

Inflammatory Bowel Disease

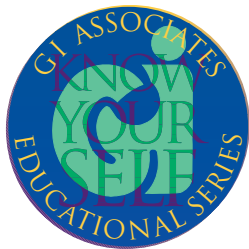


Inflammatory Bowel Disease

The term *inflammatory bowel disease* (sometimes called IBD) is a catch-all term that refers to many diseases, but all of those are generally categorized as one of two major forms: *ulcerative colitis* or *Crohn's disease*. Other names for inflammatory bowel disease that you may have heard are: *colitis*, *mucous colitis*, *regional enteritis*, *ileitis*, *terminal ileitis* and perhaps many other variations of those terms. In spite of the many names associated with inflammatory bowel disease, it is usually described by the terms *ulcerative colitis* or *Crohn's disease*. The two diseases are similar in that both are inflammations of the gastrointestinal tract. They differ in location of the inflammation and the extent of tissue affected. Sometimes the diseases "overlap," meaning that some patients may experience symptoms of both diseases.

Location: *ulcerative colitis* generally involves the colon and/or rectum, whereas *Crohn's disease* may affect the esophagus, stomach, colon and small intestines.

Severity: *Crohn's disease* is generally considered to be the more serious of the two diseases, with a somewhat greater potential for serious complications.



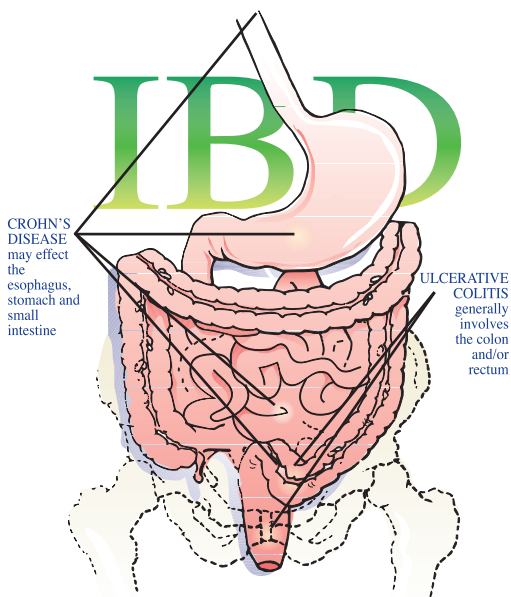
Extent: *Ulcerative colitis* typically involves one or two layers of tissue that line the affected area, whereas *Crohn's disease* may involve all layers of tissue.

Clinicians consider both diseases "stubborn" to diagnose and to treat. They are often hard to diagnose because symptoms are similar to many other illnesses. The best

treatment may be difficult even for experts to determine because the cause of the problem is unknown and because what works well for one patient may not necessarily work well for others.

The two diseases are considered *chronic diseases*, which means that they don't "go away." Even though some people never have a recurrence after treatment, most often there will be uncomfortable "flare-ups" of the disease, even with the best of treatment. But, most patients with inflammatory bowel disease have long periods of time free from major symptoms, during which their usual routines are not affected to a great degree.

Inflammatory bowel diseases should be considered serious illnesses, for which appropriate medical treatment is a must to avoid life-threatening complications. Once diagnosed, it is extremely important for the patient to follow the physician's orders, to avoid negative impact on one's daily life.

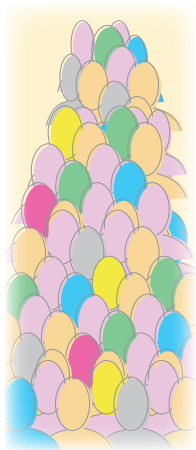


What causes inflammatory bowel disease?

No one really knows what causes inflammatory bowel disease, though much research has been done. The role of genetics, infection, the immune system, allergy and stress have been explored; but none of those factors have been implicated as the cause of the problem. The possibility of emotional causes has been extensively researched. It is known that emotional upset can cause symptoms to grow worse, but experts agree that the disease is not caused by stress or emotional upset.

