CROHN'S & COLITIS
FOUNDATION OF AMERICA

Living with Ulcerative Colitis

What's Inside?

Understanding the diagnosis	1
What is ulcerative colitis?	2
Will it ever go away?	3
A brief introduction to the gastrointestinal (GI) tract	3
Who gets ulcerative colitis?	5
What causes ulcerative colitis?	6
What are the signs and symptoms?	7
Making the diagnosis	10
Some questions to ask your doctor	11
Treatment	13
Managing your symptoms	15
Other considerations	18
Surgery	18
Diet and nutrition	19
Complementary and alternative therapies	21
Stress and emotion	21
General health maintenance	22
Living your life	23
Hope for the future	25
Knowledge and support is power!	27
Glossary of terms	29
About CCFA	Inside back cover

Understanding the diagnosis

Your doctor has just told you that you have ulcerative colitis (UC). Now what?

Quite possibly, you have never even *heard* of this condition before. In fact, most people are unfamiliar with ulcerative colitis, and now you are coping with your diagnosis.

To start, you probably have lots of questions. Some of the most commonly asked ones are:

- What is ulcerative colitis?
- How did I get it?
- Will I be able to work, travel, or exercise?
- Should I be on a special diet?
- What are my treatment options?
- Will I need surgery?
- How will ulcerative colitis change my life, both now and in the future?
- Can ulcerative colitis be cured and what is the outlook (prognosis)?

The purpose of this brochure is to answer those questions, and to walk you through the key points about ulcerative colitis and what you may expect in the future. You won't become an expert overnight, but you'll learn more and more as time goes by. The more informed you are, the better you can manage your disease and become an active member of your own healthcare team.

What is ulcerative colitis?

Ulcerative colitis (UC) belongs to a group of conditions known as *inflammatory bowel diseases (IBD)*.

UC is a chronic inflammatory condition of the colon (large intestine) that often occurs in teenagers and young adults, but also can occur in older individuals. The symptoms can include abdominal pain, bowel urgency, diarrhea, and blood in the stool. The inflammation begins in the rectum and extends up the colon in a continuous manner. While there is currently no known cure, there are many effective therapies to keep the inflammation under control.

When reading about inflammatory bowel diseases, you need to know that ulcerative colitis is not the same thing as Crohn's disease, another type of IBD. The symptoms of these two illnesses are quite similar, but the areas affected in your body are different. Crohn's disease may affect any part of the gastrointestinal (GI) tract, but ulcerative colitis is limited to the colon—also called the large intestine. Crohn's disease can also affect the entire thickness of the bowel wall, while ulcerative colitis only involves the innermost lining of the colon. Finally, in Crohn's disease, the inflammation of the intestine can "skip"—leaving normal areas in between patches of diseased intestine. In ulcerative colitis, this does not occur. In only 10 percent of cases are there overlapping features of both ulcerative colitis and Crohn's disease, a condition called *indeterminate colitis*.

Will it ever go away?

No one knows exactly what causes ulcerative colitis. Also, no one can predict how the disease—once it is diagnosed—will affect a particular person. Some people go for years without having any symptoms, while others have more frequent flare-ups, or attacks, of their disease activity. However, one thing is certain: ulcerative colitis is a chronic condition.

Chronic conditions are ongoing situations. They can be controlled with treatment, but not cured. That means that the disease is a long-term condition. In fact, most medical illnesses, such as diabetes, high blood pressure, and heart disease, are successfully treated but not cured. Occasionally, people may develop severe complications that can be serious—such as colorectal cancer—but this occurs in a very small number of people afflicted with IBD. Studies show that people with IBD usually have the same life expectancy as people without IBD. It is important to remember that most people who have ulcerative colitis lead full, happy, and productive lives.

A brief introduction to the gastrointestinal (GI) tract

Most of us aren't very familiar with the GI tract, even though it occupies a lot of "real estate" in our bodies.

Here's a quick overview: The GI tract (see figure 1) actually starts at the mouth. It follows a twisting and turning course and ends, many yards later,

at the rectum. In between are a number of organs that all play a part in processing and transporting food through the body.

The first is the esophagus, a narrow tube that connects the mouth to the stomach. Food passes through the stomach and enters the small intestine. This is the section where most of our nutrients are absorbed. The small intestine leads to the colon, or large intestine, which connects to the rectum.

The principal function of the colon is to absorb excess water and salts from the waste material (what's left after food has been digested). It also stores solid waste, converting it to stool, and excretes it through the anus.

The inflammation in ulcerative colitis usually begins in the rectum and lower colon, but it also can involve the entire colon. When inflammation occurs, the primary functions are affected, including the absorption of water. As a result, diarrhea can be a very common symptom during flares of UC.

