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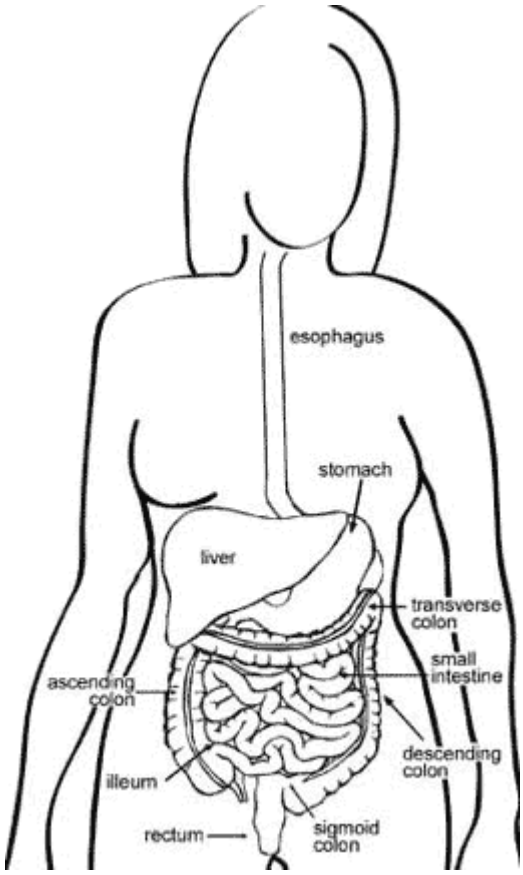
The National Women's Health Information Center
A project of the U.S. Department of Health and Human Services, Office on Women's Health

# Frequently Asked Questions about Inflammatory Bowel Disease

## What is inflammatory bowel disease?

Inflammatory bowel disease (IBD) is a chronic disorder that causes an inflamed and swollen digestive tract or intestinal wall. When the digestive tract becomes inflamed or swollen with IBD, sores (ulcers) form and bleed. This in turn, can cause abdominal pain, watery diarrhea, blood in the stool, fatigue, reduced appetite, weight loss, or fever. The two most common forms of IBD are *ulcerative colitis (UC)* and *Crohn's disease (CD)*.

A healthy digestive system removes nutrients from food so they can be absorbed into the bloodstream. It then stores the unwanted waste until it passes out of the body. Food moves from the esophagus to the small intestine, where the nutrients are absorbed. The leftover water and waste move to the large intestine (colon), then through the rectum and out the anus.




## Who is affected by IBD?

IBD affects millions of people throughout the world, but is more common in people who live in regions farther away from the equator (like North America, Europe, and Australia). Estimates from 1994 show 1 million cases in the United States alone. The disease most often develops during the second and third decades of life in both men and women. The average age of diagnosis is 27. A second, but much smaller, peak of new cases occur in people after age 65. Overall, women and men are equally affected by IBD. In the past, whites have been shown to have the highest risk for the disease, especially people of Jewish and European descent.

## What causes IBD?

No one knows exactly what causes IBD, but these things may all play a role: an unknown virus or bacterium, heredity, and the environment. Your digestive tract may become inflamed when your body tries to fight off an invading bacterium, or the inflammation can result from the virus or bacterium itself.

The most recent data shows that rates of IBD are similar in whites and Americans of African descent, but the disease is rare in Africa itself, which points to the role of the environment. Some of the environmental factors linked to IBD are a lifestyle with little activity, higher socioeconomic status, and living in a more developed country.

Besides the environment, IBD can also run in families. About 15 to 30 percent of people with IBD have a relative with the disease. Studies are looking at whether a certain gene or group of genes makes a person more likely to get IBD. In 2001, the first gene for CD was found. An abnormal form of the gene known as *Nod2* occurs twice as often in persons with CD as in the general population. In the abnormal form of this gene, some of the body's power to fight bacteria is missing, and it has been known for a long time that there is a link between bacteria in the gut and CD.

Stress does not cause IBD. As with other illnesses though, stress can worsen the symptoms of IBD. There also is no known link between eating certain kinds of foods and getting IBD, but changing your diet can help reduce symptoms and replace lost nutrients.

