

understanding
IBD
INFLAMMATORY
BOWEL DISEASE

A patient's guide from your doctor and





To help you understand and manage your condition, the AGA Institute provides you with the following information, designed to give you some basic facts, to help you better understand your condition and to serve as a starting point for discussions with your doctor.

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is a term that refers to both ulcerative colitis and Crohn's disease.

- ▶ Ulcerative colitis is a disease of the colon in which inflammation of the lining of the large intestine occurs.
- ▶ Crohn's disease causes inflammation of the lining and wall of the large and/or small intestine. When inflamed, the lining of the intestinal wall is red and swollen, becomes ulcerated, and bleeds.

It is important to know about each of these illnesses and how they may affect you.

Causes of IBD

The cause(s) of IBD are not known, but there are several theories. One theory is based on genetics, indicating that IBD does run in families. About 15 percent to 30 percent of patients with IBD have a relative with the disease. There is research underway to find out if a specific gene or a group of genes makes a person more susceptible to getting the disease.

Many changes in the body's immune system (body's natural defense system against disease) have been discovered in patients with IBD. What is still unknown is what causes those changes to happen. There is a large amount of research being done in this area, including studies to find out if IBD is caused by an infectious agent.

There is little evidence that stress causes IBD. As with other illnesses, stress may aggravate symptoms and require a treatment program.

IBD occurs most frequently in people in their late teens and twenties. There have been cases in children as young as two years old and in older adults in their seventies and eighties. Men and women have an equal chance of getting the disease.

IBD Basics

- The two major illnesses that are recognized most often as inflammatory bowel disease are ulcerative colitis and Crohn's disease.
- Men and women are affected equally by IBD.
- The most common symptoms of ulcerative colitis, which occurs in the inner lining of the colon (large intestine) or rectum, are diarrhea, abdominal cramps and rectal bleeding.
- Patients suffering from Crohn's disease, an inflammation and ulceration process that occurs in the deep layers of the intestinal wall, experience pain in the abdomen, often in the lower right side, diarrhea, weight loss and occasionally bleeding.
- Both Crohn's disease and ulcerative colitis are illnesses with periods of remission (when you feel well) and relapse (when you feel ill).
- There are many different types of treatment plans that your doctor can prescribe to control the symptoms of IBD, and each of these has specific actions and side effects.

Ulcerative Colitis

Most often, ulcerative colitis occurs in young people 15 to 40 years of age. Ulcerative colitis occurs only in the inner lining of the colon (large intestine) or rectum. When it is located only in the rectum, it is called **proctitis**. Inflammation of the rectum and colon keeps water from being absorbed into the bloodstream and results in diarrhea.

Ulcerative colitis is an illness that has periods of remission (time when you feel well) and relapse (time when you feel ill).

Symptoms of Ulcerative Colitis

The most common symptoms of ulcerative colitis are:

- ▶ Diarrhea
- ▶ Abdominal cramps
- ▶ Rectal bleeding
- ▶ Frequent fever
- ▶ Nausea

Other symptoms include:

- ▶ Fatigue
- ▶ Weight loss
- ▶ Loss of appetite
- ▶ Abdominal pain
- ▶ Joint pain
- ▶ Liver problems
- ▶ Loss of body fluids and nutrients
- ▶ Bleeding, leading to anemia (a low count of red blood cell causing fatigue)
- ▶ Redness and swelling of the eyes

No one knows for sure why problems outside the colon are linked with colitis. These problems may improve when the ulcerative colitis is managed.

Half of the people who have ulcerative colitis have only mild symptoms.

Some people with severe symptoms of ulcerative colitis must go to the hospital to correct malnutrition and stop diarrhea and loss of blood. In the hospital, a patient may need a treatment program including a special diet and feeding through a vein. Sometimes surgery is needed.

Ulcerative Colitis and the Risk of Colon Cancer

The risk of colon cancer is higher in ulcerative colitis patients with involvement of the entire colon and in patients who have had the diagnosis for eight to 10 years or more. Patients with a diagnosis of left-sided ulcerative colitis for 15 to 20 years also fall into a higher risk group for developing cancer. Individuals who fall into these groups should consult their gastroenterologist and plan for periodic colonoscopy with biopsy.

Diagnosing Ulcerative Colitis

To find out if you have ulcerative colitis, your gastroenterologist must take your medical history and perform a physical examination. The exam may include blood tests and samples of a bowel movement. You may also need to undergo a colonoscopy.

