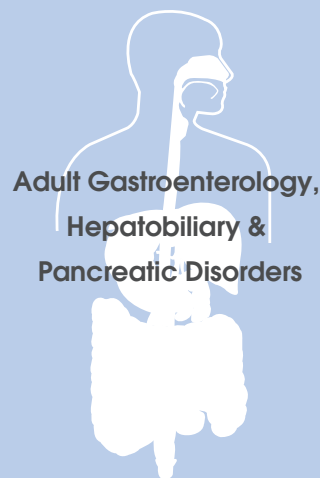


Patient Education

Inflammatory Bowel Disease



Definition

The intestines, sometimes called the bowel, can be injured in many different ways. The bowel can be infected by a wide variety of viruses, bacteria or parasites. It may be damaged by chemical poisoning, radiation exposure, surgery, physical injury, or disturbances of its blood supply. Any of the above may cause acute or **chronic** inflammation.

In addition, there are other, mysterious diseases that attack the bowel wall, causing chronic intestinal inflammation and bringing misery and disability to hundreds of thousands of people throughout the world.

These bewildering and stubborn illnesses of unknown cause are called Inflammatory Bowel Disease (IBD).

What is IBD?

Inflammatory bowel disease is a name given to a group of chronic digestive diseases of the small and large intestines (see figure).

Your doctor may refer to your particular condition by any one of several terms including **colitis**, **proctitis**, **enteritis**, and **ileitis**. Most often, doctors divide IBD into two groups: **ulcerative colitis** and **Crohn's disease**.

Ulcerative colitis causes ulcers and inflammation of the lining (mucosa) of the colon (large intestine). It almost always involves the rectum and usually causes a bloody diarrhea.

Crohn's disease is an inflammation that extends into the deeper layers of the intestinal wall. The disease either is limited to one or more segments of the small intestine (30 percent), usually the ileum (ileitis), or involves both the ileum and the colon (**ileocolitis**) (50 percent).

In the remaining 20 percent, Crohn's disease is confined to the colon (Crohn's colitis). Sometimes inflammation may also affect the mouth, esophagus (gullet), stomach, duodenum, appendix or anus.

Both ulcerative colitis and Crohn's disease are chronic conditions and may recur over a lifetime. On the other hand, many people will have long periods - sometimes years - when they will be free of symptoms. Unfortunately, doctors cannot predict with certainty when the disease will go into remission or when the symptoms will return.

What are the Symptoms of IBD?

The most common symptoms of IBD are diarrhea and abdominal pain. Ulcerative colitis usually causes rectal bleeding as well. Crohn's disease also may cause rectal bleeding, but less often than does ulcerative colitis. In either disease, inflammation, fever, and bleeding may be serious and persistent, leading to weight loss and **anemia** (low red blood cell count). Children may also suffer stunted growth and delayed development.

What Causes IBD?

There are many theories about what causes IBD, but none are proven. The current leading theory suggests that some agent, possibly a virus or an atypical bacterium, interacts with the body's

own immune defense system to trigger an inflammatory reaction in the intestinal wall.

Although there is much scientific evidence that patients with IBD have abnormalities of the immune system, doctors do not know whether these abnormalities are a cause or a result of the disease.

Doctors do believe, however, that there is little basis for the idea that Crohn's disease and ulcerative colitis are caused by emotional distress or are the product of an unhappy childhood.

How Common is IBD?

It is estimated that between one and two million Americans suffer from IBD. Men and women are affected about equally. Some people seem to be more likely targets for these diseases. For instance IBD seems to be more common among Jews than non-Jews and more prevalent among whites than blacks, Orientals, Hispanics, or Native Americans, although no population group is immune from attack.

Also, the number of people who contract Crohn's disease has increased steadily over the last several decades. The incidence has, in the past, been highest in North America, the British Isles, northwestern Europe and Scandinavia. In recent years, an increase in frequency was observed in developing nations throughout the rest of the world. Doctors cannot yet explain why these changes are occurring.

What is the Effect of IBD in Children?

Children who get IBD are apt to be more severely affected than adults. Their disease is often more widespread. Manifestations such as fever or anemia, or complications such as joint involvement, tend to be more prominent.

Slowed growth and delayed sexual maturation are often problems. The impact of these chronic diseases on young patients and their families can be particularly cruel.

Does IBD Run in Families?

About 25 percent of people with Crohn's disease or ulcerative colitis have a blood relative with some form of IBD, most often a brother or sister, and sometimes a parent or child.

Studies have not yet answered the question of whether this tendency is due primarily to heredity or to environment.

For patients with IBD who are considering having children, it is comforting to know that the overwhelming majority of pregnancies will result in normal children. Also, the normal course of pregnancy and delivery is usually not impaired by the presence of IBD in the mother.

How is IBD Diagnosed?

Ulcerative colitis is usually relatively easy for the doctor to recognize. If bloody diarrhea is what caused you to go to the doctor's office, the doctor will probably examine your rectum with an instrument called a **proctoscope** or **sigmoidoscope**. In many cases, the doctor will obtain a culture of the stool and order a **barium enema** x-ray.