## What is ulcerative colitis (UC)?

Ulcerative colitis (UC) causes inflammation and sores called ulcers in the top layers of the inner lining of the large intestine (colon) or rectum. It most often occurs in the lower part of the colon and rectum, but may affect the whole colon. When it is located only in the rectum, it is called *proctitis*. It most often occurs in young people between the ages of 15 and 40.

## What are the symptoms of UC?

The most common symptom is diarrhea because the inflammation keeps water from being absorbed into the bloodstream and makes the colon empty often. Inflammation also kills healthy colon lining cells, which causes ulcers to form and bleed, and make pus and mucus. Other symptoms include bloody diarrhea, severe abdominal cramps, nausea, and frequent fever. Most people with UC have times when they feel well (remission) and times when they feel sick (relapse). About half of the people with UC only have mild symptoms. In severe cases, people can become malnourished and may need to have a special diet or be fed fluids through a vein.

## What are the complications of UC?

UC also can cause problems like arthritis, inflammation in the eye, liver disease, skin rashes, anemia, and kidney stones. No one knows why these problems occur outside of the colon. They may occur when the immune system triggers inflammation in other parts of the body. These problems are usually mild and go away when the colitis is treated. Osteoporosis can occur due to low Calcium and vitamin D intake through dairy products, poor absorption of nutrients in the body, inflammation, and use of corticosteroids (for treatment of UC).

## How do I know if I have UC?

In order to find out if you have UC, your doctor will examine you and may order blood tests or samples of a bowel movement to check for blood or germs. She also may give you a *barium enema*, which is an x-ray of the colon, or a *flexible sigmoidoscopy* or *colonoscopy*, screening tests that allow the doctor to see the inside lining of the colon.

## Differences Between UC and CD

| DISEASE | UC | CD |
|---|---|---|
| **SYMPTOMS** | • Diarrhea<br>• Bloody Diarrhea<br>• Pus or mucus in the stool<br>• Severe abdominal cramps<br>• Nausea<br>• Frequent fever | • Diarrhea<br>• Rectal bleeding<br>• Weight loss<br>• Pain & tenderness in abdomen, especially the lower right side<br>• Low-grade fever<br>• Anemia<br>• Sometimes constipation because of a blockage<br>• Slowed growth and delayed sexual development in some childhood cases |
| **PARTS OF DIGESTIVE SYSTEM AFFECTED** | • *Only the top layers of the walls of* the colon or rectum (most often in the lower part of the colon and rectum) | • *Deep in the lining* of the walls of the colon and/or small intestine<br>• Any part of the digestive tract from mouth to anus |

## What is Crohn's disease (CD)?

Crohn's disease (CD) most commonly causes inflammation deep in the lining of the walls of the large intestine (colon) and/or the small intestine, but also can affect any part of the digestive tract from the mouth to the anus. Sometimes CD can affect other parts of the upper digestive tract with ulcers forming in the stomach, upper small intestine, or the esophagus. About one-third of cases of CD affect the small bowel, usually involving the ileum (the last portion of the small intestine that connects to the large intestine or colon). Nearly half of all cases involve both small and large bowel. About 20 percent of cases are in the colon alone. Lesions near the anus occur in about one-quarter to one-third of persons with CD but are rarely the only sole site of CD. Like UC, CD also is an illness that brings periods of remission and relapse.

## What are the symptoms of CD?

The earliest most common symptoms are pain in the abdomen, especially the lower right side, tenderness, and often diarrhea. Constipation, weight loss, rectal bleeding, and low-grade fever also may occur. Bleeding may be bad enough to cause anemia or an unhealthy, low level of iron in the blood. Children with CD may have slowed growth and delayed sexual development in some cases.

## What are the complications of CD?

The most common problem with CD is blockage of the intestine. Because swelling and scar tissue thicken the bowel wall, the intestine passage can become closed off. *Fistulas*, or abnormal connections between the intestine and other organs, can form from ulcers in the intestine, breaking through into other parts of the intestines or surrounding tissues of the bladder, vagina, or skin. They often form around the anus and rectum.

