?

Although considerable progress has been made in IBD research, investigators do not yet know what causes this disease. Studies indicate that the inflammation in IBD involves a complex interaction of factors: the genes the person has inherited, the immune system, and something in the environment. Foreign substances (antigens) in the environment may be the direct cause of the inflammation, or they may stimulate the body's defenses to produce an inflammation that continues without control. Researchers believe that once the IBD patient's immune system is "turned on," it does not know how to properly "turn off" at the right time. As a result, inflammation damages the intestine and causes the symptoms of IBD. That is why the main goal of medical therapy is to help patients regulate their immune system better.

CCFA-sponsored research has led to progress in the fields of immunology, the study of the body's immune defense system; microbiology, the study of microscopic organisms with the power to cause disease; and genetics. Many scientists now believe that the interaction of an outside agent (such as a virus or bacterium) with the body's immune system may trigger the disease, or that such an agent may cause damage to the intestinal wall, initiating or accelerating the disease process. Through CCFA's continuing research efforts, much more will be learned and a cure will eventually be found.

How Common is Inflammatory Bowel Disease (IBD)?

It is estimated that as many as one million Americans have IBD -- with that number evenly split between Crohn's disease and ulcerative colitis. Males and females appear to be affected equally. Crohn's disease may occur in people of all ages, but it is primarily a disease of adolescents and young adults, affecting mainly those between 15 and 35. However, Crohn's disease can also occur in people who are 70 or older and in young children as well. In fact, 10 percent of those affected -- or an estimated 100,000 -- are youngsters under the age of 18.

Who Gets IBD?

IBD tends to run in families, so we know that genes definitely play a role in the IBD picture. Studies have shown that about 20 to 25 percent of patients may have a close relative with either Crohn's or ulcerative colitis. If a person has a relative with the disease, his or her risk is about 10 times greater than that of the general population. If that relative happens to be a brother or sister, the risk is 30 times greater.

Researchers have been working actively for some time to find a link to specific genes that control the transmission of this illness. Recently, an important breakthrough was achieved when the first gene for Crohn's disease was identified by a team of IBD investigators. The researchers were able to pick out an abnormal mutation or alteration in a gene known as NOD2/CARD 15.. This mutation, which limits the ability to recognize bacteria as harmful, occurs twice as frequently in Crohn's patients as in the general population. There is no way to predict which, if any, family members will develop Crohn's disease. The data further suggest that more than one gene may be involved. Thanks to new technologies, researchers are closing in on the additional genes that may be involved in IBD.

Race and Ethnicity

IBD also appears to affect certain ethnic groups more than others. For example, American Jews of European descent are four to five times more likely to develop IBD than the general population. IBD has long been thought of as a disease predominantly affecting whites; the prevalence rate (the number of people with a disease at a given time) among whites is 149 per 100,000. However, there has been a steady increase in reported cases of both Crohn's disease and ulcerative colitis among African Americans. The prevalence rates among Hispanics and Asians are lower than those for whites and African Americans.

Environment

For reasons that are not yet clearly understood, IBD is largely a disease of the developed world, and is found principally in the U.S. and Europe. Similarly, Crohn's disease and ulcerative colitis are reported to be more common in urban than in rural areas, and in northern than in southern climates. Moreover, the frequency of disease increases when specific groups of people move from underdeveloped to developed countries, and vice versa.

What Are the Symptoms?

Persistent diarrhea (loose, watery, or frequent bowel movements), crampy abdominal pain, fever, and, at times, rectal bleeding: These are the hallmark symptoms of Crohn's disease, but they vary from person to person and may change over time. Loss of appetite and subsequent weight loss also may occur. However, the disease is not always limited to the GI tract; it can also affect the joints, eyes, skin, and liver. Fatigue is another common complaint. Children who have Crohn's disease may suffer delayed growth and sexual development.

Some patients may develop tears (fissures) in the lining of the anus, which may cause pain and bleeding, especially during bowel movements. Inflammation may also cause a fistula to develop. A fistula is a tunnel that leads from one loop of intestine to another, or that connects the intestine to the bladder, vagina, or skin. Fistulas occur most commonly around the anal area. If this complication arises, you may notice drainage of mucus, pus, or stool from this opening.