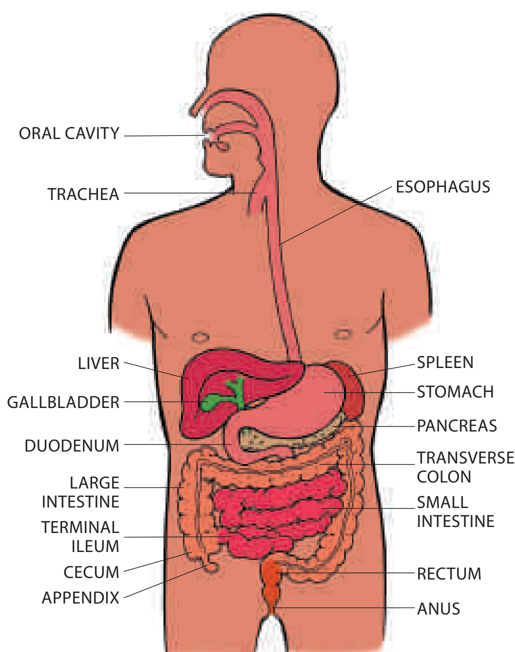


Figure 1

Who gets ulcerative colitis?

Approximately 1.4 million Americans have either ulcerative colitis or Crohn's disease.

That number is almost evenly split between the two conditions. Here are some quick facts and figures:

- About 30,000 new cases of Crohn's disease and ulcerative colitis are diagnosed each year.
- On average, people are more frequently diagnosed with ulcerative colitis between the ages of 15 and 25, although the disease can occur at any age.
- Males and females appear to be affected equally.
- Men are more likely than women to be diagnosed with ulcerative colitis in their 50s and 60s.
- While UC can affect those from any ethnic background, Caucasians develop it more than other groups. It is especially prevalent among the Eastern European Jewish population.
- Both ulcerative colitis and Crohn's disease are diseases found mainly in developed countries, more commonly in urban areas rather than rural ones, and more often in northern climates than southern ones. However, some of these disease patterns are gradually shifting. For example, the number of cases of IBD is increasing in developing parts of the world, including China, India, and South America.

The genetic connection

Researchers have discovered that ulcerative colitis tends to run in families. In fact, the risk of developing IBD is between 5.2 percent and 22.5 percent for first-degree relatives of an affected person. It is also dependent on which family member has IBD, ethnicity, and the type of IBD—either Crohn's disease or ulcerative colitis. Your genes clearly play a role, although no specific pattern of inheritance has yet been identified. That means that right now there is no way to predict which, if any, family members will develop ulcerative colitis.

What causes ulcerative colitis?

No one knows the exact cause(s) of the disease.

One thing is certain: Nothing that you did made you get ulcerative colitis. You didn't catch it from anyone. It wasn't anything that you ate or drank that brought the symptoms on. Leading a stressful lifestyle didn't bring it on. So, above all, don't blame yourself!

What are some of the likely causes? Most experts think there is a *multifactorial* explanation. This means that it takes a number of factors working in combination to bring about ulcerative colitis. The three leading factors suspected of contributing to UC are:

1) Environmental

2) Genetic

3) An inappropriate reaction by the body's immune system

It's likely that a person inherits one or more genes that make him or her susceptible to ulcerative colitis. Then something in the environment triggers an abnormal immune response. (Scientists have not yet identified the environmental "trigger" or "triggers.") Whatever the trigger is, it prompts the person's immune system to "turn on" and launch an attack in the large intestine. That's when the inflammation begins. Unfortunately, the immune system doesn't "turn off," so the inflammation continues, damaging the lining of the colon and causing the symptoms of ulcerative colitis.

What are the signs and symptoms?

As the intestinal lining becomes more inflamed and ulcerated, it loses its ability to absorb water from the waste material that passes through the colon.

That, in turn, leads to a progressive loosening of the stool—in other words, diarrhea. The damaged intestinal lining may begin producing a lot of mucus in the stool. Moreover, ulceration in the lining can also cause bleeding, causing the stool to become bloody in substance. Eventually, that blood loss may lead to a low red blood cell count, also called *anemia*.

Most people with ulcerative colitis experience an urgency to have a bowel movement as well as crampy abdominal pain. The pain may be stronger on the left side, but it can be anywhere in the abdomen.

Together, these may result in loss of appetite and subsequent weight loss. These symptoms, along with anemia, can lead to fatigue. Children with ulcerative colitis may fail to develop or grow properly.

