

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	4
Who gets ulcerative colitis?	5
What causes ulcerative colitis?	7
What are the signs and symptoms?	8
Making the diagnosis	10
Some questions to ask your doctor	11
Treatment	13
Medications	13
Treatment approaches	16
Managing your symptoms	17
Medications for ulcerative colitis	18
Other considerations	20
Surgery	20
Possible complications	21
Paying for treatment	21
Diet and nutrition	22
Complementary and alternative therapies	25
Stress and emotion	25
General health maintenance	26
Living your life	27
Hope for the future	29
Knowledge and support is power!	30
Glossary of terms	33
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. After reading through this brochure you can also find helpful information and videos at www.cffa.org/what-are-crohns-and-colitis/newly-diagnosed/.

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 at any age. 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.

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*.

IBD (ulcerative colitis and Crohn's disease) can be confused with irritable bowel syndrome (IBS). IBD and IBS may sound similar, and they share some of the same symptoms, but they are different conditions. Symptoms of IBS

include diarrhea, constipation, and abdominal pain. Getting a correct diagnosis is important because treatment for IBS differs from treatment for IBD. It should be noted that some people with ulcerative colitis also have IBS.

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 symptom attack, of their disease activity. However, one thing is certain: ulcerative colitis is a chronic condition.

Chronic conditions are ongoing. They often can be controlled with treatment, but not cured. In fact, many chronic medical conditions, such as diabetes, high blood pressure, and heart disease, are successfully treated.

In the case of ulcerative colitis, medications are available that can control the disease symptoms. While the medications do not actually cure the disease, many people can go for long periods of time without symptoms (called remission). Use of medications also can lower the chances of developing complications later on (described on [page 21](#)). Even during times of remission, it is important to continue taking medications and to see the doctor regularly.

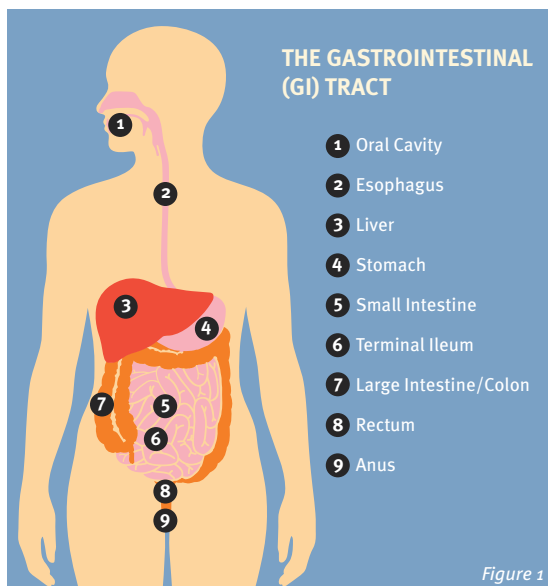
Studies show that people with IBD usually have the same life expectancy as people without IBD. It is important to remember that most people who have ulcerative colitis lead full, happy, and productive lives.

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

First is the oral cavity (mouth), followed by 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, which is eliminated through the anus.

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 ulcerative colitis are diagnosed each year.
- On average, people are more frequently diagnosed with ulcerative colitis between the ages of 15 and 35, although the disease can occur at any age.
- Males appear to be affected more than females.
- Men are more likely than women to be diagnosed with ulcerative colitis in their 50s and 60s.
- Ulcerative colitis is more common among caucasians, but it can affect people of any racial or ethnic group.

- Both ulcerative colitis and Crohn's disease are more commonly found in developed countries, urban areas, and northern climates. 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. Studies have shown that 5% to 20% of affected individuals have a first-degree relative with IBD. No specific pattern of inheritance has yet been identified, meaning there is no way to predict which, if any, family members will develop ulcerative colitis.

Family members of people diagnosed with ulcerative colitis do not need to automatically be tested. If they develop symptoms, they should be evaluated by a gastroenterologist. Several conditions have symptoms that are similar to IBD, so it is important to get an accurate diagnosis.