Crohn's disease is not so easily diagnosed because the symptoms are not always so dramatic, and because the affected part of the intestine may not be within easy reach of a sigmoidoscope.

However, if you have experienced chronic abdominal pain, diarrhea, fever, weight loss, and anemia, the doctor will examine you for signs of Crohn's disease. The diagnosis can almost always be established by a good medical history and a thorough x-ray examination of the digestive tract, including an **upper gastrointestinal (GI) series**, a careful small bowel study, and a barium enema.

Can IBD Be Cured?

No medicine has yet been found to cure Crohn's disease or ulcerative colitis, but several drugs are helpful in controlling the disease process and symptoms. Your doctor will work with you to find which treatments will work best for you.

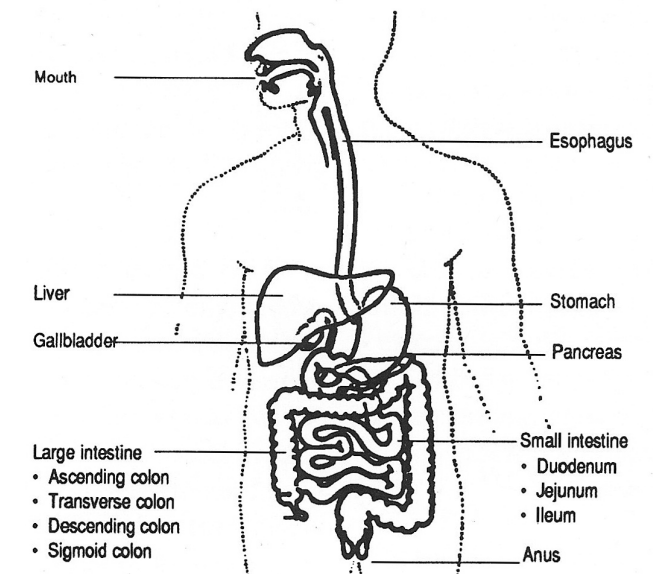
Abdominal cramps and diarrhea may be alleviated by drugs. The drug **sulfasalazine** often lessens the inflammation. More serious cases may require cortisone-related medication.

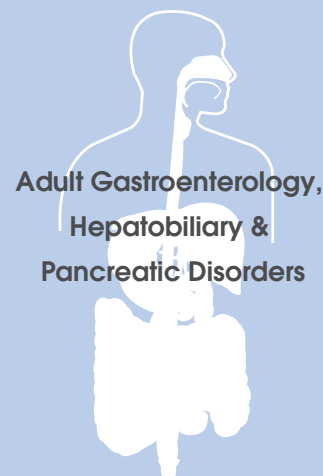
Some cases of IBD have improved with certain very potent anti-infective agents or with drugs that suppress the body's immune system. These are relatively new treatments for IBD and, because they sometimes produce severe reactions, they are not used routinely. It is very important that you take only those medications your doctor has prescribed for you.

Can Diet Control IBD?

No special diet is proven effective to prevent IBD or help most IBD patients.

Some patients find their symptoms are made worse by milk, alcohol, hot spices or roughage. But there are no hard-and-fast



Patient  
EducationInflammatory  
Bowel  
Disease

rules for the majority of IBD patients.

Let your common sense tell you if you need to avoid any foods that seem to make your symptoms worse. Maintaining good general nutrition and adequate caloric intake is far more important than emphasizing or avoiding any particular food. Also, large doses of vitamins are useless and may even produce harmful side effects.

Your doctor may recommend nutritional supplements, especially for youngsters with growth retardation. Special high-calorie liquid formulas are sometimes used for this purpose. A small number of patients may need periods of **intravenous feeding**, a procedure called **total parenteral nutrition** (TPN) or **hyperalimentation**.

These techniques can help patients who temporarily need extra nutrition, those whose bowels need to rest, or those whose bowels cannot absorb enough nourishment from food taken by mouth. Such techniques are not in themselves a cure for the disease.

## Can Surgery Cure Ulcerative Colitis?

Surgery can cure ulcerative colitis. Although most patients cope effectively with this disease for many years, about one-third will eventually require removal of the colon.

In the standard form of this operation, the entire colon and rectum are removed. A small opening (**stoma**) is made in the front of the abdominal wall and the tip to the lower small intestine (ileum) is then brought through. The stoma is fitted with a pouch to collect waste products. This external opening to the intestine is called an **ileostomy**.

Cosmetically more appealing options to this standard procedure were recently developed, but they are controversial because they are more often prone to complications.

One such procedure is called a continent ileostomy. In this operation, a pouch is created out of the ileum inside the wall of the lower abdomen. The pouch is emptied regularly through a valve on the outside of the abdomen and a small tube.

