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Ulcerative Colitis & Proctitis

About Ulcerative Colitis & Proctitis

When you first learn that you have ulcerative colitis, you will probably feel overwhelmed. You may not even have heard of ulcerative colitis until now. And even if you are familiar with the disorder, the information you have may be pretty limited. That's all about to change. Clearly, you will have many questions about how this disease will affect you -- both now and down the road. For example, you'll want to know:

- Will I be able to work, travel, and exercise?
- Should I be on a special diet?
- How will other people react to my illness?
- Could my medications have side effects?
- How will ulcerative colitis change my life?

Learning all you can is an important step toward taking charge of your illness -- and your life. The following is an overview of ulcerative colitis. It is designed to help you understand more about the diagnosis and treatment of this illness, and its impact on the day-to-day lives of patients and their families. The better informed you are about ulcerative colitis, the more equipped you'll be to participate as an active member of your healthcare team.

What is Ulcerative Colitis?

Ulcerative colitis is a chronic (ongoing) disease of the colon, or large intestine. The disease is marked by inflammation and ulceration of the colon mucosa, or innermost lining. Tiny open sores, or ulcers, form on the surface of the lining, where they bleed and produce pus and mucus. Because the inflammation makes the colon empty frequently, symptoms typically include diarrhea (sometimes bloody) and often crampy abdominal pain.

The inflammation usually begins in the rectum and lower colon, but it may also involve the entire colon. 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 and colon. Ulcerative colitis, on the other hand, affects only the colon. The inflammation 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.

Both illnesses do have one strong feature in common. They are marked by an abnormal response by the body's immune system. The immune system is composed of various cells and proteins. Normally, these protect the body from infection. In people with IBD, however, the immune system reacts inappropriately. Mistaking food, bacteria, and other materials in the intestine for foreign or invading substances, it launches an attack. In the process, the body sends white blood cells into the lining of the intestines, where they produce chronic

inflammation. These cells then generate harmful products that ultimately lead to ulcerations and bowel injury. When this happens, the patient experiences the symptoms of IBD.

Neither ulcerative colitis nor Crohn's disease should be confused with irritable bowel syndrome (IBS), a disorder that affects the motility (muscle contractions) of the colon. Sometimes called "spastic colon" or "nervous colitis," 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.

What Causes Ulcerative Colitis?

Although considerable progress has been made in IBD research, investigators do not yet know what causes this disease. Studies indicate that the inflammation in IBD involves a complex interaction of factors: the genes the person 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 an 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. That is why the main goal of medical therapy is to help patients regulate their immune system better.

CCFA-sponsored research has led to progress in the fields of immunology, the study of the body's immune 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 to the intestinal wall, initiating or accelerating the disease process. Through CCFA's continuing research efforts, much more will be learned and a cure will eventually be found.

How Common is IBD and Ulcerative Colitis?

It is estimated that as many as one million Americans have IBD, with that number evenly split between Crohn's disease and ulcerative colitis. Males and females appear to be affected equally.

On average, people are diagnosed with ulcerative colitis in their mid-30s, although the disease can occur at any age. Men are morel likely than women to be diagnosed with ulcerative colitis in their 50s and 60s. There is a greater incidence of ulcerative colitis among whites than in non-whites, 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.

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 may be associated with crampy abdominal pain and severe urgency to have a bowel movement. The diarrhea may begin slowly or quite suddenly. Loss of appetite and subsequent weight loss are common, as is fatigue. In cases of severe bleeding, anemia may also occur. In addition, there may be skin lesions, joint pain, eye inflammation, and liver disorders. Children with ulcerative colitis may fail to develop or grow properly.

Approximately half of all patients with ulcerative colitis have relatively mild symptoms. However, others may suffer from severe abdominal cramping, bloody diarrhea, nausea, and fever. The symptoms of ulcerative colitis do tend to come and go, with fairly long periods in between flare-ups in which patients may experience no distress at all. These periods of remission can span months or even years, although symptoms do eventually return. The unpredictable course of ulcerative colitis may make it difficult for physicians to evaluate whether a particular course of treatment has been effective or not.

Types of Ulcerative Colitis and Their Associated Symptoms

The symptoms of ulcerative colitis, as well as possible complications, will vary depending on the extent of inflammation in the rectum and the colon. Because of this, it is very important for you to know which part of your intestine the disease affects.