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 on the symptoms. It is not sexually transmitted. Leading a stressful lifestyle didn't bring it on. So, above all, don't blame yourself!

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) An environmental trigger
- 2) A genetic component
- 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 result in 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)
- 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). 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 pain on the left side of the abdomen.
- **Pan-ulcerative (total) or pancolitis:** Affects the entire colon. Symptoms include loss of appetite, bloody diarrhea, abdominal pain, and weight loss.

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 brochure, "Diagnosing and Managing IBD," available at www.cffa.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?



Treatment

There are very effective treatments available that can control your UC and may 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 three main goals of treatment for ulcerative colitis are:

- 1) Achieving remission (defined as the absence or decrease of symptoms)
- 2) Maintaining remission
- 3) Improving quality of life

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 may flare up at times. 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.

Medications

Physicians have been using a number of medications for the treatment of ulcerative colitis for many years. Others are more recent breakthroughs. These medications are given in different dosages, formulations, and for different lengths of time.

- 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?

Some medications are taken as pills that are swallowed, while others are administered intravenously (through a vein) or injected under the skin. Topical therapies are given rectally, as suppositories, enemas, creams, and ointments. Taking your ulcerative colitis medication(s) as prescribed reduces the risk of a flare up. [See pages 18 & 19](#) for a list of medications for ulcerative colitis.

The most commonly prescribed medications fall into five basic categories:

- **Antibiotics:** These medications may be used for infections. There is no substantial scientific evidence to support the long term use of antibiotics in the treatment of ulcerative colitis.
- **Aminosalicylates:** These include drugs that contain 5-aminosalicylic acid (5-ASA). 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. They should not be used for long periods of time 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:** These medications represent the latest class of therapy used for people with ulcerative colitis who have not responded well to conventional therapy. These medications are antibodies grown in the laboratory that stop certain proteins in the body from causing inflammation. *For detailed information on treatment options, view our "Understanding IBD Medications and Side Effects" brochure at www.ccfa.org.*

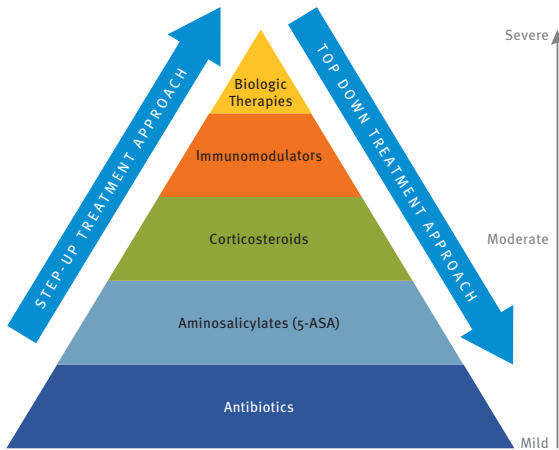


Figure 2

Treatment approaches

With the right treatment, people with ulcerative colitis should expect to achieve a life without symptoms. Patients should have an open dialogue with their doctor and inform them if they are still experiencing symptoms of ulcerative colitis while on treatment. During these discussions, patients can ask their doctor about other available treatment options.

There are a number of treatment approaches that may be used (See Figure 2). A “Step-up Strategy,” which is the traditional approach, is appropriate for many patients. With this strategy the mildest, medications are used first. Patients with moderate-to-severe disease upon diagnosis may benefit from a “Top-Down Strategy,” in which more aggressive treatment is used earlier to induce and maintain remission. This approach minimizes steroid use and associated side effects. It promotes early healing of the lining of the intestines. However, the increased potential for side effects and infections must be justified against the benefits of treatment. The strategy that is chosen depends on the individual patient.

Managing your symptoms

The best way to control ulcerative colitis and reduce the risk of flares 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.