During this test, a small flexible tube will be inserted into the anus by your doctor and slowly passed along the colon, allowing your doctor to see the lining of the colon. If necessary, the doctor can take a tissue sample called a biopsy to make a diagnosis of your condition. To learn more about colonoscopy, read the AGA Institute brochure on that topic in your gastroenterologist's office or visit www.gastro.org/patient.

Medications Available for Ulcerative Colitis

There are many drugs that are effective for the treatment of ulcerative colitis. The goal of treatment is to induce and maintain remission and to improve the patient's quality of life.

- ▶ **Aminosalicylates:** These drugs are the first-line treatment for many patients with mild or moderate ulcerative colitis, as well as for patients who have relapsed. The drugs, which contain 5-ASA, help control inflammation, but may have side effects such as nausea, vomiting, heartburn, diarrhea and headache. They are administered either orally, through an enema or in a suppository, depending on the location of the colon inflammation.
- ▶ **Corticosteroids:** Patients with moderate to severe ulcerative colitis, or who do not respond to aminosalicylates, may use these drugs to reduce inflammation. They may cause side effects such as weight gain, acne, facial hair, hypertension, diabetes, mood swings, bone mass loss and increased risk of infection. Patients should not take long-term corticosteroids, but they are very effective for short-term use.
- ▶ **Immunomodulators:** For patients who do not respond to aminosalicylates or corticosteroids, or who may be dependent on corticosteroids, immunomodulators may be helpful. These drugs reduce inflammation by affecting the immune system. They are administered orally, but are slow-acting and it may take up to six months for patients to feel the effects. A number of complications may arise including pancreatitis, hepatitis, reduced white blood cell count and increased risk of infection.
- ▶ **Biologic treatments:** Some patients may require medications that target specific proteins in the body's immune system to help control the development of inflammation. Tumor necrosis factor (TNF) can cause your immune system to attack healthy tissues in your body and cause inflammation and damage. Anti-TNF medications recognize, attach to and block the action of TNF. Blocking TNF does not cure inflammatory bowel disease, but it may reduce the inflammation caused by TNF in your body. These agents are used for the treatment of moderate to severe ulcerative colitis that does not respond to standard therapies (aminosalicylate substances, corticosteroids or immunosuppressive agents).

Crohn's Disease

Crohn's is a chronic disease that has periods of remission (time when you feel well) and relapse (when you feel ill).

Crohn's disease is an inflammation and ulceration process that occurs in the deep layers of the intestinal wall. The most common area affected is the lower part of the small intestine, called the **ileum**, and the first part of the colon. This type of Crohn's disease is called **ileocolitis**.

Crohn's disease can infrequently affect any part of the upper gastrointestinal tract. **Aphthous ulcers**, which are similar to cold sores, are common. Ulcers can also occur in the esophagus, stomach and upper small intestine (duodenum). It is difficult to tell these ulcers from peptic ulcers except by biopsy exam.

Symptoms of Crohn's Disease

The most common symptoms of Crohn's disease are:

- ▶ Pain in the abdomen, often in the lower right side.
- ▶ Diarrhea.
- ▶ Weight loss.
- ▶ Rectal bleeding.
- ▶ Fever.

Chronic bleeding may lead to a low red blood cell count called anemia. Children who develop Crohn's disease may have delayed development and stunted growth.



Diagnosing Crohn's Disease

To find out if you have Crohn's disease, your gastroenterologist must take your medical history and do a physical exam. The exam may include blood tests and samples of a bowel movement. Other tests are the same as described in the section on ulcerative colitis, such as colonoscopy. In addition, a small bowel x-ray or capsule endoscopy may be required. To learn more about capsule endoscopy, read the AGA Institute brochure on that topic in your gastroenterologist's office or visit www.gastro.org/patient.

Crohn's Disease Complications

The most common complication of Crohn's disease is **blockage of the intestine**. Blockage or **stricture** occurs when the disease thickens the bowel wall with swelling and scar tissue. The intestinal passage becomes smaller and smaller, until it is completely closed.

Fistulas are a common complication of this disease. Fistulas occur when ulcers in the intestine break through the intestinal wall making tunnels into surrounding tissues of the bladder, vagina or into the skin. Fistulas occur frequently around the anus and rectum. These fistulas can become infected and may result in abscess formation. Treatment programs are used to manage infected fistulas, but surgery is often needed.