Nutrition problems are common with CD. Many people have deficiencies of proteins, calories, and vitamins. These can be caused by not eating enough, loss of protein within the intestine, or poor absorption. Osteoporosis also is a threat because of low Calcium and vitamin D intake through dairy products, poor absorption of nutrients in the body, or the use of corticosteroids (for treatment of CD or inflammation itself). Some persons with CD have problems with arthritis, their skin, inflammation in the eyes or mouth, kidney stones, gallstones, or other diseases of the liver. Some of these problems get better during treatment for disease in the digestive system, but some are treated separately.

## How do I know if I have CD?

In order to find out if you have CD, your doctor will examine you and may order blood tests to check for anemia (low iron levels) which could be a sign of bleeding in the intestine, or samples of a bowel movement to check for blood or germs. She also may do an *upper gastrointestinal (GI) series* to look at the small intestine. This is an x-ray that can show inflammation or other problems in the intestine. You also could have a barium enema, which is an x-ray of the colon, or the same screenings tests used to diagnose UC, flexible sigmoidoscopy or colonoscopy. These tests allow the doctor to view the lining of the colon. A CT scan may also be used to look for inflammation inside and outside the bowel.

## Is IBD related to Irritable Bowel Syndrome (IBS)?

UC and CD are different from *irritable bowel syndrome* (IBS), that is a condition that includes a group of symptoms mainly affecting the colon, or large intestine. Symptoms of IBS may include crampy pain, bloating, gas, mucus in the stool, and changes in bowel habits. IBS is also called *spastic colon* or *spastic bowel*. IBS is not a disease and does not cause inflammation, bleeding, damage to the bowel, or cancer or other serious diseases. It is called a functional disorder, which means that there is no sign of disease when the colon is examined, but the bowel doesn't work as it should. There is no direct relationship between IBS and either UC or CD, although some people with UC or CD also have IBS.

## What are the signs of IBD? When should I see my health care provider?

See your health care provider if you see blood in the stool, have a change in bowel habits lasting longer than 10 days, or if you have any of the following symptoms that do not improve with over-the-counter medicines.

- Severe abdominal cramps or pain
- Severe diarrhea or bloody diarrhea
- Weight loss
- Unexplained fever lasting more than 1 or 2 days

- Extreme fatigue
- Loss of appetite
- Nausea

Although UC and CD usually are not fatal, they can cause serious problems. Sometimes symptoms are bad enough that a person has to be hospitalized. For example, a person may have severe diarrhea that causes dehydration and needs to be treated with fluids through his/her vein.

## Can IBD be prevented?

Because no one knows exactly what causes IBD, it is hard to try to prevent. But, if you have IBD, you can make changes in your diet and lifestyle to control your symptoms. You might need to limit dairy products, try low-fat foods, experiment with how much protein and fiber you eat, avoid problem "gassy" foods, and eat smaller and more frequent meals. It also is important to get enough rest and avoid stress since being tired or overly upset can make your symptoms worse. Your health care provider can tell you the things to try to make you feel better.

## How is IBD treated?

While there is no cure for IBD, treatments can help control symptoms. Besides changing diet and lifestyle to control symptoms, most people with UC and CD are treated with medications. In severe cases of disease, a person may need surgery to remove the diseased colon.

## What medications are used to treat IBD?

Treating IBD with drugs is complicated and might require several "trial runs." It is very important to keep track of how well the drugs are working, what side effects you are having, and report all details to your health care provider.

Most people who have mild to moderate disease are first treated with drugs called *aminosalicylates*. These medications are aspirin-like medications such as *5-ASA agents (*a combination of the drugs *sulfonamide, sulfapyridine, and salicylate)*. They can be given either orally or rectally to help control inflammation. Side effects can include heartburn, nausea, vomiting, diarrhea, and headache. These drugs include *mesalamine* and *sulfazalazine*, which have fewer side effects and can relieve symptoms in more than 80 percent of people with UC in the lower colon and rectum. A newer drug form of mesalamine called *Colazal* is reported to have even fewer side effects.