You may be able to take over-the-counter (OTC) medications to help relieve those symptoms. Before taking any OTC products, speak with your doctor who can tell you how and when to take them and at what dose. OTC products that may help include loperamide (Imodium®) to control diarrhea, anti-gas products, and digestive aids. To reduce fever or ease joint pain, speak with your doctor about taking acetaminophen (Tylenol®) rather than non-steroidal anti-inflammatory medications (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 symptoms, please read our brochure, “Managing Flares and Other IBD Symptoms” at www.ccfa.org.*

Medication Log

Keep track of your medication regimen on a daily basis. Fill in your medication information under each category and leave some space to record any changes, such as dosage, number of times taken, symptoms, or side effects.

You can also use our interactive tracker tool, GI Buddy (www.ccfa.org/gibuddy), online or as a mobile app.

Name of Medication	Name, Dose, and/or Medical Reason	Symptoms or Side Effects	Problems (are you taking OTC, Combos, or Special Instructions)

Physician Name: _____ Phone Number: _____

Information Resource Center
888.8VCOLITIS (8416)
One (800.822) www.ccfa.org

Medications for Ulcerative Colitis

Class of Drugs	Generic Name (Trade Name)	Indication	Route of Delivery
Biologic therapies	Infliximab (Remicade®) Adalimumab (Humira®) Golimumab (Simponi®) Vedolizumab (Entyvio™)	For people with moderate to severe ulcerative colitis. Effective for maintaining remission and for tapering people off steroids.	Intravenous or self injection
Immunomodulators	Azathioprine (Imuran®, Azasan®) Mercaptopurine (Purinethol®) Cyclosporine (Neoral®, Gengraf®, Sandimmune®)	For use in people who have not responded adequately to aminosalicylates and corticosteroids. Useful for reducing dependency on corticosteroids. May take up to three months to work.	Oral or intravenous
Corticosteroids	Prednisone (Deltasone®) Prednisolone (Pediapred Oral Liquid®, Medrol®) Budesonide (UCERIS™)	For the treatment of people with moderate to severe ulcerative colitis. Effective for short-term control of flares.	Oral, rectal, or intravenous (by vein)
Aminosalicylates (5-ASA)	Sulfasalazine (Azulfadine®) Mesalamine (Delzicol™, 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
Antibiotics	Metronidazole (Flagyl®) Ciprofloxacin (Cipro®, Proquin®)	For the treatment of infections.	Oral or intravenous

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 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 pouch. *To learn more about these surgeries, please read CCFA's "Surgery for Crohn's Disease and Ulcerative Colitis" brochure at www.ccfa.org.*

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), and *toxic megacolon* (a rare development). Occasionally, people may develop complications that can be serious—such as colorectal cancer—but this occurs in a very small number of people afflicted with IBD.

Infection is also a concern. There is a rise of *Clostridium difficile* infection, particularly in hospitalized patients. The symptoms of this bacterial infection, including diarrhea and colon inflammation, mimic those of IBD flares. People with ulcerative colitis are at greater risk for the infection than those with Crohn's disease, and all IBD patients treated with immunosuppressive drugs or antibiotics are at increased risk. Early testing and rapid start of appropriate medical therapy can improve individual outcomes and avoid the risk of complications.

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.*

Paying for treatment

Obtaining health insurance or financial assistance to cover healthcare costs can be challenging for those who need it most. However, there have been a lot of changes in access to health insurance in hopes of trying to help individuals and families gain access to affordable healthcare.

If your concern is the cost of prescription medications or ostomy supplies, some companies offer patient assistance programs, which provide assistance to those who need help paying for their medication and supplies. Further, there are a few nonprofit organizations that offer financial assistance to people diagnosed with Crohn's disease and ulcerative colitis who cannot afford the out-of-pocket expenses associated with their medical care.

Finally, if necessary, you can get free or low cost medical treatment at community health centers, which are funded mostly by the federal government.

To learn more about financial assistance programs and resources that can provide patient assistance, information pertaining to federal laws/guidelines, and general insurance information contact the Irwin M. and Suzanne R. Rosenthal IBD Resource Center.



