



About Ulcerative Colitis



CROHN'S
&
COLITIS
FOUNDATION
OF AMERICA

The Crohn's & Colitis Foundation of America is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis. CCFA sponsors basic and clinical research of the highest quality. The foundation also offers a wide range of educational programs for patients and healthcare professionals, and provides supportive services to help people cope with these chronic intestinal diseases. CCFA programs are supported solely by contributions from the public.

We hope that this brochure will help you to better understand these illnesses, and to become an active member of your healthcare team.

When you first learn that you have ulcerative colitis, it's natural

to feel overwhelmed. You need the answers to so many questions: Will I be able to work, travel, exercise? Could my medications have side effects? Should I be on a special diet? How will other people react to my illness? Learning all you can is an important step toward taking charge of your illness—and your life. This booklet offers an overview of ulcerative colitis, its diagnosis and treatment, and its impact on the day-to-day lives of patients and their families.

We've also included a glossary of medical and surgical terms. If you would like more information about specific topics, please call CCFA to order other brochures in this series. You'll find a complete list on the inside back cover.

WHAT IS ULCERATIVE COLITIS?

Ulcerative colitis is an inflammatory disease of the colon (the large intestine). It is characterized by inflammation and ulceration of the colon's innermost lining. Symptoms typically include diarrhea (sometimes bloody) and, often, abdominal pain.

When ulcerative colitis affects only the lowest part of the colon, the rectum, it is called *ulcerative proctitis*. If the disease affects only the left side of the colon, it is called *limited* or *distal* colitis. If it involves the entire colon, it is termed *pancolitis*.

Ulcerative colitis differs from another inflammatory bowel disease (IBD), Crohn's disease. Crohn's can affect any area of the gastrointestinal (GI) tract, including the small intestine. Ulcerative colitis affects only the colon. The inflammation usually involves the entire rectum and extends up the colon in a continuous manner. There are no areas of normal intestine between the areas of diseased intestine. In contrast, such so-called "skip" areas may occur in Crohn's disease. Ulcerative colitis affects only the innermost lining of the colon, whereas Crohn's disease can affect the entire thickness of the bowel wall. Ulcerative colitis and Crohn's disease are different from irritable bowel syndrome (IBS), a disorder that affects the motility (muscle contractions) of the colon. Sometimes called "spastic colon," IBS is not characterized by intestinal inflammation. It is, therefore, a much less serious disease than ulcerative colitis. IBS bears no direct relationship to either ulcerative colitis or Crohn's disease.

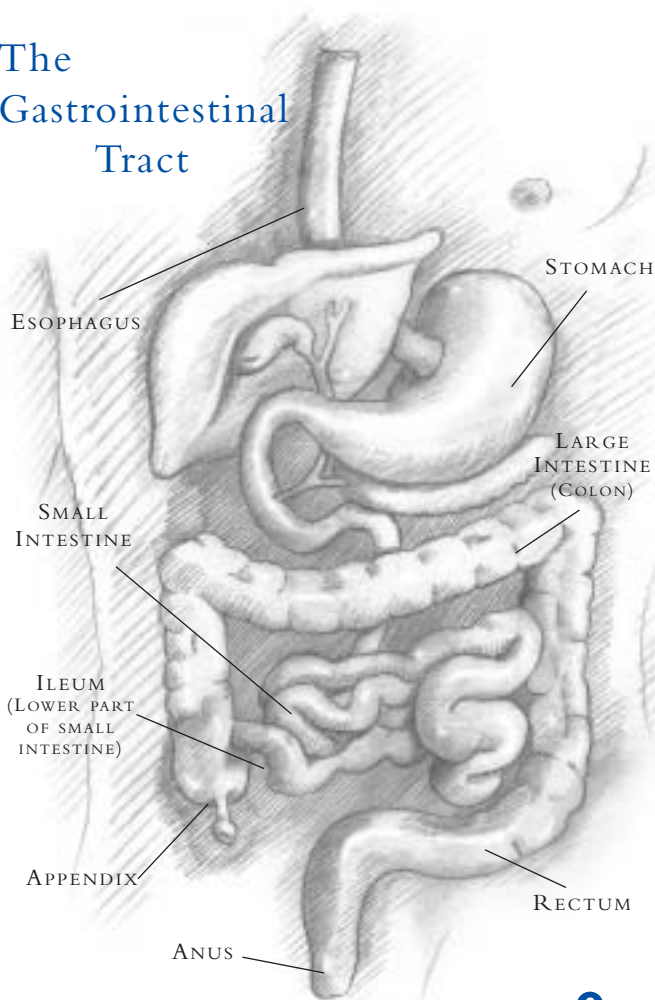
HOW COMMON IS ULCERATIVE COLITIS?