Medications Available for Crohn's Disease

While there is no cure for Crohn's disease, there are a number of medications that can help control inflammation and relieve symptoms like abdominal pain, diarrhea and rectal bleeding. A patient's treatment will depend on location and severity of disease, complications and response to previous treatments.

- ▶ **Anti-Inflammation Drugs:** Usually the first line of treatment, these drugs help control inflammation. Potential side effects include nausea, vomiting, diarrhea, heartburn and headache.
- ▶ **Corticosteroids:** In patients with Crohn's disease, corticosteroids provide very effective results. The drugs are usually prescribed in large doses in the beginning, when the disease is at its worst, and then lowered once symptoms are under control. They may cause side effects such as weight gain, acne, facial hair, hypertension, diabetes, mood swings, bone mass loss and increased risk of infection.
- ▶ **Immunomodulators:** Immunomodulators, or immunosuppressive agents, block the immune reaction that contributes to inflammation. Common side effects include nausea, vomiting and diarrhea as well as a decreased ability to fight infections.
- ▶ **Biologic treatments:** Some patients may require medications that target specific proteins in the body's immune system to help control the development of inflammation. Tumor necrosis factor (TNF) can cause your immune system to attack healthy tissues in your body and cause inflammation and damage. Anti-TNF medications recognize, attach to and block the action of TNF. Blocking TNF does not cure inflammatory bowel disease, but it may reduce the inflammation caused by TNF in your body. These agents are used for the treatment of moderate to severe Crohn's disease that does not respond to standard therapies (aminosalicylate substances, corticosteroids or immunosuppressive agents) and for the treatment of open, draining fistulas.

Adapted from NIH Publication No. 06-3410; February 2006: www.digestive.niddk.nih.gov

Staying informed is an important aspect of dealing with IBD.

Treatment for IBD

Your gastroenterologist will discuss with you a treatment plan that may include any of the following:

- ▶ Nutrition
- ▶ Emotional support
- ▶ Medical therapy
- ▶ Surgery

There are many different types of treatment plans that your doctor can prescribe to control the symptoms of IBD, and each of these has specific actions and side effects. Be sure to follow all of your doctor's directions. Never stop your treatment plan until you have completed it or your doctor instructs you to stop.

Nutrition

While what you eat does not cause IBD, foods can cause or worsen symptoms when the disease is active.

The goal of nutritional management for people with IBD is to modify the diet to decrease digestive symptoms while maintaining adequate nutrient intake. Your doctor may do a nutritional assessment to determine if you are taking in enough calories, vitamins and minerals. When nutritional needs are not being met, your doctor may suggest a liquid supplement.

Coping with IBD

Although IBD is a chronic disease that has periods of remission and relapse, most people have a normal life span and many have a good quality of life. For those who have chronic and continuing symptoms, the following apply:

- ▶ Know your body and how IBD affects you.
- ▶ Learn to care for yourself — have control over those things you can control.
- ▶ Develop a support system that works for you: family, friends and support groups.
- ▶ Be sure to follow instructions from your medical team.

When Is Surgery Needed?

Most people who have IBD respond to their treatment program, including medications and nutritional planning. Many patients have mild episodes of illness after long periods of feeling well. Your doctor will consider surgery usually when certain conditions are present. Surgery may be needed if there is:

- ▶ A large amount of bleeding.
- ▶ Long-lasting and serious illness.
- ▶ Ulceration that makes a hole in the intestinal wall.
- ▶ Medical treatment plan that is not controlling the disease.
- ▶ Obstruction.
- ▶ Cancer.