Symptoms may range from mild to severe. Because Crohn's is a chronic disease, patients will go through periods in which the disease flares up, is active, and causes symptoms. These episodes are followed by times of remission -- periods in which symptoms disappear or decrease and good health returns. In general, though, people with Crohn's disease lead full, active, and productive lives.

Types of Crohn's Disease and Associated Symptoms

The symptoms and complications of Crohn's disease differ, depending on what part of the intestinal tract is inflamed. That's why it is important for you to know which part of your intestine is affected by Crohn's disease. Your doctor may also refer to your illness by various names based on the principal area involved. The following are five types of Crohn's disease, together with their presenting symptoms:

- ***Ileocolitis***: The most common form of Crohn's, affecting the ileum and colon. Symptoms include diarrhea and cramping or pain in the right lower part or middle of the abdomen. Often accompanied by significant weight loss.
- ***Ileitis***: Affects the ileum. Symptoms same as ileocolitis. Complications may include fistulas or inflammatory abscess in right lower quadrant of abdomen.
- ***Gastroduodenal Crohn's disease***: Affects the stomach and duodenum (the first part of the small intestine). Symptoms include loss of appetite, weight loss, and nausea. Vomiting may indicate that narrowed segments of the bowel are obstructed.
- ***Jejunioileitis***: Produces patchy areas of inflammation in the jejunum (upper half of the small intestine). Symptoms include abdominal pain (ranging from mild to intense) and cramps following meals, as well as diarrhea. Fistulas may form.
- ***Crohn's (granulomatous) colitis***: Affects the colon only. Symptoms include diarrhea, rectal bleeding, and disease around the anus (abscess, fistulas, ulcers). Skin lesions and joint pains are more common in this form of Crohn's than in others.

How is Crohn's Disease Diagnosed?

There is no single test that can establish the diagnosis of Crohn's disease with certainty. To determine the diagnosis, physicians evaluate a combination of information from the patient's history and physical exam. They examine the results of laboratory tests, X-rays, and findings on endoscopy and pathology tests, and exclude other known causes of intestinal inflammation. X-ray tests may include barium studies of the upper and lower GI tract. Endoscopy tests may include flexible sigmoidoscopy and, sometimes, colonoscopy, which allow the doctor to directly examine the colon with a lighted tube that is inserted through the anus. During these tests, biopsies may be obtained. This procedure involves the removal of a small piece of tissue for closer analysis. It is important to make sure that an infection is not causing the patient's symptoms, so one routine test is to examine the stool for harmful organisms. Because Crohn's disease

often mimics other conditions and symptoms may vary widely, it may take some time to arrive at the correct diagnosis.

What Medications are Used to Treat This Disease?

Because there is no cure for Crohn's disease, the goal of medical treatment is to suppress the inflammatory response. This step accomplishes two important goals: It allows the intestinal tissue to heal and it also relieves the symptoms of fever, diarrhea, and abdominal pain. Once the symptoms are brought under control (this is known as *inducing remission*), medical therapy is used to decrease the frequency of disease flares (this is known as *maintaining remission*, or *maintenance*).

Several groups of drugs are used to treat Crohn's disease today. They are:

1. ***Aminosalicylates (5-ASA)***: This class of anti-inflammatory drugs includes sulfasalazine and oral formulations of mesalamine, such as Asacol,[®] Colazal,[®] Dipentum,[®] or Pentasa,[®] and 5-ASA drugs also may be administered rectally (Canasa[®] or Rowasa[®]). These medications typically are used to treat mild to moderate symptoms.
2. ***Corticosteroids***: Prednisone and methylprednisolone are available orally and rectally. Corticosteroids nonspecifically suppress the immune system and are used to treat moderate to severely active Crohn's disease. (By "nonspecifically," we mean that these drugs do not target specific parts of the immune system that play a role in inflammation, but rather, that they suppress the entire immune response.) These drugs have significant short- and long-term side effects and should not be used as a maintenance medication. If you cannot come off steroids without suffering a relapse of your symptoms, your doctor may need to add some other medications to help manage your disease.
3. ***Immune modifiers***: Azathioprine (Imuran[®]), 6-MP (Purinethol[®]), and methotrexate. Immune modifiers, sometimes called *immunomodulators*, are used to help decrease corticosteroid dosage and also to help heal fistulas. In addition, immune modifiers can help maintain disease remission.
4. ***Antibiotics***: metronidazole, ampicillin, ciprofloxacin, others.