It is estimated that there are up to 1,000,000 Americans with either ulcerative colitis or Crohn's disease, roughly half of that number for each disease. Ulcerative colitis is predominantly a disease of the young. Most cases are diagnosed before age 30, although the disease can occur at any age, including the later decades of life. Indeed, a much smaller number of patients may develop the disease between the ages of 50 and 70. There is a greater incidence of ulcerative colitis in Caucasians than in minority groups, and a higher incidence in Jews than in non-Jews.

IS ULCERATIVE COLITIS INHERITED?

We know that ulcerative colitis can tend to run in families. Studies have shown that up to 20 percent of people with ulcerative colitis will have a close relative with either ulcerative colitis or Crohn's disease. Most often, the affected relative of the colitis patient will also have ulcerative colitis. However, based on current research, there does not appear to be a clear-cut pattern to this inheritance. Researchers continue to seek specific genes involved in the cause of the diseases. At this time, however, there is no way to predict which, if any, family members will develop ulcerative colitis or Crohn's disease.

The Gastrointestinal Tract



WHAT ARE THE SYMPTOMS OF ULCERATIVE COLITIS?

The first symptom of ulcerative colitis is a progressive loosening of the stool. The stool is generally bloody and can be associated with crampy abdominal pain and severe urgency to have a bowel movement. The diarrhea may begin slowly or quite suddenly. In addition, there may be skin lesions, pains in the joints and, in children, failure to grow properly.

HOW IS ULCERATIVE COLITIS DIAGNOSED?

Physicians diagnose ulcerative colitis based on patients' clinical history, as described above. The first goal of medical tests is to differentiate ulcerative colitis from infectious causes of diarrhea. Accordingly, stool tests are performed to eliminate the possibility of bacterial, viral, and parasitic causes of diarrhea. Following this, the patient generally undergoes an evaluation of the colon, using one of two tests. To perform a sigmoidoscopy, the doctor passes a flexible instrument into the rectum and lower colon. This test allows the doctor to visualize the extent and degree of inflammation in these areas. A total colonoscopy is a similar exam, which visualizes the entire colon. Using these techniques, your physician can determine the category of disease to be ulcerative proctitis, limited colitis, or pancolitis. The investigating physician may take samples of the colon lining, called biopsies, and send these to a pathologist for further study. Ulcerative colitis can thus be distinguished from other diseases of the colon that cause rectal bleeding, including Crohn's disease of the colon, diverticular disease, and cancer.

WHAT MEDICATIONS ARE USED TO TREAT ULCERATIVE COLITIS?

Currently, no medical cure for ulcerative colitis exists, but effective medical treatment can suppress the inflammatory process. This permits the colon to heal, and relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain. As such, the treatment of ulcerative colitis involves medicines that decrease the abnormal inflammation in the colon lining and thereby control the symptoms.

Three major classes of medication are used today to treat ulcerative colitis:

1. *Aminosalicylates* include aspirin-like drugs that contain 5-aminosalicylic acid (5-ASA). Examples are mesalamine (Asacol®, Canasa®, Colazal®, Pentasa®, or Rowasa®), olsalazine (Dipentum®) and sulfasalazine (Azulfidine®). These drugs can be given either orally or rectally, and alter the body's ability to create and maintain inflammation. Without inflammation, symptoms such as diarrhea, rectal bleeding, and abdominal pain can be diminished greatly. Aminosalicylates are effective in treating mild to moderate episodes of ulcerative colitis, and are also useful in preventing relapses of this disease.
2. *Corticosteroids* include prednisone and methylprednisolone. These medications can be given orally, rectally, or intravenously. Corticosteroids are used for patients with moderate to severe disease. These drugs affect the body's ability to create and maintain inflammation. Although steroids can be quite effective for short-term control of acute episodes of colitis (i.e., flare-ups), they are not recommended for long-term use due to side effects.
3. *Immunomodulatory medicines* include azathioprine (Imuran®), 6-mercaptopurine (6-MP), and, recently, cyclosporine. As a group, they alter the immune cells' interaction with the inflammatory process. Immunomodulators are generally administered orally. They are used in selected patients when aminosalicylates and corticosteroids have been either ineffective or only partially effective. Azathioprine and 6-MP have been useful in reducing or eliminating some patients' dependence on corticosteroids. They also may be useful in maintaining remission in selected refractory ulcerative colitis patients (that is, patients who do not respond to standard medications). However, these medications can take as long as three months to begin their beneficial effects.