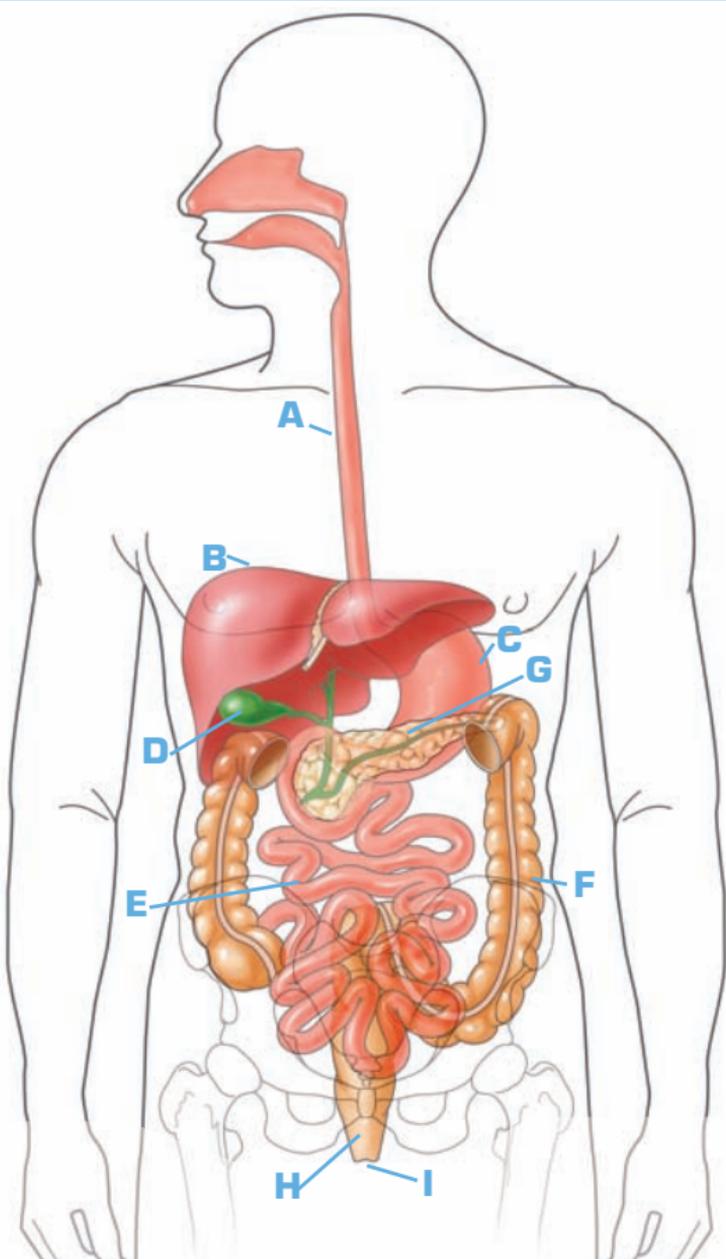
There are several surgical choices. Each has advantages and disadvantages. The surgeon and patient must decide on the best option.

Normal Digestive Function

Digestion of food begins in the mouth and moves through the esophagus, stomach, and the small and large intestine. In the mouth, stomach and small intestine, food is mixed with digestive juices. The digestive juices break the food down into smaller chemical pieces or nutrients. These nutrients move along the small intestine, which is made up of three parts: the duodenum, jejunum and ileum. The nutrients are absorbed into the bloodstream through the small intestine and carried to all parts of the body. Nutrients are needed for the body to grow and remain healthy.

The water and solid waste that remain after the nutrients are absorbed move into the large intestine. Most of the remaining water is absorbed into the bloodstream from the colon. The solid waste is passed out of the body as a bowel movement through the anus.

Your Digestive System



A. Esophagus

B. Liver

C. Stomach

D. Gallbladder

E. Small Intestine

F. Large Intestine

G. Pancreas

H. Rectum

I. Anus

Go to www.gastro.org/patient for more information on digestive health and tests performed by gastroenterologists and to find an AGA member physician in your area.

The American Gastroenterological Association (AGA) is dedicated to the mission of advancing the science and practice of gastroenterology. Founded in 1897, the AGA is one of the oldest medical-specialty societies in the U.S. Our 16,000 members include physicians and scientists who research, diagnose and treat disorders of the gastrointestinal tract and liver. The AGA Institute runs the organization's practice, research and educational programs.

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The Digestive Health Initiative® (DHI) is an AGA Institute initiative that offers educational programs on digestive disorders for individuals who are affected by a digestive disease, in an effort to educate the larger health-care community.

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**For more information about digestive diseases,
please visit the AGA Web site at www.gastro.org.**

The AGA Institute offers the information in these brochures for educational purposes to provide accurate and helpful health information for the general public. This information is not intended as medical advice and should not be used for diagnosis. The information in these brochures should not be considered a replacement for consultation with a health-care professional. If you have questions or concerns about the information found in these brochures, please contact your health-care provider. We encourage you to use the information and questions in these brochures with your health-care provider(s) as a way of creating a dialogue and partnership about your condition and your treatment.