Beyond the intestine

In addition to having symptoms in the GI tract, some people also may experience a variety of symptoms in other parts of the body associated with ulcerative colitis. Signs and symptoms of the disease may be evident in:

- eyes (redness, pain, and itchiness)
- mouth (sores)
- joints (swelling and pain)
- skin (tender bumps, painful ulcerations, and other sores/rashes)
- bones (osteoporosis)
- kidney (stones)
- liver (primary sclerosing cholangitis, hepatitis and cirrhosis)—a rare development

All of these are known as *extraintestinal* manifestations of ulcerative colitis because they occur outside of the intestine. In some people, these actually may be the first signs of ulcerative colitis, appearing even years before the bowel symptoms. In others, they may occur right before a flare-up of the disease.

The range of symptoms

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 tend to come and go.

In between flares, people may experience no distress at all. These disease-free periods (known as *remission*) can span months or even years, although symptoms typically do return eventually. The unpredictable course of ulcerative colitis may make it difficult for doctors to evaluate whether a particular treatment program has been effective or whether remission occurred on its own.

Types of ulcerative colitis and their associated symptoms

The symptoms of ulcerative colitis will vary depending on the extent of inflammation and the location of the disease within the large intestine. Accordingly, it is very important for you to know which part of your intestine is affected. Listed below are some of the most common types of ulcerative colitis:

- **Ulcerative proctitis:** Bowel inflammation is limited to the rectum. Because of its limited extent (usually less than six inches of the rectum), ulcerative proctitis tends to be a milder form of ulcerative colitis. Symptoms include rectal bleeding, urgency, and rectal pain.

- **Proctosigmoiditis:** Colitis affecting the rectum and sigmoid colon (the lower segment of colon located right above the rectum). Symptoms include bloody diarrhea, cramps, and tenesmus (straining to have a bowel movement). 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 in the upper left abdomen). Symptoms include loss of appetite, weight loss, bloody diarrhea, and severe pain on the left side of the abdomen.

- **Pan-ulcerative (total) or pancolitis:** Affects the entire colon. Symptoms include loss of appetite, bloody diarrhea, severe abdominal pain, and weight loss.

Possible complications

Complications are by no means inevitable or even frequent—especially in appropriately treated patients. But they are common enough, and cover such a wide range, that it is important to be acquainted with them.

Early recognition often means more effective treatment. Complications can include profuse intestinal bleeding (including clots of blood in the stool), severe abdominal distension (swelling), and *toxic megacolon* (a rare development).

Please speak with your doctor regarding any other possible complications. *For further information on complications, please read our brochure, "Managing Flares and Other IBD Symptoms." This is available at www.ccfa.org or by calling 888.MY.GUT.PAIN (888-694-8872) to order a copy.*

Making the diagnosis

How does a doctor determine you have ulcerative colitis?

The path toward diagnosis begins by taking a complete patient and family medical history, including full details regarding symptoms. A physical examination is also performed.

Since a number of other conditions can produce the same symptoms as UC, your doctor relies on various medical tests to rule out other potential causes for your symptoms, such as infection.

Tests may include:

- **Stool tests:** Used to rule out infection or to reveal blood.

- **Blood tests:** May detect the presence of inflammation and antibodies.
- **Sigmoidoscopy:** Examines the rectum and lower third of the colon.
- **Colonoscopy:** Examines the entire colon and end of the small intestine.

For further information on diagnosing ulcerative colitis, please see our fact sheet, "Diagnosing IBD," available at www.ccfa.org.

Some questions to ask your doctor

It is important to establish good communications with your doctor.

It is common to forget to ask some critical questions during your office visit. Here is a list of questions that may be helpful for your next office visit:

- Could any condition other than my disease be causing my symptoms?
- What tests do I need to have to get to the root of my symptoms?
- Should I have these tests during the time of a flare-up or on a routine basis?
- What parts of my GI tract are affected?
- How will I know if my medication needs to be adjusted?
- Approximately how long should it take to see some results, or to find out that this may not be the right medication for me?

- What are the side effects of the medication? What should I do if I notice them?
- What should I do if the symptoms return? What symptoms are considered an emergency?
- If I cannot schedule a visit right away, are there any over-the-counter medication options that can assist with my prescribed medication? If so, which ones?
- Should I change my diet or take nutritional supplements? If so, can you recommend a dietitian or any specific nutritional supplements?
- Do I need to make any other lifestyle changes?
- When should I come back for a follow-up appointment?

Treatment

There are very effective treatments available that may control your UC and even place it into remission.

These treatments work by decreasing the abnormal inflammation in the lining of the colon. This permits the colon to heal. It also relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain.