Don't fall into the guilt trap! A person diagnosed with inflammatory bowel disease should not feel guilty — we only have a certain amount of control over disease processes.

Who is affected?



Between 1 and 2 million Americans have inflammatory bowel disease, with about 100,000 new cases diagnosed each year. Trends reveal that it is becoming more common than in years past. Ulcerative colitis is the most common of the two problems, with 1 in every 1,000 people having ulcerative colitis and about 1 in every 3,000 having Crohn's disease. So, Crohn's disease is the less common of the two.

Inflammatory bowel disease may develop at any age, but most commonly appears during young adult years, in the 20's and 30's.

Slightly more women than men develop the disease. More white people than black people are affected. The disease occurs 3 to 7 times more often among people of the Jewish faith.

Northerners develop inflammatory bowel disease more frequently than Southerners, and the typical patient has above average intelligence and educational level.

There seems to be an inherited tendency to develop inflammatory bowel disease, yet many people have no family history of the disorder. Only 15 to 30 percent of diagnosed patients have a relative with either ulcerative colitis or Crohn's disease.

What are the symptoms of inflammatory bowel disease?

It is not unusual for a person to have had inflammatory bowel disease for a long time before being diagnosed, because the early symptoms may be rather vague, and because the symptoms may be very similar to many other common illnesses. Most often, some abdominal discomfort, diarrhea, or loss of appetite will be present early in the course of the disease. An "upset stomach" may be noticed more frequently than before, after having overeaten or after an emotional upset.

The major symptoms that occur in both ulcerative colitis and Crohn's disease are diarrhea and abdominal cramps. Some people with inflammatory bowel disease have one or two loose stools a day, whereas others may have twenty or

more. Diarrhea tends to be worse with ulcerative colitis than with Crohn's disease. Similarly, stools are more apt to contain blood with ulcerative colitis than with Crohn's disease. It is not unusual for the patient to awaken in the middle of the night with an urge to have a bowel movement.

Complications of inflammatory bowel disease

If the disease is allowed to continue without treatment, symptoms will grow worse, with extreme cramping, tenderness, and possibly fever. Diarrhea will become more frequent, unpredictable and difficult to control. Loss of weight occurs in 65 to 75 percent of patients. Also, anemia, dehydration, weakness, fatigue and dizziness are not uncommon.

Because the intestine is responsible for absorbing nutrients in food eaten, without treatment, inflammatory bowel disease can interfere with that process, causing malnutrition.

Other complications that can occur include arthritis and skin rashes (especially with ulcerative colitis), eye inflammations, liver disease, ulceration and bleeding, infection, or intestinal blockage.

As mentioned earlier, in Crohn's disease, all layers of tissue in the affected area may be involved, therefore actual tears in tissue, called *fissures* may occur. *Abscesses* (walled-off areas of infection) may develop within the bowel. Another serious complication, occurring more often in

Crohn's disease is the formation of *fistulas*, which are abnormal tunnel-like connections to other parts of the body.

Fistulas can become very problematic because the open tunnel can be filled with bacteria from intestinal contents and may empty into other areas of the body, causing acute infection.

Because of the damage to tissue that may develop, loops of intestine may actually get stuck together (adhere to each other), called an *adhesion*. *Stenosis* (narrowing) of intestines making the passage more prone to blockage, is also common in Crohn's disease.

Less common, life-threatening conditions that may occur are *hemorrhage* and actual *rupture of the bowel*.

Diagnosis of inflammatory bowel disease

Diagnosis of inflammatory bowel disease is usually based on a thorough medical history, physical examination, stool tests, X-rays, and endoscope examinations that allow the physician to look directly at the affected tissue. Some blood tests may also be used. Since many other diseases may have similar symptoms, diagnosis is often complicated, because other diseases must be ruled out.

It is not unusual for symptoms to have been present for months or years and the patient to have been treated for various other GI diseases before a definite diagnosis can be made.



How is inflammatory bowel disease treated?