WHAT IS THE ROLE OF SURGERY IN ULCERATIVE COLITIS?

In one-quarter to one-third of patients, medical therapy is not completely successful, or complications arise. Under these circumstances, surgery may be considered. This operation involves the removal of the colon (colectomy). Unlike Crohn's disease, which can recur after surgery, ulcerative colitis is "cured" once the colon is removed.

Depending on a number of factors, including the extent of the disease and the patient's age and overall health, one of two operations may be recommended. The first involves the removal of the entire colon and rectum, with the creation of an ileostomy or external stoma (an opening on the abdomen through which wastes are emptied into a pouch, which is attached to the skin with adhesive). Many people today are able to take advantage of new surgical techniques, which have been developed to remove the colon, maintain bowel continuity and continence, and avoid an ileostomy. These techniques involve creating an internal pouch from the small bowel and attaching it to the anal sphincter muscle, thereby maintaining bowel integrity and eliminating the need for the patient to wear an external ostomy appliance. (Further information on surgery and ulcerative colitis can be found in CCFA's brochure on surgery.)

IS NUTRITION IMPORTANT IN MANAGING THIS DISEASE?

Good nutrition is essential in any chronic disease but especially in this illness, because diarrhea and rectal bleeding can rob the body of fluids, electrolytes, and nutrients. Maintaining proper nutrition is important in the medical management of ulcerative colitis.

Specific foods play no role in causing the disease. However, when your disease is active, you may find that bland, soft foods may cause less discomfort than spicy or high-fiber foods. Except for restricting milk products in lactose-intolerant patients (see glossary) or restricting caffeine when severe diarrhea occurs, most gastroenterologists recommend a well-balanced diet for their patients.

CAN EMOTIONAL STRESS TRIGGER ATTACKS OF ULCERATIVE COLITIS?

Because body and mind are so closely interrelated, emotional stress can influence the symptoms of ulcerative colitis—or, for that matter, any chronic illness. Although the disease occasionally recurs after a patient has been experiencing emotional problems, there is no proof that stress causes ulcerative colitis.

It is much more likely that the emotional distress that patients sometimes feel is a reaction to the symptoms of the disease itself. People with ulcerative colitis should receive understanding and emotional support from their families and physicians.

CCFA offers local mutual support groups to help patients and their families cope with ulcerative colitis and Crohn's disease.

IS IT POSSIBLE FOR PEOPLE WITH ULCERATIVE COLITIS TO LEAD A NORMAL LIFE?

While it is a serious chronic disease, ulcerative colitis is not a fatal illness. Some patients will experience symptoms that range from mild to severe at times. Most people with ulcerative colitis continue to lead normal, useful, and productive lives, even though they may need to take medication and occasionally need to be hospitalized. Maintenance medication has been shown to significantly decrease flare-ups of ulcerative colitis. In between disease flares, most patients feel well and are relatively free of symptoms.

WHAT ARE THE CAUSES OF ULCERATIVE COLITIS?

Researchers do not know what causes this disease. They do not believe it is caused by emotional stress, or by food, or that it is transmitted directly from one person to another. Research has shown that the inflammation in IBD involves a complex interaction of the genes a patient 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 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. This is why the main goal of medical therapy is to help patients regulate their immune system better.

CCFA continues to sponsor research into the causes of this mysterious ailment. Many of these studies have been carried out in the fields of immunology, the study of the body's 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 of the intestinal wall, initiating or accelerating the disease process. Through our research efforts, much more will be learned that may lead to better treatments, prevention, and ultimately, a cure.