(888) 694-8872 | info@ccfa.org

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. And 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.
- **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. Nutrients in the body 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, Nutrition and Inflammatory Bowel Disease" 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 at www.ccfa.org.*

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



ulcerative colitis and a helpful chart for your records, view our “General Healthcare Maintenance” fact sheet at www.ccfa.org.

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.

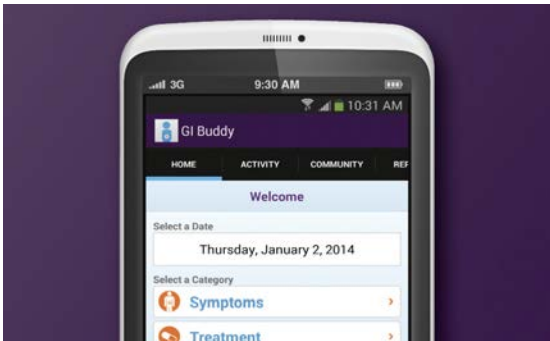
- Learn coping strategies from others. Your local CCFA chapter offers support groups as well as informational meetings.

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 health 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*

- 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.
- Download GI Buddy
This disease management tool is available online or as a mobile app at www.cdfa.org/gibuddy. GI Buddy provides an array of features, including symptom and diet tracking, as well as comprehensive, personalized reports that can be shared with your healthcare team.



- Join CCFA's free online community at www.ccfacommunity.org to get the support you need through participation in discussion boards and an online support group, or by reading/sharing 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.

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. 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, 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 website at www.cdfa.org/trials/, or call 888.MY.GUT.PAIN (888-694-8872).*

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.

You can also take part in finding a cure through CCFA Partners. This program is designed to improve the quality of life for those with IBD through research and education. *To learn more visit www.ccfapartners.org.*

Knowledge and support is power!

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

■ Local Education and Support Programs

To find programs, support groups and events in your area, go online to www.ccfa.org/chapters to find your local CCFA chapter.

■ “Power of Two”

CCFA’s “Power of Two” mentorship program allows patients seeking guidance on a specific issue to speak with a peer from within the IBD community who has traveled a similar path or has had a similar experience. To find out more, contact your local chapter.

■ Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center)

The IBD Help Center is a free service designed to provide you with disease-specific information, guidance and support. Our Information Specialists can be reached by calling 888.MY.GUT.PAIN (888-694-8872) Monday through Friday, 9 a.m. to 5 p.m. Eastern Time, or by e-mailing info@ccfa.org.

■ CCFA Online Community

CCFA hosts a free website 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 www.ccfacommunity.org/.



■ I’ll Be Determined

I’ll Be Determined is here to help you learn more about Crohn’s disease and ulcerative colitis, and your choices in managing them. We offer tools and resources, the perspectives of IBD patients and experts, and a chance to connect with people like you www.ibdetermined.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:* www.ccfa.org/kidsteens/about_camp or call the IBD Help Center at CCFA.

■ Membership

By joining CCFA, you’ll get:

- *Under the Microscope*, our newsletter with research updates
- News, educational programs and supportive services from your local CCFA chapter
- 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 nearest you.*

■ **Take Steps for Crohn's & Colitis** is CCFA's national walk program. 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.*

■ **Team Challenge**
Team Challenge is CCFA's endurance training and fundraising program. With our Half Marathon and Triathlon Training Programs, you'll train for a rewarding and exciting endurance event at one of our great destination races while raising vital funds for research into these diseases. *Visit www.ccteamchallenge.org.*



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.

Mucosal (singular): Also known as mucous membrane, moist tissue that lines and protects the body.

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).

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About CCFA

Founded in 1967, the Crohn's & Colitis Foundation of America (CCFA) is a nonprofit, volunteer-driven organization whose mission is to cure Crohn's and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

We can help! Contact us at:

888.MY.GUT.PAIN

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