People with more severe IBD also can be treated with *corticosteroids,* such as *prednisone* and *hydrocortisone,* to reduce inflammation. Side effects of these drugs can include weight gain, acne, facial hair, high blood pressure, mood swings, and a higher risk of infection. A newly approved drug called *Entocort EC* is a steroid therapy that causes fewer side effects in people with mild to moderate CD in the ileum (the last portion of the small intestine that connects to the large intestine or colon).

Drugs that block the immune system's reaction to inflammation are also used to treat CD. Side effects can include nausea, vomiting, diarrhea, and higher risk of infection. People with moderate to severe CD who do not respond to 5-ASA agents, corticorsteroids, or immune system drugs, or who have open, draining fistulas may be given a drug called *infliximab* (Remicade). This is the first treatment approved for CD and works to remove a protein produced by the immune system that may cause inflammation. Studies are looking at its long-term safety and effectiveness. *Azathioprine* and *6-mercaptopurine (*6-MP*)* also can be used with steroids, and seem to be the most effective immunosuppressive drugs for the long-term management of both CD and UC. They are proven effective for steroid-dependent, chronically active, and steroid-resistant disease.

Antibiotics also are used to treat disease and heal fistulas in the small intestine.

Drugs like antidiarrheals, laxatives, and pain relievers also can be given to help relieve symptoms. Every person should talk with her doctor first before taking these drugs since some may be too harsh for the system or can make symptoms worse.

## What types of surgery are used to treat IBD?

There are different types of surgery used to treat IBD. For CD, surgery is necessary at some point in the lifetime of about half of persons with this disease.

Surgery can relieve symptoms or correct problems like blockages or bleeding in the intestine. Surgery to remove part of the intestine can help CD but cannot cure it. The inflammation tends to return next to the area of intestine that has been removed. Therefore, people considering surgery should carefully weigh the risks and benefits compared to other treatments.

Types of surgery for CD include:

- **Colectomy (colon removal)** – A part of the colon or the entire colon and rectum may be removed. A *colostomy* or *ileostomy* may be done after the diseased colon is removed. A colostomy or ileostomy creates an opening on the abdomen (stoma) for the drainage of stool (feces) from the large intestine (colon) or small intestine (ileum) and may be temporary or permanent.

- **Small bowel resection** – The diseased parts of the small bowel can be removed and the two healthy ends are sewn back together. If it is necessary to spare the intestine from its normal digestive work while it heals, a temporary opening (stoma) of the intestine onto the abdomen (ileostomy) may be done. A temporary ileostomy will be closed and repaired later. If a large portion of the bowel is removed, the ileostomy may be permanent.

For UC, persons with severe cases of this disease may need surgery to remove the diseased colon. Some of the IBD-related problems that cause health care providers to consider surgery include growth retardation, steroid dependency, serious medication side effects, cancer or pre-cancerous changes, disease that is unresponsive to medication, narrowing of the colon, and *extraintestinal disease* (disease caused by IBD in areas outside of the digestive tract).

Types of surgery for UC include:

- **Colectomy, or colon removal** (see *Colectomy*, *Types of surgery for CD*, above). About 25 to 40 percent of people with UC must have surgery to remove the colon because of bleeding, severe illness, rupture of the colon, or risk of cancer. For years, individuals who had colons removed had to wear a "bag" outside their bodies to collect waste from the digestive system. Recent surgical techniques make that no longer necessary in the vast majority of persons with CD.

- **Ileoanal pouch anastomosis (IPPA)** – The colon and interior of the rectum is removed during this surgery. An internal pouch is created from part of the *ileum* (the end of the small intestine), by pulling a portion of the ileum through the wall of the rectum and attaching it to the anus. This allows a person to continue to eliminate waste through the anus**.** While some people can have this surgery done all at once, this procedure is usually done in two stages. The colon and interior of the rectum are removed and a temporary ileostomy is created. Once the pouch has healed (about six to eight weeks), the temporary ileostomy is closed, restoring waste elimination through the anus.

## I have IBD and need surgery, have I failed at managing my disease?

Nothing could be further from the truth. Surgery for IBD often is viewed as a "failure" by both the person who has IBD and her doctor. But surgery, in combination with pre- and post- operative medical therapy, can lead to the best results for the person's health and quality of life.