Glossary

- 5-aminosalicylic acid (5-ASA)**—the active component of sulfasalazine; known generically as mesalamine.
- anemia**—lower than normal amounts of hemoglobin and red blood cells in the blood.
- ankylosing spondylitis**—a chronic inflammatory disease of the spine and adjacent joints, which is seen in some persons with Crohn’s disease or ulcerative colitis. The disease overwhelmingly affects males, usually before age 30, and causes pain and stiffness in the joints of the spine, hips, neck, jaw, and rib cage. Occasionally, joints of the spine may become fused (ankylosis). Anti-inflammatory drugs, physical therapy, and, occasionally, surgery are used in treatment.
- arthralgia**—pains in the joints, frequently experienced by persons with IBD.
- arthritis**—the inflammation of a joint, accompanied by pain, swelling, heat, or redness. In some cases there are structural changes.
- aseptic (or “avascular”) necrosis of the hip**—a complication of the prolonged use of high-dose steroids, in which one or both of the hip joints may suddenly and without warning undergo massive deterioration.
- azathioprine**—an immunosuppressive drug sometimes used in the treatment of ulcerative colitis that has not responded to other medications. This drug has been shown to be helpful in reducing or eliminating the dependence on corticosteroids in some patients.
- barium enema**—an x-ray examination of the colon and rectum after liquid barium has been infused through the rectum.
- biopsy**—a small piece of tissue taken from the body for examination under the microscope. A biopsy is taken by a special instrument attached to the endoscope during examination of the rectum, colon, stomach, etc. A biopsy is used to confirm the diagnosis of Crohn’s disease or ulcerative colitis, or to check periodically for the possibility of cancer.
- colectomy**—the surgical removal of the colon. See also *proctocolectomy*.
- colonoscopy**—a test in which a flexible, lighted tube is inserted through the rectum to examine

the colon. Biopsies may be taken as part of this test. Sedatives are usually given to make this procedure more tolerable.

continent ileostomy—the surgical creation of an ileal pouch inside the lower abdomen, which collects waste after colectomy for ulcerative colitis. No bag appliance is required, and the pouch is emptied regularly with a small tube inserted through a nipple opening in the lower front part of the abdomen.

cortisone—an anti-inflammatory drug, part of a group of drugs known as glucocorticosteroids. Cortisone is used to reduce inflammation in Crohn's disease and ulcerative colitis, and may be taken by mouth in tablet form, intravenously, or through the rectum in enema, suppository, or foam preparations.

dysplasia—alterations in the cells of the colon seen under the microscope after biopsies have been performed. Severe dysplasia in IBD indicates that cancer cells may begin growing in the colon, and that surgery may be necessary.

edema—the accumulation of excessive amounts of fluid in the tissues, resulting in swelling.

endoscopy—a general term for the examination through a lighted tube of any natural body opening. Types of endoscopy include gastroscopy, sigmoidoscopy, and colonoscopy.

erythema nodosum—red swellings occasionally seen on the lower legs during flareups of Crohn's disease and ulcerative colitis. These lesions are an indication that disease is active, and they usually subside without a trace when the disease is treated.

exacerbation—an aggravation of symptoms or an increase in the activity of disease; a relapse.

febrile—running a fever. The presence of fever in a patient with IBD is an indication of increased disease activity.

folic acid—one of the vitamins responsible for the maintenance of red blood cells. Folic acid deficiency may occur in IBD patients, especially in those taking sulfasalazine, and can be corrected by taking oral supplements of the vitamin.

gastroenterologist—a physician specially trained in the diagnosis and treatment of patients with gastrointestinal disease. Your local medical society can provide a list of gastroenterologists.

granulomas—microscopic abnormalities characteristic of Crohn's disease.