One common subcategory of ulcerative colitis is ulcerative proctitis. For approximately 30% of all patients with ulcerative colitis, the illness begins as ulcerative proctitis. In this form of the disease, bowel inflammation is limited to the rectum. Because of its limited extent (usually less than the six inches of the rectum), ulcerative proctitis tends to be a milder form of ulcerative colitis. It is associated with fewer complications and offers a better outlook than more widespread disease. In addition to ulcerative proctitis, there are several other types of ulcerative colitis. The following is a description of each type, together with some commonly associated symptoms and potential intestinal complications:

- ***Proctosigmoiditis:*** Colitis affecting the rectum and the sigmoid colon (the lower segment of colon located right above the rectum). Symptoms include bloody diarrhea, cramps, and tenesmus. Moderate pain on the lower left side of the abdomen may occur in active disease.
- ***Left-sided colitis:*** Continuous inflammation that begins at the rectum and extends as far as the splenic flexure (a bend in the colon, near the spleen). Symptoms include loss of appetite, weight loss, diarrhea, severe pain on the left side of the abdomen, and bleeding.
- ***Pan-ulcerative (total) colitis*****:** Affects the entire colon. Symptoms include diarrhea, severe abdominal pain, cramps, and extensive weight loss. Potentially serious complications include massive bleeding and acute dilation of the colon (toxic megacolon), which may lead to perforation (an opening in the bowel wall). Serious complications may require surgery.

How is Ulcerative Colitis Diagnosed?

Physicians make the diagnosis of ulcerative colitis based on the patient's clinical history, a physical examination, and a series of tests. The first goal of these tests is to differentiate ulcerative colitis from infectious causes of diarrhea. Accordingly, stool specimens are obtained and analyzed to eliminate the possibility of bacterial, viral, or parasitic causes of diarrhea. Blood tests can check for signs of infection as well as for anemia, which may indicate bleeding in the colon or rectum. Following this, the patient generally undergoes an evaluation of the colon, using one of two tests -- a sigmoidoscopy or total colonoscopy.

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, but it visualizes the entire colon. Using these techniques, your physician can detect inflammation, bleeding, or ulcers on the colon wall, as well as determine the extent of disease. During these procedures, the doctor 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.

Another diagnostic procedure that may be used is a barium enema X-ray of the colon. After the colon is filled with barium, a chalky white solution, an X-ray is taken. The barium shows up white on the X-ray, providing a detailed picture of the colon and any signs of disease.

What Medications are Used to Treat Ulcerative Colitis?

Currently, there is no medical cure for ulcerative colitis. However, effective medical treatment can suppress the inflammatory process. This accomplishes two important goals: It permits the colon to heal and it also relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain. As such, the treatment of ulcerative colitis involves medications that decrease the abnormal inflammation in the colon lining and thereby control the symptoms.
Four major classes of medication are used today to treat ulcerative colitis:

1. ***Aminosalicylates (5-ASA):*** This class of anti-inflammatory drugs includes sulfasalazine and oral formulations of mesalamine, such as Asacol®, Colazal®, Lialda®, Dipentum®, or Pentasa®, and 5-ASA drugs also may be administered rectally (Canasa® or Rowasa®). These medications typically are used to treat mild to moderate symptoms. 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:*** Prednisone and methylprednisolone are available orally and rectally. Corticosteroids nonspecifically suppress the immune system and are used to treat moderate to severely active ulcerative colitis. (By "nonspecifically," we mean that these drugs do not target specific parts of the immune system that play a role in inflammation, but rather, that they suppress the entire immune response.) These drugs have significant short- and long-term side effects and should not be used as a maintenance medication. If you cannot come off steroids without suffering a relapse of your symptoms, your doctor may need to add some other medications to help manage your disease.
3. ***Immune modifiers***: Azathioprine (Imuran®), 6-MP (Purinethol®), and methotrexate. Immune modifiers, sometimes called*immunomodulators*, are used to help decrease corticosteroid dosage . Azathioprine and 6-MP have been useful in reducing or eliminating some patients' dependence on corticosteroids. They also may be helpful 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 before their beneficial effects begin to work.

4. ***Antibiotics***: metronidazole, ampicillin, ciprofloxacin, others.
5. ***Biologic therapies:*** Infliximab (Remicade®). Biologic therapies are the newest class of drugs used for people suffering from moderate-to-severe ulcerative colitis. These drugs are made from antibodies that bind with certain molecules to block a particular action. The intestinal inflammation of ulcerative colitis is a result of various processes, or "pathways." Because a biologic drug targets a specific pathway, it can help reduce inflammation. That targeted action also keeps side effects to a minimum.

Complications of Ulcerative Colitis

Complications are by no means an inevitable or even a frequent consequence of ulcerative colitis, especially in appropriately treated patients. But they are sufficiently common and cover such a wide range of manifestations that it is important for patients and physicians to be acquainted with them. Early recognition often means more effective treatment.

Local complications of ulcerative colitis include profuse bleeding from deep ulcerations, perforation (rupture) of the bowel, or simply failure of the patient to respond appropriately to the usual medical treatments.