5. *Biologic therapies.* In August 1998, the FDA approved the first biologic therapy for Crohn's disease. This was infliximab (Remicade®), which is indicated for moderately to severely active Crohn's in patients *who have not responded adequately to conventional therapy*. It is also approved for reducing the number of draining enterocutaneous fistulas. In June of 2002, infliximab was approved by the FDA for a new indication - maintaining remission. Infliximab is given by infusion.

Infliximab is a chimeric (a hybrid consisting of 75 percent human, 25 percent mouse protein) monoclonal antibody. The antibody works by blocking the immune system's production of tumor necrosis factor-alpha (TNF-alpha). This is a cytokine (chemical) that intensifies inflammation.

Several other biologic agents for both Crohn's disease and ulcerative colitis are being studied in clinical trials currently, but none are yet commercially available.

Complications of Crohn's Disease

The most common complication of Crohn's disease is obstruction or blockage of the intestine due to swelling and the formation of scar tissue. The result is thickening of the bowel wall and a significantly narrowed intestinal passage. Symptoms of intestinal obstruction include crampy pain around the mid-abdomen, frequently associated with vomiting. The abdomen may also become bloated and distended. Medications may relieve the obstruction by reducing the local area of inflammation, but surgery may be required if the obstruction is severe and does not respond to medical treatment. Surgery may also be indicated if the blockage recurs frequently.

Another complication is sores or ulcers within the intestinal tract. Sometimes these deep ulcers turn into tracts -- called fistulas -- that connect different parts of the intestine. But fistulas may also tunnel into surrounding tissues such as the bladder, vagina, or skin. These abnormal passages, which affect about 30 percent of people with Crohn's disease, often become infected. If the fistula is small, medical

treatment may be sufficient to heal it. Large or multiple fistulas, on the other hand, may signal the need for surgery, particularly if they are accompanied by fairly persistent symptoms, such as fever or abdominal pain. Occasionally a fistula forms an abscess, or collection of pus, near the intestine. This is a pocket of infection that requires drainage either through a catheter inserted by a radiologist or a special drain that is surgically inserted. The areas around the anus and rectum are often involved. In addition to fistulas, cracks or fissures may also develop in the lining of the mucus membrane of the anus.

Another type of complication commonly encountered in people with Crohn's disease is related to malnutrition or the presence of nutritional deficiencies. These are deficiencies of proteins, calories, and vitamins. They generally do not develop unless the disease is extensive and of long duration, conditions that may contribute to inadequate dietary intake and poor absorption of nutrients. Medical treatment is usually effective in the replacement of nutrients. For example, a deficiency in vitamin B-12 can be corrected by an injection of this vitamin. Similarly, an iron deficiency can be reversed by taking this mineral in liquid or tablet form. Nutritional supplements, containing both vitamins and minerals, are available in concentrated form.

What Is the Role of Surgery?

Two-thirds to three-quarters of patients with Crohn's disease will require surgery at some point during their lives. Surgery becomes necessary in Crohn's disease when medications can no longer control the symptoms. It may also be performed to repair a fistula or fissure. Another indication for surgery is the presence of an intestinal obstruction or other complication, such as an intestinal abscess. In most cases, the diseased segment of bowel and any associated abscess is removed; this is called a resection. The two ends of healthy bowel are then joined together in a procedure called an anastomosis. While resection and anastomosis may allow many symptom-free years, this surgery is not considered a cure for Crohn's disease, because the disease frequently recurs at or near the site of anastomosis.

An ileostomy also may be required when surgery is performed for Crohn's disease of the colon. After the surgeon removes the colon, he brings the small bowel to the skin, so that waste products may be emptied into a pouch attached to the abdomen. This procedure is needed if the rectum is diseased and cannot be used for an anastomosis.