The two basic goals of treatment are to achieve remission and, once that is accomplished, to *maintain* remission. If remission cannot be established, then the next goal is to decrease the disease in order to improve the patient's quality of life. Some of the medications used to accomplish this may be the same, but they are given in different dosages and for different lengths of time.

There is no "one size fits all" treatment for everyone with ulcerative colitis. The approach must be tailored to the individual because each person's disease is different. Medical treatment can bring about remission, which can last for months to years, but the disease will flare up at times from the reappearance of inflammation or from a particular trigger. Flares may indicate the need to change the dose, frequency, or type of medication. Although the medications used for ulcerative colitis are aimed at controlling inflammation and maintaining a state of remission, some can also be used to address symptoms of a flare.

Physicians have been using a number of medications for the treatment of ulcerative colitis for many years. Others are more recent break-

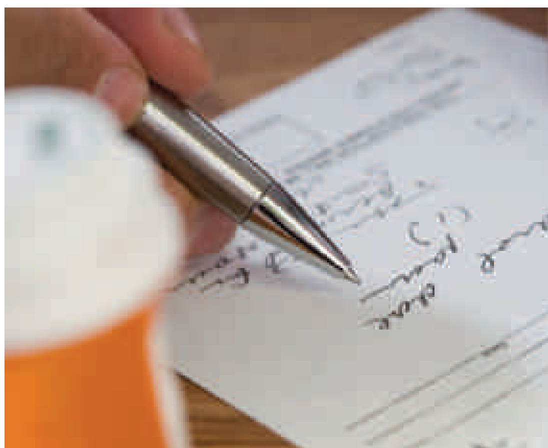
throughs. The most commonly prescribed fall into four basic categories:

- **Aminosalicylates:** These include drugs that contain 5-aminosalicylic acid (5-ASA). Examples are sulfasalazine, mesalamine, olsalazine, and balsalazide. These drugs work at the level of the lining of the GI tract to decrease inflammation. They also are useful as a maintenance treatment in preventing relapses of the disease.

- **Corticosteroids:** These medications affect the body's ability to launch and maintain an inflammatory process. In addition, they work to keep the immune system in check. They are effective for short-term control of flare-ups; however, they are not recommended for long-term or maintenance use because of their side effects. 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.

- **Immunomodulators:** This class of medications modulates the body's immune system response so it cannot cause ongoing inflammation. Immunomodulators generally are used in people in whom aminosalicylates and corticosteroids haven't been effective or have been only partially effective. They may be useful in reducing or eliminating the need for corticosteroids. They also may be effective in maintaining remission in people who haven't responded to other medications given for this purpose. Immunomodulators may take several months to begin to work.

- **Biologic therapies:** Biologic therapies, also known as anti-TNF agents, represent the latest class of therapy used for people with ulcerative colitis who have not responded well to conventional therapy. TNF (tumor necrosis factor) is a chemical produced by our bodies to cause inflammation. Antibodies are proteins produced to attach to these chemicals



and allow the body to destroy the chemical and reduce the inflammation. *For further detailed information on treatment options, view our "Understanding IBD Medications and Side Effects" brochure at www.ccfa.org.*

Managing your symptoms

Even when there are no side effects, or just minimal ones, it may seem like a nuisance to be on a steady regimen of medication. Seek support from your healthcare provider. Remember, though, that taking maintenance medication can significantly reduce the risk of flares in ulcerative colitis. In between flares, most people feel quite well and free of symptoms.

The best way to control ulcerative colitis is by taking medications as recommended by your doctor. However, medications may not immediately get rid of all the symptoms that you are experiencing. You may continue to have occasional diarrhea, cramping, nausea, and fever.

Talk to your doctor about which over-the-counter (OTC) medications you can take to help relieve those symptoms. These may include Lomotil® and loperamide (Imodium®) and should be taken as needed to control diarrhea. Most anti-gas products and digestive aids may also be safe to use. To reduce fever or ease joint pain, speak with your doctor about taking acetaminophen