Although there is no known cure, much is known about treating the disease, to allow the patient to lead a normal life. Treatment may consist of all or some of the following: *diet*, *medications*, including *steroids* (to decrease inflammation), *antibiotics* (to curb infection) and *immunosuppressive drugs* (to suppress the body's reaction to the disease) are often used. In addition, medications to control the symptoms of diarrhea and cramping are often used.

Diet

In general, the patient's diet need not be altered to a great degree. Some patients may have difficulties digesting milk and milk products or spicy foods. If a patient's nutritional status have been greatly altered by the disease, nutritional therapy (replacement of fluids, vitamins and minerals) may be necessary.

NO DAIRY



Low residue diets that reduce bulk or fiber may help. In some cases diets may be prescribed that have no residual (waste) matter at all. That means that when all the necessary nutrients are absorbed, there is no waste matter left to pass through the patient's intestine, allowing the bowel to rest. Such a diet is known as an *elemental*, *elimination*, or *exclusion* diet. It may be necessary for the patient's digestive system to be given an even greater rest, therefore, sometimes, the patient will be fed through a blood vein with an



I.V. (intravenous) feeding until his/her condition improves.

Surgery

When the disease is very severe, surgery may be necessary. Partial or complete *resection* (removal) of the colon and/or ileum sometimes requires the formation of an opening through the abdomen to allow the patient to have bowel movements.

A plastic pouch is worn over the opening to collect the waste matter. The opening, known as either an *ileostomy* or *colostomy*, may be either permanent or temporary, depending on how much of the tissue has been removed. Such a surgical procedure is only used when the disease becomes a great threat to the patient's well being, and possibly life. Though the change may be somewhat distasteful and difficult to adjust to, when thought of in terms of life-saving it is welcomed by many. The procedure is often considered a cure, because the diseased area has been removed and patients usually feel much better as a result.

Rest

Rest is often prescribed during flare-ups of the disease, to help the body deal with the illness and to allow recovery from the flare-up.



Follow-up care

Long-term follow-up care of the disease by a gastroenterologist is very important, because people who have ulcerative colitis or Crohn's disease for an extended period of time are more prone to developing certain types of cancer. Periodic screening examinations are important to detect and treat the problem early, when chances for effective treatment are better.

In summary...

The challenges represented by inflammatory bowel disease are many, but working with your GI doctor, the problem can be managed in such a way that interference of the disease in your daily life will be minimized.

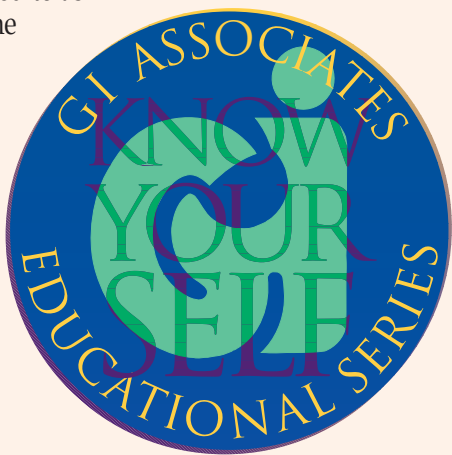
When it won't go away

Usually, illnesses don't last very long. When we are not feeling well, we assume that we'll feel better soon. Even very uncomfortable illnesses, such as the flu are self-limiting, meaning that they eventually go away. Because we know that such illnesses are temporary, we can handle them without major disruption to our lives and normal routines.

Chronic diseases, such as inflammatory bowel disease do not go away, therefore, like persons with other types of chronic disease, those with inflammatory bowel disease must literally learn to *live with it*.

A chronic illness may range from mild to severe, in terms of symptoms and the degree of discomfort involved. Also, the degree to which a person's normal routine is affected depends on how severe the illness is, how well the patient follows the prescribed treatment, and the general life situation of the patient (including family support, the presence or absence of stress, adequate finances, etc.). Sometimes, through the appropriate treatment, the disease can be *arrested*, which means that the patient may be symptom-free for a period of time. That period of time is often known as *remission*. When symptoms grow worse, it is sometimes referred to as an *exacerbation* of the disease.