The overall goal of surgery in Crohn's disease is to conserve bowel and return the individual to the best possible quality of life.

The Role of Nutrition

There is no evidence that any particular foods cause or contribute to Crohn's disease or other types of IBD. Once the disease has developed, however, paying special attention to diet may help reduce symptoms, replace lost nutrients, and promote healing.

Good nutrition is essential for anyone who has a chronic disease, but it is especially important in Crohn's disease for several reasons. First, the appetite is often reduced in people with Crohn's. Second, chronic diseases tend to increase the energy or caloric needs of the body. This is particularly true during episodes of disease "flares." And third, Crohn's is associated with diarrhea and poor absorption of dietary protein, fat, carbohydrates, and water. All these symptoms rob the body of fluids, nutrients, and a wide variety of vitamins and minerals. Restoring and maintaining proper nutrition is a vital part of the medical management of Crohn's disease.

When Crohn's disease is active, soft, bland foods may cause less discomfort than spicy or high-fiber foods. Except for restricting milk in lactose-intolerant patients, most gastroenterologists try to be flexible in planning the diets of their Crohn's patients. A healthy diet should contain a variety of foods from all food groups. Meat, fish, poultry, and dairy products (if tolerated) are sources of protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrate; margarine and oils are sources of fat.

Emotional Factors and Coping With Crohn's Disease

Because body and mind are so closely interrelated, emotional stress can influence the course of Crohn's disease-or, for that matter, any other chronic illness. Although people occasionally experience emotional problems before a flare-up of their disease, this does not imply that emotional stress causes the illness. There is no evidence to show that stress, anxiety, or tension is responsible for Crohn's disease. No single personality type is more prone to develop Crohn's than others, and no one "brings on" the disease by poor emotional control.

It is much more likely that the emotional distress that patients sometimes feel is a reaction to the symptoms of the disease itself. It is not surprising that some patients find it difficult to cope with a chronic illness. Such illnesses seem to pose a threat to their entire quality of life -- their physical and emotional well-being, social functioning, and sense of self-esteem. People with Crohn's disease should receive understanding and emotional support from their families and physicians. Although formal psychotherapy is generally not necessary, some patients are helped considerably by speaking with a therapist who is knowledgeable about IBD or about chronic illness in general. CCFA offers local support groups to help patients and their families cope with IBD.

Coping techniques for dealing with Crohn's disease may take many forms. Attacks of diarrhea, pain, or gas may make people fearful of being in public places. In such a situation, some practical advance planning may help alleviate this fear. For instance, find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation ahead of time. Some people find it helps to carry along extra underclothing or toilet paper for particularly long trips. When venturing further afoot, always consult with your physician. Travel plans should include a large enough supply of your medication, its generic name in case you run out or lose it, and the name of physicians in the area you may be visiting.

People with Crohn's disease accept the diagnosis with a wide range of emotions. Some people are angry for a time. Others feel a sense of relief at finally knowing what it is that has made them ill. While it certainly may help to come to terms with Crohn's in a straightforward manner, since this approach may maximize your ability to be part of your health care team right from the start, everyone is different. Each person with the disease must adjust to living with Crohn's in their own way. There should be no guilt, no self-reproaches, or blame placed on others as you come to grips with your illness. There are resources and information available, such as local support groups and IBD education seminars. No one with Crohn's should ever feel alone. As you go about your daily life as normally as possible, try pursuing some of the same activities that you did before your diagnosis. Some days, you may not feel up to it. Other days, you will want to give it all you've got. Only you can decide what's right for you. It will help to follow your physician's instructions and maintain a positive outlook, and to take an active role in your care. That's the basic (and best) prescription.

While Crohn's is a serious chronic disease with many complications, it is not considered a fatal illness. Most people with the illness may continue to lead useful and productive lives, even though they may be hospitalized from time to time, or need to take medications. In between flare-ups of the disease, many individuals feel well and may be relatively free of symptoms. But again, everyone is different, and it is up to you and your physician to find the treatment that works best for you.

The preceding information provided by:

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For more information on CCFA and Crohn's Disease please visit their site at: <http://www.ccfa.org/>