## What research is being done on new treatments for IBD?

Studies are looking at the use of human growth hormone (HGH) combined with a high-protein diet to treat CD. In a clinical trial, people treated this way had fewer symptoms after one month, and the benefits continued. The long-term risks and benefits are still being studied. Studies also are looking at the use of a gene-based drug to help growth of healthy tissue in people with UC, as well as new medications to use against factors that cause or promote inflammation.

## Is there a link between IBD and colon cancer?

Having IBD can increase your chances for getting colon cancer. The risk of cancer gets higher the longer and the more the colon is involved. For example, if only the lower colon and rectum are involved, the risk of cancer is not higher than normal. But, if the whole colon is involved, the risk of cancer may be as great as 32 times the normal rate.

People who have had IBD throughout their colon for at least eight years, or IBD in only the left colon for at least 15 years should have a screening colonoscopy every 1 to 2 years to check for precancerous changes in the cells of the colon lining. This screening won't reduce the risk for getting colon cancer, but can help find cancer early when it is easier to treat.

## Does having IBD increase my chances of getting cancer? Is there any way to tell if I am developing cancer?

Some studies have found that persons with IBD have a much higher risk for other cancers for reasons not yet known. For CD, these include skin and bladder cancers. For UC, there have been reports of increased risk for connective-tissue and brain cancers, nonmelanoma skin cancers, and bone and endometrial cancers.

The most widely available test to find pre-cancerous or cancerous tissues at an early, curable stage in persons with IBD is *endoscopy* with *biopsy* of the colon. An endoscope is a device with a flexible tube and light that allows your doctor to see parts of your digestive system. The tube is inserted through the mouth or anus while you are sedated. A colonoscopy shows the entire colon, a sigmoidoscopy shows the two feet of the colon closest to the anal opening only. A biopsy is when your doctor takes small samples of tissue during the endoscopy to study under a microscope.

## How is fertility affected in women with IBD?

Women with UC or inactive CD do not seem to have related fertility problems, but women with active CD or women with UC who have had an IPAA do experience more problems with fertility. Women who have inactive disease at the time of conception are no more likely to have a flare of their disease during pregnancy than if they were not pregnant. Flares are more likely to occur in the first trimester and right after the baby is born.

## Is pregnancy safe for women with IBD?

Pregnancy and delivery can be relatively normal in women with IBD. Even so, women with IBD should discuss their illness with their health care providers before pregnancy. Most medications used for IBD are safe or likely safe in pregnancy. Surgery, if necessary, is safest in the second trimester. Pre-term birth or early delivery has been reported to be increased 2 to 3-fold in women with IBD, although most children born to women with IBD are unaffected.

## For more information…

You can find out more about inflammatory bowel disease by contacting the National Women's Health Information Center at (800) 994-9662 (WOMAN) or the following organizations:

**National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK)**
Internet Address: www.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: www.ccfa.org

**Pediatric Crohn's & Colitis Association, Inc.**
Phone Number(s): (617) 489-5854
Internet Address: pcca.hypermart.net

**The American College of Gastroenterology**
Phone Number(s): (703) 820-7400
Internet Address: www.acg.gi.org

**American Gastroenterological Association**
Phone Number(s): (301) 654-2055
Internet Address: www.gastro.org

**North American Society for Pediatric Gastroenterology, Hepatology and Nutrition**
Phone Number(s): (215) 233-0808
Internet Address: www.naspgn.org

**Social Security Administration**
Information on Disability Benefits
Phone Number(s): (800) 772-1213
Internet Address: www.ssa.gov

This FAQ was adapted from the NIDDK's fact sheets, "Ulcerative Colitis" and "Crohn's Disease," and from the scientific program and abstracts presented at "The State of the Art in the Management of Inflammatory Bowel Disease" conference, sponsored by the HHS Office on Women's Health and the Society for Women's Health Research, December 12-13, 2001 in Washington, D.C.

*This FAQ has been reviewed by Jacqueline Lee Wolf, M.D., of Harvard Medical School.*
*August 2002*