Medications for Ulcerative Colitis

Class of Drugs	Generic Name (Trade Name)	Indication (Use)	Route of Delivery
Aminosalicylates (5-ASA)	sulfasalazine (Azulfadine®) mesalamine (Asacol®, Asacol HD®, Lialda®, Pentasa®, Rowasa®, Apriso™, Canasa®) olsalazine (Dipentum®) balsalazide (Colazal®)	Effective for the treatment of people with mild-to-moderately active ulcerative colitis. Also useful in maintaining remission.	Oral or rectal
Corticosteroids	prednisone (Deltasone®) prednisolone (Pediapred Oral Liquid®, Medrol®)	For the treatment of people with moderate-to-severe ulcerative colitis. Effective for short-term control of flares.	Oral, rectal, or intra-venous (by vein)
Immunomodulators	azathioprine (Imuran®, Azasan®) 6-mercaptopurine (Purinethol®) cyclosporine (Neoral®, Gengraf®, Sandimmune®)	For use in people who have not responded adequately to aminosalicylates and corti-costeroids. Useful for reducing dependency on corticosteroids. May take up to three months to work.	Oral or intravenous
Biologic therapies	infliximab (Remicade®)	For people with moderate-to-severe ulcera-tive colitis. Effective for maintaining remis-sion and for tapering people off steroids.	Intravenous
Antibiotics	metronidazole (Flagyl®) ciprofloxacin (Cipro®, Proquin®)	For the treatment of infections of ulcerative colitis.	Oral or intravenous

(Tylenol®) rather than non-steroidal anti-inflammatory drugs (NSAIDs), such as aspirin, ibuprofen (Advil®, Motrin®), and naproxen (Aleve®), since NSAIDs may irritate your digestive system. Be sure to follow the guidelines and instructions on the over-the-counter products that you do take. *For further information on managing the symptoms of ulcerative colitis, please read our brochure, "Managing Flares and Other IBD Symptoms."*

Other considerations

Surgery

Most people with ulcerative colitis respond well to medical treatment and may never have to undergo surgery. However, between 25 percent and 33 percent of individuals may require surgery at some point.

Sometimes surgery is indicated to take care of various complications. These include severe bleeding from deep ulcerations, perforation (rupture) of the bowel, and toxic megacolon.

Surgery may also be considered to remove the entire colon and rectum (a *proctocolectomy)* when medical therapies no longer control the disease well or when precancerous changes are found in the colon. Unlike Crohn's disease, which can recur after surgery, ulcerative colitis actually is "cured" once the colon is removed. However, because ulcerative colitis is a disease that affects the immune system, extraintestinal symptoms that occurred prior to surgery—such as joint pain or skin conditions—may recur even after the colon is removed.

Depending on a number of factors, including the extent of disease and the person's age and overall health, one of two surgical approaches may be recommended. The first involves an external pouch, known as an *ileostomy*, which is an opening on the abdomen through which

waste is emptied into a synthetic bag attached to the abdominal wall. The second is an internal pouch called an *ileal pouch-anal anastomosis (IPAA)*, or “j-pouch,” created by attaching the small bowel to the anal sphincter muscle, which eliminates the need for an external ostomy appliance. *To learn more about these surgeries, please read CCFA’s surgery brochure*.

Diet and nutrition

You may wonder if eating any particular foods caused or contributed to your ulcerative colitis. The answer is “no.” However, once the disease has developed, paying attention to your diet may help you reduce symptoms, replace lost nutrients, and promote healing.

There is no one single diet or eating plan that will work for everyone with ulcerative colitis. Dietary recommendations must be tailored just for you—depending on what part of your intestine is affected and what symptoms you have. Ulcerative colitis varies from person to person and even changes within the same person over time. What worked for your friend with ulcerative colitis may not work for you. What worked for you last year may not work for you now.

There may be times when modifying your diet can be helpful, particularly during a flare. Some diets may be recommended at different times by your physician, including:

- **Low-salt diet**—Used during corticosteroid therapy to reduce water retention.
- **Low-fiber diet**—Used to avoid stimulating bowel movements in ulcerative colitis.
- **Low-fat diet**—Typically recommended during a flare when fat absorption may become an issue.
- **Lactose-free diet**—For those who have an intolerance to dairy products.

- **High-calorie diet**—For those who experience weight loss or growth delay.

Some patients with IBD may become deficient in certain vitamins and minerals (including vitamin B-12, folic acid, vitamin C, iron, calcium, zinc, and magnesium) or have trouble ingesting enough food to meet their caloric needs. Your doctor can identify and correct these deficiencies through vitamin and nutritional supplements.

Keeping a food diary can be a big help. It allows you to see the connection between what you eat and the symptoms that may follow. If certain foods are causing digestive problems, then try to avoid them. Although no specific foods worsen the underlying inflammation of ulcerative colitis, certain ones may tend to aggravate the symptoms. Here are some helpful tips:

- Reduce the amount of greasy or fried foods in your diet, which may cause diarrhea and gas.
- Eat smaller meals at more frequent intervals.
- Limit consumption of milk or milk products if you are lactose intolerant.
- Avoid carbonated beverages if excessive gas is a problem.
- Restrict caffeine when severe diarrhea occurs, as caffeine can act as a laxative.
- Bland, soft foods may be easier to tolerate than spicy foods.
- Restrict your intake of certain high-fiber foods such as nuts, seeds, corn, and popcorn. Because they are not completely digested by the small intestine, these foods may cause diarrhea. That is why a low-fiber, low-residue diet is often recommended.