In an even newer operation, ileoanal anastomosis, only the diseased inner lining of the rectum is removed, leaving the outer muscle coats of the rectum (a procedure sometimes called a "pull-through") and attached just above the anus. Because the rectal muscles are left intact, stool can be passed normally.

Your doctor will explain the possibilities and recommended which form of surgery is best for you. The most important thing to remember, however, is that removal of the colon and rectum provides a total and permanent cure for ulcerative colitis, regardless of the type of procedure performed.

## Does Surgery Cure Crohn's Disease?

Crohn's disease can be helped by surgery, but it cannot be cured by surgery. The inflammation tends to return in areas of the intestine immediately next to the area that was removed. Even so, about two-thirds of Crohn's disease patients require surgery, either to provide relief from chronic disability or to correct specific complications. Unfortunately, neither the continent ileostomy nor the ileoanal anastomosis can be used in Crohn's disease patients require surgery, either to provide relief from the chronic disability or to provide relief from chronic disability or to correct specific complications. Unfortunately, neither the continent

ileostomy nor the ileoanal anastomosis can be used in Crohn's disease patients because of the likelihood of recurrence of the disease.

## What Are the Complications of IBD?

Most people with IBD never suffer from any complications, but some do. For example, dangerous complications may arise when severe ulcerative colitis is processing rapidly, with ulceration extending deep into the bowel wall.

In such cases, paralysis and distention of the colon (toxic dilation), bleeding, **perforation**, or **peritonitis** (inflammation of the lining of the abdominal cavity) may occur. These uncommon problems often require surgery.

If the disease is sufficiently widespread throughout the colon, and lasts for many years, patients with ulcerative colitis may be at increased risk of cancer of the colon or rectum. Since these cancers have a more favorable outcome when caught in the early stages, patients should see their doctors for regular colon examinations.

Crohn's disease affects deeper layers of the bowel wall than those affected by ulcerative colitis. It often involves the small intestine but frequently spares the rectum. For these reasons, frank rectal bleeding is less common in Crohn's disease than in ulcerative colitis. Because of the tendency of Crohn's disease to thicken the bowel wall with swelling and fibrous scar tissue, **intestinal obstruction** or "blockage" is the principal complication of long-standing cases.

Crohn's disease may also cause deep ulcer tracts to burrow all the way through the bowel wall into surrounding tissues, into surrounding tissues, into adjacent segments of intestine, or into other nearby organs such as the urinary bladder or vagina.

These abnormal tunnels or passageways between the inflamed intestine and adjoining tissues are called fistulas. They are common complications of Crohn's disease and are often associated with pockets of infection or abscesses.

The anus and rectum are particularly susceptible to these problems in Crohn's disease, so that complicated fistulas or abscesses in this region are often a hallmark of the diagnosis. Fistulas can sometimes be treated with medication, but in many cases they must be drained surgically.

In addition to the damage IBD produces in and around the intestine, there are other complications that may affect more distant parts of the body. These systemic complications include various forms of arthritis, skin problems, inflammation in the eyes or mouth, kidney stones, gallstones, or other diseases of the liver and biliary system.

Some of these problems respond to the same treatment as the intestinal symptoms of IBD, but others require separate management.

## Questions for the Future

There are many questions about IBD that scientists have yet to answer. What is the cause of IBD? Why does the disease run in families? How does it spread or produce complications? What is the best treatment? These and other questions are being studied.

Researchers are already improving methods of diagnosis,

identifying ways to detect early colorectal cancer, and developing newer, safer, and more effective medical and surgical therapies.

Suggestions for the Newly  
Diagnosed Patient

You probably have many questions about your disease, your symptoms, and your treatment that cannot be answered in this short fact sheet. You should seek this information from your doctor. You may find it useful to write down some of your questions and concerns before your next visit. This list will help you organize your thoughts and ensure you obtain information you need.

Some symptoms of IBD, such as abdominal pain and diarrhea, can make you feel alone and isolated. Discussing concerns and trading coping tips with other IBD patients may be helpful. Knowing what to expect can help you explain your illness to friends and family and can make living with the disease and its treatments a little more bearable. Remember, most people with IBD continue lead useful, productive lives. Between periods of disease activity, patients may feel quite well and remain relatively free of symptoms. Even though there may be long-term needs for medication, and even periods of hospitalization, most IBD patients hold productive jobs, marry, raise families, and function successfully at home and in society.

## Sources For More Information

The National Foundation for Ileitis and Colitis distributes brochures on a wide variety of topics concerning IBD, including complications, pregnancy, diet and nutrition, government benefits and services, special problems in childhood and adolescence, and emotional factors. The United Ostomy Association provides materials on surgical procedures, stoma care, sex for men and women with ostomies, and many more topics. Both organizations also sponsor peer support groups. For more information, check your telephone directory for local chapters or write to:

- National Foundation for Ileitis and Colitis, 444 Park Avenue South, 11th Floor, New York, NY 10016;
- United Ostomy Association  
2001 West Beverly Boulevard, Los Angeles, CA 90057