- gut**—another word for intestine or bowel.
- hemorrhoids**—painful, dilated veins of the lower rectum and anus.
- hyperalimentation**: see total parenteral nutrition.
- ileoanal anastomosis**—a newer operation for ulcerative colitis in which the rectal tube is retained after colectomy. The innermost mucosal layer of the rectum is stripped off, and a pouch is made from ileum and attached directly above the anus. This preserves continence, and allows the patient to evacuate in the normal manner through the anus. This operation is also known as the “pull-through” or Parks operation.
- ileostomy**—the diversion of fecal waste through a surgically created opening of the ileum to the body wall. Waste collects in a bag appliance attached to the skin by special adhesive.
- incontinence**—in IBD, the inability to retain feces, usually because of rectal inflammation.
- irritable bowel syndrome (IBS)**—altered motility (muscle contractions) of the small and large intestine, causing diarrhea and abdominal discomfort. IBS is mistakenly called “spastic colitis,” though it does not cause inflammation of the colon and has no relationship to ulcerative colitis.
- lactase deficiency/lactose intolerance**—the decrease or absence of the enzyme lactase, which enables the small intestine to digest lactose (milk sugar). People with lactose intolerance experience diarrhea, abdominal discomfort, and gas after ingesting milk or milk products.
- lactose tolerance test**—a test involving the drinking of a liquid rich in milk sugar. Blood samples are then taken over a period of time to determine whether there is a deficiency in lactase.
- leukocytosis**—an increased number of white blood cells in circulation.
- 6-mercaptopurine (6-MP)**—an immunosuppressive drug sometimes used to treat ulcerative colitis that has not responded to other medications. This drug has been shown to be helpful in reducing or eliminating the dependence on corticosteroids in some patients.
- mesalamine**—the generic name for 5-ASA, a relatively nontoxic and well-tolerated drug used to treat inflamed intestine.
- mucus**—a whitish substance produced by the intestine, that may be found in the stool.
- nasogastric tube**—a thin, flexible tube passed through the nose or mouth into the stomach.

The NG tube is necessary to aspirate fluids and air that collect in the stomach when the bowel is obstructed or after intestinal surgery.

occult blood—nonvisible blood in the stool, often an indication of disease activity. Simple laboratory tests can determine the presence of occult blood.

olsalazine—an oral preparation of 5-ASA containing two 5-ASA molecules bonded together.

perforation—an abnormal opening in the bowel wall that causes intestinal contents to enter the normally sterile abdominal cavity.

perianal—the area around the anal opening, which often becomes inflamed and irritated in persons with IBD.

peritonitis—a complication of intestinal perforation that results in the inflammation of the abdominal cavity covering (peritoneum).

prednisone—a form of cortisone given in tablet form to reduce the inflammation of Crohn's disease or ulcerative colitis.

proctocolectomy—the surgical removal of the entire colon and rectum.

pyoderma gangrenosum—a type of sore that sometimes occurs on the extremities of persons with ulcerative colitis or Crohn's disease.

remission—a lessening of symptoms and a return to good health.

resection—the surgical removal of a diseased portion of intestine. Reattachment of the two ends of healthy bowel is called anastomosis.

sigmoidoscopy—a test in which a lighted tube is passed through the rectum into the sigmoid colon. Biopsies may be taken through the sigmoidoscope. Sedation is not usually needed.

SMA₁₂—a laboratory test that allows for the measurement of 12 blood chemistries from a single blood sample.

sulfasalazine—a medication combining a sulfa component with a drug in the aspirin family. Sulfasalazine is used in mild to moderate attacks of ulcerative colitis and to maintain remission.

tenesmus—a persistent urge to empty the bowel, usually caused by inflammation of the rectum.

total parenteral nutrition (TPN)—the intravenous infusion of all nutrients through a catheter placed in a large vein near the collar bone. TPN is used to insure adequate nutrition in severely ill or malnourished IBD patients, to rest the bowel,

and to prepare poorly nourished patients for surgery.

toxic megacolon—acute dilation of the colon in ulcerative colitis (or occasionally in Crohn's disease), which may lead to perforation.

upper GI series—an x-ray examination of the esophagus, stomach, and duodenum, performed in the fasting patient after the ingestion of liquid barium. The duration of the examination can be prolonged to allow for visualization of the entire small intestine, including the terminal ileum. The x-ray is then known as an upper GI series with small-bowel follow-through.



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CROHN'S & COLITIS FOUNDATION
OF AMERICA

NATIONAL HEADQUARTERS
386 Park Avenue South
17th Floor
New York, NY 10016-8804

Tel: 800.932.2423

e-mail: info@ccfa.org

www.ccfa.org

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