Maintaining proper nutrition is important in the management of ulcerative colitis. Good nutrition is essential in any chronic disease, but especially

for UC. Abdominal pain and fever can cause loss of appetite and weight loss. Diarrhea and rectal bleeding can rob the body of fluids, minerals, and electrolytes. These are nutrients in the body that must remain in proper balance for the body to function properly.

That doesn't mean that you must eat certain foods or avoid others. Most doctors recommend a well-balanced diet to prevent nutritional deficiency. 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 carbohydrates; margarine and oils are sources of fat. A dietary supplement, like a multivitamin, can help fill the gaps. For more information, you may want to talk with a dietitian and read our "Diet and Nutrition" brochure, available at www.ccfa.org.

Complementary and alternative therapies

Some people living with ulcerative colitis look to complementary and alternative medicines (CAM) to use together with conventional therapies to help ease their symptoms. CAM therapies may work in a variety of ways. They may help to control symptoms and ease pain, enhance feelings of well-being and quality of life, and possibly boost the immune system. Speak with your doctor about the best therapies for your situation. *For further information on complementary and alternative therapies, view our "Complementary and Alternative Medicine" fact sheet*.

Stress and emotion

Ulcerative colitis affects virtually every aspect of a person's life. If you have ulcerative colitis, you're bound to have questions about the relationship between stress and emotional factors and this disease.

Although the disease occasionally recurs after a person has been experiencing emotional problems, there is no proof that stress causes ulcerative colitis. It is much more likely that the emotional distress that people sometimes feel is a reaction to the symptoms of the disease itself. Individuals with ulcerative colitis should receive understanding and emotional support from their families and doctors. Because depression can be associated with chronic illness, a doctor may recommend an anti-depression medication and/or a referral to a mental health professional. Although formal psychotherapy usually isn't necessary, some people are helped considerably by speaking with a therapist who

is knowledgeable about IBD or about chronic illness in general. In addition, CCFA offers local support groups to assist patients and their families in coping with ulcerative colitis and Crohn's disease. *Please review the list of other resources CCFA offers in the "Knowledge & Support Is Power" section at the end of this brochure*.

General health maintenance

It is important to continue general health maintenance. While working with your gastroenterologist, also remember to speak with your primary care healthcare provider about other important issues, including vaccinations, oral health, colonoscopy screening, mammogram

screening, and periodic blood testing. *For detailed information on general healthcare maintenance in ulcerative colitis and a helpful chart for your records, view our "General Healthcare Maintenance" fact sheet*.

Living your life

Learning you have ulcerative colitis may be difficult and stressful. As time goes on, this fact will not always occupy the top spot in your mind. In the meantime, don't hide your condition from family, friends, and co-workers. Discuss it with them and let them help and support you.

You'll learn that there are numerous strategies that can make living with ulcerative colitis easier. Coping techniques for dealing with the disease may take many forms. For example, attacks of diarrhea or abdominal pain may make people fearful of being in public places. But that isn't necessary. All it takes is some practical advanced planning.

You may want to incorporate some of the following steps into your plans:

- Find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation.
- Carry extra underclothing, toilet paper, or moist wipes when traveling.
- When venturing further away or for longer periods of time, speak with your doctor first. Travel plans should include a long-term supply of your medication, its generic name in case you run out or lose it, and the names of doctors in the area you will be visiting.

Try to go about your daily life as normally as possible, pursuing activities as you did before your diagnosis. There's no reason for you to sit out on things that you have always enjoyed or have dreamed of doing one day.

- Learn coping strategies from others. Your local CCFA chapter offers support groups as well as informational meetings. The groups help you to share what you know with others, too.
- Develop a support network of family and friends to help you manage your disease.
- Bring a family member or friend to your doctor's appointment for support.
- Join CCFA's free online community at www.ccfacommunity.org to get the support you need through participation in discussion boards and personal stories.
- Follow your doctor's instructions about taking medication (even when you are feeling perfectly well).
- Maintain a positive outlook. That's the basic—and best—prescription!

While ulcerative colitis is a serious chronic disease, it is not a fatal illness. There's no doubt that living with this illness is challenging—you have to take medication and, occasionally, make other adjustments. It's important to remember that most people with ulcerative colitis are able to lead rich and productive lives.

Remember, too, that taking maintenance medication can significantly decrease flares of ulcerative colitis. In between flares, most people are free of symptoms and feel well.

Hope for the future

Investigators all over the world are devoted to research for patients with ulcerative colitis.

