Ulcerative Colitis

What is ulcerative colitis?
Ulcerative colitis is one of the major forms of inflammatory bowel disease. The other major form is Crohn's disease. Ulcerative colitis is felt to be due to abnormalities in the immune system, but the specific cause is unknown. Ulcerative colitis is thought of as a disease of younger people. Most people are in their teens or twenties when it starts. However, a small group of people will develop ulcerative colitis later in life. Ulcerative colitis starts in the lowest portion of the intestines, the rectum. Although it may be limited to the rectum (ulcerative proctitis), it often progresses up the colon to involve the left side or even all of the colon (pan colitis).

What are the symptoms?
Most people with ulcerative colitis will have crampy or aching abdominal pain along with bloody diarrhea. Many experience tenesmus which is the urgent need to pass bowel movements. The abdomen may feel swollen, bloated or tender.

These symptoms usually come on gradually over days to months. Occasionally, the onset may be more sudden and other problems such as gastroenteritis or other forms of infectious colitis will need to be ruled out. These early symptoms are caused by inflammation, ulcers in the lining (mucosa) of the bowel and swelling of the walls of the intestines.

Over time, the bowel may become scarred and narrowed, leading to nausea, vomiting, further pain and constipation. These are symptoms of obstruction or blockage of the colon.

Although most symptoms of ulcerative colitis arise from the colon and rectum, the disease involves the immune system of the entire body. Therefore, other parts of the body may be affected. These extra-intestinal manifestations may cause skin swelling (erythema nodosum), skin ulceration (pyoderma gangrenosum), eye inflammation (iritis), joint inflammation (arthritis or ankylosing spondylitis), or liver problems (primary sclerosing cholangitis). Generalized symptoms such as fatigue, poor appetite, loss of weight, or poor growth in children are also common.

These symptoms vary depending on how active the disease is. The symptoms generally parallel the activity of the disease, so when the disease is very active, the symptoms are worse. The disease typically follows a waxing and waning course which may be affected by nutritional state, medications, and even emotional health.

Complications that may occur with ulcerative colitis:
- Anemia – Low red blood cell counts
- Acute, fulminant or toxic colitis – when the disease suddenly becomes very active and the person becomes very sick very quickly.
- Bowel obstruction
- Cancer of the intestines – The risk of cancer rises after 8 to 10 years of disease, particularly when the entire colon has been involved.
- Primary Sclerosing Cholangitis – inflammation, scarring and narrowing of the liver bile ducts.
What causes ulcerative colitis?
No one really knows what causes ulcerative colitis, although there is much work being done to find out. We do know that a number of gene abnormalities (mutations) increase the risk of getting ulcerative colitis. These mutations may be inherited (passed from parent to child) or may develop spontaneously. These mutations cause changes in how the immune system works. As many as 50 different genes are thought to have some effect. Up to 20% of people with ulcerative colitis have a relative that has also had a form of inflammatory bowel disease, and twins are more like to develop it than less related people. Ulcerative colitis is more common in people that are from European and Scandinavian countries. People from European Jewish families also have a higher rate of ulcerative colitis than others. Although ulcerative colitis is less common in Africa and Asia, it does occur in all parts of the world.

Certain factors in the environment may trigger the development of ulcerative colitis, particularly in a person who is prone to it because of their genes. These might include a stomach flu (gastroenteritis), another infection or an allergy. Normally, parts of the immune system are turned on to fight infections and allergies. Once the problem has resolved, the immune system is supposed to settle down and allow the inflammation it generates to resolve. However, it appears that ulcerative colitis may be due to continued inflammation when the immune system does not turn these effects off.

What is the difference between Crohn’s disease and ulcerative colitis?
The major difference between Crohn’s disease and ulcerative colitis is that Crohn’s disease can occur anywhere along the intestinal tract, from the mouth to the anus, while ulcerative colitis is limited to the rectum and colon. Crohn’s disease may effect different parts of the intestines with normal regions in between (skip lesions) while ulcerative colitis is a continuous process, starting the in the rectum and moving up the colon. If there is active disease in the small bowel, than it cannot be ulcerative colitis. Ulcerative colitis is more commonly associated with liver disease. Up to half of people with Crohn’s disease will have an anal problem such as anal canal ulcers or fissures, abscesses (boils), fistulas (tunnels) or large swollen anal skin tags. These rarely occur with ulcerative colitis.

How is ulcerative colitis diagnosed?
After a full physical examination, a series of tests are used to identify the problem in the intestines and to find what portions are involved. Usually, a colonoscopy to evaluated the colon, and a CT scan and/or an MRI are performed. An upper GI study with swallowed barium is commonly used to check on the small intestine, however MR enterography is starting to replace this. Blood tests and stool studies are performed to look for infections.

As noted, if there is active disease in the small bowel, than the diagnosis is likely to be Crohn’s disease and it cannot be ulcerative colitis. Also, a small portion of people thought to have ulcerative colitis will turn out to have Crohn’s disease when their disease returns in the small intestine after the colon and rectum have been removed. When the disease only affects the colon, the diagnosis may not be clear. There is no definitive test that can separate Crohn’s from ulcerative colitis in this situation. Granulomas are swirls of cells and connective tissue that may be seen in diseased tissue under the microscope. When a pathologist reports this finding, the most likely diagnosis is Crohn’s disease. However, only about one third of patients with Crohn’s disease will have granulomas. There are tests that look at several antibodies in the blood. Certain patterns are statistically more likely to be Crohn’s disease or ulcerative colitis, but even this is not definitive.

How is ulcerative colitis treated?

Medications
The primary goal of treatment is to reduce the inflammation caused by an overactive immune system. There are a large number of medications available for treatment of IBD and more are being developed. Some suppress a large part of the immune system which can expose the patient to complications such as infections. Others are targeted at more specific parts of the immune system but have other side effects.

