Inflammatory Bowel Disease

What is inflammatory bowel disease?

*Inflammatory bowel disease (IBD)* is not a single disorder, but rather is a group of similar diseases. Most are felt to be due to abnormalities in the immune system, but the cause of many is unknown. Common to all is crampy abdominal pain, diarrhea, and swelling and inflammation of the intestines.

There are a number of diseases that are grouped within IBD. The most common are *Crohn’s disease* and *ulcerative colitis*, which effects up to 2 million people in the United States. Less common diseases such as *collagenous colitis*, *lymphocytic colitis* and *Behcet’s disease* also fall in this category. *Indeterminant colitis* is an inflammatory process involving only the colon which, when initially found, cannot be diagnosed as either Crohn’s disease or ulcerative colitis with certainty. Over time it may become clear which one it is. IBD is *not* related to irritable bowel syndrome (IBS).

IBD 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 IBD later in life.

What are the symptoms of IBD?

Most people with IBD will develop crampy or aching abdominal pain along with diarrhea or blood in the stools and 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 acute appendicitis will need to be ruled out. These early symptoms are caused by inflammation, ulcers in the lining (mucosa) 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 intestines. Sometimes, as in Crohn’s disease, the ulcers in the bowel may burrow through the wall resulting in an *abscess* or pocket of infection. This can also lead to a *fistula* or tunnel which may lead into another portion of the bowel, bladder, uterus, vagina, stomach or skin.

Although most symptoms of IBD arise from the intestinal tract, 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 which specific disease you have and 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. These diseases typically follow a waxing and waning course which may be affected by nutritional state, medications, and even emotional health.

Complications that may occur with IBD:

- Anemia – Low red blood cell counts
- Fistulas
- Abdominal abscesses
- Anal disease including perianal abscesses, fistulas, ulcers and swollen skin tags. These are primarily seen with Crohn’s disease.
- 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.

What causes IBD?

No one really knows what causes IBD, 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 IBD. 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 one third of people with IBD have a relative that has also had IBD, and twins are more like to develop it than less related people. IBD is more common in people that are from European and Scandinavian countries. People from European Jewish families also have a higher rate of IBD than others. Although IBD 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 IBD, 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 IBD 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 IBD 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 evaluate 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. Because ulcerative colitis only occurs in the colon and rectum, once these are surgically removed there is a high likelihood of curing the disease. Crohn’s disease is rarely cured with surgery because it may come back anywhere in the intestine. So surgery is used to manage complications of the disease or failure to respond to medications. However, 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 IBD 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 IBD, when corticosteroids cannot be reduced or when there is a significant risk of cancer, surgery is indicated.

The approach to surgery is different in people with Crohn’s disease and ulcerative colitis. Because ulcerative colitis only occurs in the colon and rectum, there is a high likelihood of curing the disease once these are removed. Crohn’s disease, however, is rarely cured with surgery because it may come back anywhere in the intestine.

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. The anus and anal sphincter muscles may be kept when a pelvic pouch (ileo-anal) procedure is planned.

Surgery for Crohn’s disease is primarily used to treat complications of the disease. Surgery does not cure the disease although prolonged periods without any symptoms may be enjoyed. About 70-80% of people with Crohn’s disease will need surgery for either acute or chronic reasons. Acute complications requiring surgery include toxic colitis, bowel perforation, severe bleeding, or abscesses. More commonly, chronic problems such as strictures (narrowing) and obstruction, fistulas, malnutrition, weight loss, dependence on steroid medications, and disease that does not adequately respond to medical treatment are addressed with surgery. Surgery may involve drainage of abscesses, treatment of fistulas, removal of segments of diseased bowel, or opening of narrowed areas (stricturoplasty).

Inflammatory bowel disease is often a chronic and life-long problem. However, with current medical and surgical treatments, most people can live long and productive lives. Close cooperation between patient, physician and surgeon is critical for the best management of your disease.

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. 048 v8.3