That's good news when it comes to the development of new therapies for this disease. It is a very exciting time in the development of new therapies. Researchers are uncovering the culprits involved in ulcerative colitis, and technology is making it possible to target them and block inflammation. With many experimental treatments for IBD in clinical trials, experts predict that a wave of new therapies for ulcerative colitis is on the way.

With an ever-increasing number of clinical trials of potential new IBD therapies, there is an even greater need for patient participation to see if these experimental therapies work. To locate clinical trials for ulcerative colitis therapies in your area, go to CCFA's Web site at http://www.ccfa.org/trials/, or call 888.MY.GUT.PAIN (888-694-8872).

Genetic studies also are expected to yield important insights that will drive the search for new therapies. The hope is that they may be capable of reversing the damage caused by intestinal inflammation, and even prevent the disease process from starting in the first place. It is becoming increasingly clear that a person's immune response to normal intestinal bacteria plays an important role in ulcerative colitis and Crohn's disease. A great deal of research is currently directed at understanding the composition, behavior, and precise role of intestinal

bacteria in the symptoms of IBD. It is hoped that this new knowledge will lead to new treatments to control or prevent the disease.

CCFA-sponsored research has led to huge strides 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. Through CCFA's continuing research efforts, much more will be learned and eventually a cure will be found.

For more brochures and fact sheets on Crohn's disease and ulcerative colitis, please call CCFA at 888.MY.GUT.PAIN (888-694-8872) or visit us on the Internet at www.ccfa.org.

Knowledge and support is power!

Find the answers you need to help control your ulcerative colitis by joining CCFA.

Discover great ways to manage your disease and work for a cure!

- **Support groups**
  Support groups can be especially helpful. The best help, advice, and understanding will come from interacting with people who know what you are going through from personal experience. Peers with IBD also can be a great source of information.

- **Local chapters**
  Local programs are provided through 12 regional divisions that serve all 50 states and the District of Columbia. To find programs, support groups, and events in your area, go online to http://www.ccfa.org/chapters or call CCFA's Information Resource Center (see below).

- **"Power of Two"**
  You can find support and comfort through talking to someone by phone or e-mail who knows the challenges of living with ulcerative colitis. You can also provide a helping hand to those in need of help. Our "Power of Two" Connection program will match you up based on your needs or your request to help others—answering questions, or just being there to listen.

- **Information Resource Center (IRC)**
  Information Specialists at CCFA's Information Resource Center offer information through answer chat, phone, and e-mail. The IRC is

here to help you understand the diagnosis process, treatment, and living with IBD. Information Specialists can be reached at 888.MY.GUT.PAIN (888-694-8872) Monday through Friday, 9 a.m. to 5 p.m. Eastern Time, or by e-mail at info@ccfa.org.

- **CCFA Online Community**
  CCFA hosts a free Web site where you can get the support you need in managing your condition. You'll participate in discussion boards, share or read personal stories, and much more. The Crohn's & Colitis Community is waiting for people just like you. Join today at http://www.ccfacommunity.org/.

- **Kids and Teens Web site**
  Kids and teens with IBD have their very own Web site where they can find specialized information on camps, coping in school, and other helpful tips. Check it out at http://www.ucandcrohns.org/.

- **Camp Oasis**
  CCFA Camp Oasis is a co-ed residential camp program. Its mission is to enrich the lives of children with IBD by providing a safe and supportive camp community. For more information, or to find the camp nearest to you: http://www.ccfa.org/kidsteens/about_camp or call the Information Resource Center at CCFA.

- **Membership**
  By joining CCFA, you'll get:
  - *Take Charge*, our national magazine
  - *Under the Microscope*, our newsletter with research updates
  - News, educational programs, and supportive services from your local CCFA chapter
  - Discounts on select programs and merchandise
  - An "I can't wait" card (provides help with public restroom access)
  - To contribute to research to find a cure for these challenging diseases

CCFA sponsors specific major events to increase awareness and raise funds to find a cure for Crohn's disease and ulcerative colitis. Below are just some of these events. Contact your local CCFA chapter or visit www.ccfa.org to find an event near you.

- **Take Steps for Crohn's & Colitis** is CCFA's national walk. Take Steps enables patients and families to raise money for crucial research and to build awareness about Crohn's disease and ulcerative colitis. Log on to www.cctakesteps.org to get more information.

- You can change lives, help find cures, and run or walk 13.1 miles with **Team Challenge**, CCFA's half marathon training program. When you join Team Challenge, you'll train for an exciting endurance event while raising vital funds for research. Call 866-931-2611 or visit www.ccteamchallenge.org to learn how you can bring hope by registering for a half marathon today.