Medications from several different classes may be used including anti-inflammatory drugs related to aspirin (mesalamine, sulfasalazine, balsalazide, olsalazine), corticosteroids (Prednisone), broad immune system suppressors (6 MP - mercaptopurine, azathioprine, cyclosporine, methotrexate), and focused immunomodulators (anti-TNF agents – Remicade, Humira, Cimzia). Some are taken by mouth and others are injected intravenously or beneath the skin. Corticosteroids are very effective but have major side effects including weight gain, excessive facial hair, mood swings, high blood pressure, diabetes, osteoporosis, bone fractures, cataracts, glaucoma and a decreased resistance to infections. They should not be used for more than several months at a time. Certain antibiotics including metronidazole (Flagyl) and ciprofloxacin (Cipro) also seem to have benefit, although it is not clear why. Other medications may be helpful including anti-diarrheal drugs (Imodium, Lomotil), pain medications, and nutritional supplements. Do not take these unless recommended by your doctor.

When a patient is symptom free, they are considered to be in remission. Although there is great variation, remissions may last for months to many years.

**Surgery**

When medications and lifestyle approaches are not adequate for controlling the symptoms of ulcerative colitis, when corticosteroids cannot be reduced or when there is a significant risk of cancer, surgery is indicated.

Because ulcerative colitis only occurs in the colon and rectum, there is a high likelihood of curing the disease once these are removed. Surgery for ulcerative colitis generally requires removal of the entire colon and rectum. About one third of people with ulcerative colitis will need surgery for their disease. Although there is a high likelihood of cure, a small number of people turn out to have Crohn’s disease.

**Operations for ulcerative colitis**

- **Total proctocolectomy with ileostomy**
  The entire colon, rectum and anus are removed and an end ileostomy is constructed. The loose stool empties through an opening from the small bowel to the skin on in the abdominal wall. The ileostomy protrudes about one inch from the skin. A plastic appliance (bag) that sticks to the skin is worn to collect the stool. This is a one-step operation. It is a major operation which is done all at once. Outcome is quite good, although the ileostomy is permanent. It is the simplest operative that cures the disease.

- **Total proctocolectomy with continent ileostomy – Kock pouch**
  The entire colon, rectum and anus are removed and a continent ileostomy is constructed. The continent, or Kock, pouch is an internal reservoir made from several loops of ileum so that there is room for stool to collect inside the body. The last part of the ileum is pushed into itself to create a “nipple valve.” This keeps the stool in the pouch from leaking out. The end of the small bowel is
sutured to the skin to create a flat opening in the abdominal wall. The pouch must be emptied 4-6 times per day using a firm plastic tube. The tube is inserted into the pouch through the ileostomy opening which allows the stool to flow out. This is an attractive option because a plastic appliance (bag) does not have to be worn on the skin. However, it is a much more complicated operation than the end ileostomy, and many complications may occur including loss of control and leakage. Many people need to have multiple operations to correct these problems and some will need to be converted to the end ileostomy.

- **Abdominal colectomy with ileostomy and rectal closure**
  Most of the colon is removed but the rectum is left in place. An end ileostomy is constructed and the upper end of the rectum is sutured closed. This operation is usually performed in urgent situations such as toxic colitis, or when the patient is very sick and debilitated and is likely to heal very poorly. It leaves the diseased rectum in place. Usually, another operation must be performed to remove the rectum once the person recovers.

- **Ileal pouch- Anal Anastomosis – IPAA procedure**
  Also known as a pelvic pull-through, a J-pouch, or a restorative proctocolectomy, this is the most commonly performed operation for people with ulcerative colitis today. Although it is a fairly complicated procedure, it does ultimately result in bowel motions that are passed through the anus and no ileostomy.

  The procedure is usually done in 2 steps. The first operation is the most extensive. The entire colon and almost all of the rectum are removed, leaving the anal muscles (sphincters) and anal canal. A “J” shaped pouch is made out of the last part of the small intestine (ileum) to hold stool. This is connected to the anus with sutures or a stapler (ileo-anal anastomosis). A temporary loop ileostomy is created well above the pouch so that the stool will empty into an appliance (bag) while the pouch and anal anastomosis heal. The second operation is generally performed 2-3 months later. The pouch and anastomosis are evaluated under anesthesia and then the loop ileostomy is surgically closed. This is a much smaller operation.

  After the IPAA procedure, most people have about 5 to 6 bowel movements per day. They are loose and like apple sauce or porridge. However, this varies depending on diet. Many people will take Imodium or other medications to slow the bowel movements and fiber supplements to thicken it. Most people have excellent control and can hold bowel movements as before.

  Not everyone is a candidate for an IPAA procedure. Severe disease and poor nutrition increase the risks of poor healing and infection. Therefore, a three step approach with an initial abdominal colectomy with ileostomy and rectal closure may be in order. Sometimes Crohn’s disease is found at the time of surgery or the pouch cannot reach the anus. In these cases, an end ileostomy may be performed.

  Problems can occur after the IPAA procedure including pouchitis (inflammation in the pouch), incontinence (control problems) and frequent bowel movements.

  Over 90% of people undergoing an ileal pouch-anal anastomosis will do quite well and return to a normal life style.
The timing and type of surgery to be performed will be decided by the patient and the family together.

Patient information materials developed in the Section of Colon and Rectal Surgery at Rush University Medical Center. The information contained in this brochure is believed to be accurate; however, questions about your individual health should be referred to your physician.

July 2013 - No. 051 v8.3

Rush is a not-for-profit health care, education and research enterprise comprising Rush University Medical Center, Rush University, Rush Oak Park Hospital and Rush Health.