A person with a chronic illness, such as inflammatory bowel disease may be faced with many normal concerns or challenges, such as the following:



Disappointment

Many times the diagnosis of inflammatory bowel disease has taken an extended time, because the symptoms may be vague or may resemble other illnesses. Often the patient has visited one or more physicians many times and may have spent a lot of money trying to find out what is wrong. Once the diagnosis is made, if improvement is not immediate, patients may be disappointed. Sometimes that factor may keep a person from following the physician's instructions long enough for the treatment to work well.

Denial

It is often hard for a person to accept the fact that they have inflammatory bowel disease. The physicians of GI Associates have noticed that younger patients seem to have a much harder time accepting that they have a chronic disease that will not go away. The group that is most often affected by inflammatory bowel disease are young adults, who typically do not expect something like that to interfere with their lives.

Often such patients will discontinue treatment when they start to feel better, with devastating results. Serious, even life-threatening situations, are not uncommon when a patient does not follow orders. Unfortunately, it takes a couple of real serious episodes of the disease to convince some people of the seriousness of the problem and to accept the fact that they will need to follow a treatment plan for an extended period of time.

Uncertainty

Persons with a chronic illness are often anxious because it is not known what the future has in store for them.



Loss of Independence

When a chronic illness flares up, it is often necessary to depend on other people for help. There may be periods of hospitalization or bed rest, when the patient must let others assume some of their responsibilities. Many of us simply do not like to ask for help.

Side effect of treatment

Sometimes, the side effects of treatment are unpleasant. It is important to know what side effects to expect, so that you won't be overly anxious.

Finances

The long-term aspect of any chronic disease may place a strain on one's budget, especially if a person does not have strong health insurance coverage.

Loss of strength and energy

With any extended illness, there may be a reduction in physical stamina. Very active persons tend to have trouble accepting the need to slow down.

Relationships

The long-term nature of a chronic illness can place unusual demands on relationships that are important to the patient. Because the patient will have "good days" and "bad days" or extended periods of either, it is difficult for friends and loved ones to understand that the disease is always there.

On the bright side



In spite of the many challenges faced by those with inflammatory bowel disease, most people are able to adapt in a positive manner. In fact, many experience an increased appreciation of life and a

deepening of significant relationships. As priorities change, they discover parts of themselves that they had not previously noticed. Patients find many ways to live with a chronic illness. Some things that will help are:

A good sense of humor:

If humor can be found in difficult situations, problems simply do not seem as bad.

Seek information: Reading about the illness can help prevent worry. Replace the unknown with knowledge. Your physician can suggest books or other printed materials. If you do not want to know about the problem right now, have an interested family member read up on the illness, then you can be informed in small bits, as you are ready.

Maintain a positive relationship with your physician:

A stable and ongoing relationship with your physician can help tremendously. By being an active partner in your care and communicating your needs to your physician, treatment will be more successful.

Support groups:

There are support groups for individuals with inflammatory bowel disease. Join a group! Support groups

can offer wonderful friendships and many practical ideas that will help you live with inflammatory bowel disease.

New Activities and Outside involvement:

Enjoy friends and activities other than those involved in your illness. In other words, don't let inflammatory bowel disease become the major focus of your life. The development of new interests will help divert some of your attention away from the discomfort of the illness. You may find new talents that you were unaware of. Explore that hobby or interest that you have put on the back burner for so long!

Seek help:

If the problems that you are facing seem overwhelming, to the point that your life is being negatively affected in a major, insurmountable way, seek help. Often, short-term counseling can be a life-saver when one is faced with a difficult problem. Your physicians can help you decide whether or not additional assistance might be beneficial.

These ideas are but a few suggestions that may be helpful when learning to deal with a chronic illness like inflammatory bowel disease. Most persons do learn to live successfully with the disease. Even those who have extremely demanding professional and personal lives have learned to manage the condition well, with professional help. You may be surprised to learn that former Mississippi Governor Ray Mabus had a bout of Crohn's disease in 1981. Also, former Miss Mississippi and Miss America, Mary Ann Mobley, and former President Bush's son, Marvin Bush, are among the people who are leading successful demanding lives with inflammatory bowel disease.