Glossary of terms

Aminosalicylates: Medications that include compounds that contain 5-aminosalicylic acid (5-ASA). Examples are sulfasalazine, mesalamine, olsalazine, and balsalazide.

Antibody: An immunoglobulin (a specialized immune protein) produced because of the introduction of an antigen into the body.

Antibiotics: Drugs, such as metronidazole and ciprofloxacin, that may be used when infections occur.

Antigen: Any substance that prompts an immune response in the body.

Anus: Opening at the end of the rectum that allows solid waste to be eliminated.

Biologic therapies: Drugs made from antibodies that bind with molecules to block inflammation.

Bowel: Another name for the intestine. The small bowel and the large bowel are the small intestine and large intestine, respectively.

CAM: Complementary and Alternative Medicine—a group of diverse medical and healthcare systems, practices, and products that are not generally considered part of conventional medicine.

Chronic: Long lasting or long term.

Colitis: Inflammation of the large intestine (the colon).

Colon: The large intestine.

Corticosteroids: These medications affect the body's ability to begin and maintain an inflammatory process. In addition, they work to keep the immune system in check.

Crohn's disease: A chronic inflammatory disease that primarily involves the small and large intestine, but can affect other parts of the digestive system as well. Named for Dr. Burrill Crohn, the American gastroenterologist who first described the disease in 1932.

Diarrhea: Passage of excessively frequent or excessively liquid stools.

Extraintestinal complications: Complications that occur outside of the intestine.

Flare or flare-up: Bouts or attacks of inflammation with associated symptoms.

Gastrointestinal: Referring collectively to the esophagus, stomach, and small and large intestines.

Genes: Microscopic building blocks of life that transfer specific characteristics from one generation to the next.

GI tract: Short for gastrointestinal tract.

Immune system: The body's natural defense system that fights against disease.

Immunomodulators: These include azathioprine, 6-mercaptopurine (6-MP), and cyclosporine. This class of medications basically overrides the body's immune system so that it cannot cause ongoing inflammation.

Inflammation: A response to tissue injury that is marked by redness, swelling, and pain.

Inflammatory bowel diseases (IBD): A term used to refer to a group of disorders—including Crohn's disease (inflammation in the gastrointestinal tract) and ulcerative colitis (inflammation in the colon).

Intestine: The long, tube-like organ in the abdomen that completes the process of digestion. It consists of the small and large intestines.

Large intestine: Also known as the colon. Its primary function is to absorb water and get rid of solid waste.

NSAIDs: Nonsteroidal anti-inflammatory drugs such as aspirin, ibuprofen, ketoprofen, and naproxen.

Oral: By mouth.

Osteoporosis: A disease in which the bones become porous and prone to fracture.

Rectal: Having to do with the rectum.

Rectum: Lowest portion of the colon.

Remission: Periods in which symptoms disappear or decrease and good health returns.

Small intestine: Connects to the stomach and large intestine; absorbs nutrients.

Tenesmus: A painful but unproductive urge to move the bowels.

Toxic megacolon: A serious and rare complication in which the colon widens, losing its ability to contract properly and move intestinal gas along. This can lead to perforation (rupture) and the need for immediate surgery.

Ulcer: A sore on the skin or in the lining of the GI tract.

Ulceration: The process of ulcer formation.

Ulcerative colitis: A disease that causes inflammation of the large intestine (the colon).

About CCFA

Established in 1967, the Crohn's & Colitis Foundation of America, Inc. (CCFA) is a private, national nonprofit organization dedicated to finding the cure for IBD. Our mission is to fund research; provide educational resources for patients and their families, medical professionals, and the public; and furnish supportive services for people with Crohn's or colitis.

Advocacy is also a major component of CCFA's mission. CCFA has played a crucial role in obtaining increased funding for IBD research at the National Institutes of Health, and in advancing legislation that will improve the lives of patients nationwide.

Contact CCFA for the latest information on symptom management, research findings, and government legislation. You can also become a member—see page 28 for our membership benefits. Join CCFA today by calling 888.MY.GUT.PAIN (888-694 8872) or visiting www.ccfa.org.

Crohn's & Colitis Foundation of America
Attn: Membership
386 Park Avenue South
17th Floor
New York, NY 10016

This brochure is supported by an unrestricted educational grant from Warner Chilcott.

National Office
386 Park Avenue South, 17th Floor
New York, NY 10016-8804
212.685.3440
www.ccfa.org

The Crohn's & Colitis Foundation of America is a non-profit organization that relies on the generosity of private contributions to advance its mission to find a cure for Crohn's disease and ulcerative colitis.

4/10