Another complication is severe abdominal distension. A mild degree of distention is common in individuals without any intestinal disease and is somewhat more common in people with ulcerative colitis. However, if the distention is severe or of sudden onset, and if it is associated with active colitis, fever, and constipation, your physician may suspect a serious complication of colitis, called toxic megacolon. Fortunately, this is a rare development. It is produced by severe inflammation of the entire thickness of the colon, with weakening and ballooning of its wall. The dilated colon is then at risk of rupturing. Treatment is aimed at controlling the inflammatory reaction and restoring losses of fluid,

salts, and blood. If there is no rapid improvement, surgery may become necessary to avoid rupture of the bowel.

What Is the Role of Surgery in Ulcerative Colitis?

In one-quarter to one-third of patients with ulcerative colitis, 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 surgical approaches 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). Today, many people are able to take advantage of new surgical techniques, which have been developed to offer another option. This procedure also calls for removal of the colon, but it avoids an ileostomy. By creating an internal pouch from the small bowel and attaching it to the anal sphincter muscle, the surgeon can preserve bowel integrity and eliminate the need for the patient to wear an external ostomy appliance. (Further information on surgery and ulcerative colitis can be found on this Website in the section on surgery.)

The Role of Nutrition

There is no evidence that any particular foods cause or contribute to ulcerative colitis or other types of IBD. Once the disease has developed, however, paying special attention to diet may help reduce symptoms, replace lost nutrients, and promote healing. For example, when your disease is active, you may find that bland, soft foods may cause less discomfort than raw vegetables, spicy or high-fiber foods.

Maintaining proper nutrition is important in the medical management of ulcerative colitis. 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. Except for restricting milk products in lactose-intolerant patients or restricting caffeine when severe diarrhea occurs, most gastroenterologists recommend a well-balanced diet for their patients with ulcerative colitis. A healthy diet should contain a variety of foods from all food groups. Meat, fish, poultry, and dairy products (if tolerated) are sources of protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrate; margarine and oils are sources of fat.

Emotional Stress and Coping With Ulcerative Colitis

Because body and mind are so closely interrelated, emotional stress can influence the course of ulcerative colitis -- or, for that matter, any other chronic illness. Although people occasionally experience emotional problems before a flare-up of their disease, this does not imply that emotional stress causes the illness. There is no evidence to show that stress, anxiety, or tension is responsible for ulcerative colitis. No single personality type is more prone to develop ulcerative colitis than others, and no one "brings on" the disease by poor emotional control.

It is much more likely that the emotional distress that patients sometimes feel is a reaction to the symptoms of the disease itself. It is not surprising that some patients find it difficult to cope with a chronic illness. Such illnesses seem to pose a threat to their entire quality of life-their physical and emotional well-being, social functioning, and sense of self-esteem. People with ulcerative colitis should receive understanding and emotional support from their families and physicians. Although formal psychotherapy is generally not necessary, some patients are helped considerably by speaking with a therapist who is knowledgeable about IBD or about chronic illness in general. CCFA offers local support groups to help patients and their families cope with IBD.

Coping techniques for dealing with ulcerative colitis may take many forms. Attacks of diarrhea, pain, or gas may make people fearful of being in public places. In such a situation, some practical advance planning may help alleviate this fear. For instance, find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation ahead of time. Some people find it helps to carry along extra underclothing or toilet paper for particularly long trips. When venturing further afoot, always consult with your physician. Travel plans should include a large enough supply of your medication, its generic name in case you run out or lose it, and the name of physicians in the area you may be visiting.

People with ulcerative colitis accept the diagnosis with a wide range of emotions. Some people are angry for a time. Others feel a sense of relief at finally knowing what it is that has made them ill. While it certainly may help to come to terms with ulcerative colitis in a straightforward manner, since this approach may maximize your ability to be part of your health care team right from the start, everyone is different. Each person with the disease must adjust to living with ulcerative colitis in his or her own way. There should be no guilt, no self-reproaches, or blame placed on others as you come to grips with your illness. There are resources and information available, such as local support groups and IBD education seminars. No one with ulcerative colitis should ever feel alone. As you go about your daily life as normally as possible, try pursuing some of the same activities that

you did before your diagnosis. Some days, you may not feel up to it. Other days, you will want to give it all you've got. Only you can decide what's right for you. It will help to follow your physician's instructions and maintain a positive outlook, and to take an active role in your care. That's the basic (and best!) prescription.

While ulcerative colitis is a serious chronic disease, it is not considered a fatal illness. Most people with the illness may continue to lead useful and productive lives, even though they may be hospitalized from time to time, or need to take medications. In between flare-ups of the disease, many individuals feel well and may be relatively free of symptoms. But again, everyone is different, and it is up to you and your physician to find the treatment that works best for you.

The preceding information provided by:

Crohn's & Colitis Foundation of America

For more information on CCFA and Ulcerative Colitis please visit their site at:http://www.ccfa.org/