

## Living with Ulcerative Colitis



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# Understanding the diagnosis

Your doctor has just told you that you have ulcerative colitis (UC). Now what? 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 some key points about ulcerative colitis and what you may experience 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.

Please note: All glossary terms are highlighted in **bold** font.

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### 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 **large intestine** (colon and rectum) that 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.

## How is ulcerative colitis different from Crohn's disease?

When reading about IBD, you need to know that ulcerative colitis is not the same thing as Crohn's disease, another type of IBD. The illnesses have similar symptoms, 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 and rectum. Crohn's disease can also affect the entire thickness of the **bowel** wall. while ulcerative colitis only involves the innermost lining of the colon (mucosa/submucosa). 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**. However, one thing is certain: ulcerative colitis is a chronic, incurable condition.

**Chronic** illnesses are ongoing and long-term. They can often be controlled with treatment.

In the case of ulcerative colitis, medications are available that can control 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. Even during times of remission, it is important to continue taking medications and seeing your doctor regularly.

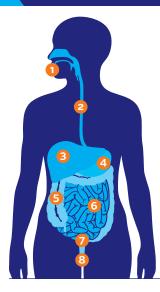
Studies show that people with UC usually have the same life expectancy as people without UC. It is important to remember that most people who have ulcerative colitis lead full, happy, and productive lives.

# A brief introduction to the gastrointestinal (GI) tract

Most of us aren't very familiar with the GI tract, but it's time you get acquainted.

Here's a quick overview: The GI tract (see figure 1) starts at the mouth. It follows a twisting and turning course and ends, many feet later, at the rectum. 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 GASTRO-INTESTINAL (GI) TRACT

- Oral Cavity (mouth)
- Esophagus (throat)
- 3 Liver
- 4 Stomach
- Large Intestine/Colon
- 6 Small Intestine
- Rectum
- 8 Anus

Figure 1

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**.

# Who gets ulcerative colitis?

Here are some quick facts and figures:

- Over the last 50 years, the number of people diagnosed with UC has been increasing.<sup>1,2</sup>
- According to CDC, the incidence of UC (the number of new cases per year) ranges from 2.2 to 14.3 cases per 100,000 people.<sup>3,4</sup>
- On average, people are diagnosed with ulcerative colitis in their mid-3os, although the disease can occur at any age.<sup>5</sup>
- Men are more likely than women to be diagnosed with ulcerative colitis in their 50s and 60s.<sup>5</sup>
- Ulcerative colitis is more common among Caucasians, but it can affect people of any racial or ethnic group.<sup>6</sup>

 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 UC is increasing in developing parts of the world, including China, India, and South America.<sup>6</sup>

### The genetic connection

Researchers have discovered that ulcerative colitis tends to run in families. In fact, the risk for developing IBD is between 1.5 percent and 28 percent for first-degree relatives of an affected person. While genetic background plays a clear role, environmental factors, such as diet, smoking, lifestyle, pollutants, and others, may impact onset, progression, and relapse of the disease. As such, while family history has a strong association with increased risk of IBD, it is currently not possible to confidently predict which, if any, family members will develop ulcerative colitis. 8,9

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

Nothing that you did made you get ulcerative colitis. You didn't catch it from anyone. It wasn't something that you ate or drank that brought the symptoms on. So, above all, don't blame yourself!

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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.

More than 200 genes have now been associated with IBD, though their exact role is still under investigation. It's likely that a person inherits one or more genes that make him or her more susceptible to ulcerative colitis. These genes then lead to an abnormal immune response to some environmental triggers. Scientists have not yet unequivocally identified specific triggers, but the bacteria in the intestine, part of our microbiome, are a leading candidate. Other environmental factors likely play a role as well. In a genetically susceptible individual, whatever the trigger is, it prompts the person's immune system to "turn on" and launch an attack in the GI system. That is when the inflammation begins. Unfortunately, the immune system doesn't "turn off," so the inflammation continues, damaging the digestive organs and causing the symptoms of ulcerative colitis.

# What are the signs and symptoms?

As the intestinal lining becomes more **inflamed** and ulcerated (small and large sores), 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, called anemia.

Most people with ulcerative colitis experience urgent bowel movements as well as crampy abdominal pain. The pain may be stronger on the left side, but it can occur 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 known as **extraintestinal manifestations**. Signs and symptoms of the disease may be evident in the:

- eyes (redness, pain, and/or changes in vision)
- mouth (sores)
- joints (swelling and pain)
- skin (tender bumps, painful ulcerations, and other sores/rashes)
- liver (primary sclerosing cholangitis and cirrhosis)—a rare development

In some people, extraintestinal manifestations 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 periods of 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 (usually less than six inches of the rectum) and is not associated with an increased risk of cancer. Symptoms include **rectal** bleeding, urgency, and rectal pain.
- 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). Proctosigmoiditis is a form of left-sided colitis as well. Symptoms include loss of appetite, weight loss, bloody diarrhea, and pain on the left side of the abdomen.
- Extensive Colitis: Affects the entire colon—continuous inflammation that begins at the rectum and extends beyond the splenic flexure. Symptoms include loss of appetite, bloody diarrhea, abdominal pain, and weight loss.

## **Making the diagnosis**

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 exclude infection or to detect inflammation (fecal calprotectin).
- **Blood tests:** May detect the presence of inflammation, abnormal antibodies, anemia, or nutritional/vitamin deficiencies.
- **Sigmoidoscopy:** Examines the rectum and lower third of the colon.
- **Colonoscopy:** Examines the entire colon and end of the small intestine.

For further information about diagnosing ulcerative colitis, please read our Diagnosing and Monitoring IBD brochure available at www.crohnscolitisfoundation.org/brochures.

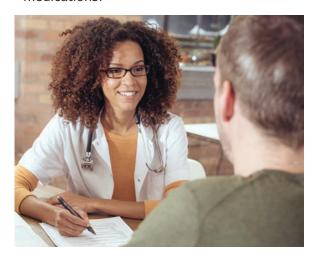
# Some questions to ask your doctor

It is important to establish good communications with your doctor. Patients will need to establish a collaborative relationship with all their healthcare providers, especially their gastroenterologist, to achieve the best long-term results.

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

- Could any condition other than my UC 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?
- 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 potential side effects of the medication?
- What should I do if I notice them?
- What should I do if my symptoms return?
- What symptoms are considered an emergency?
- If I cannot schedule a visit right away, are there any over-the-counter medications 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?
- What are my options if I can't afford my medications?



### **Treatment**

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 severity of disease in order to improve the patient's quality of life.

Treatments for ulcerative colitis work by decreasing the abnormal inflammation in the lining of the colon. This permits the colon and rectum to heal. It also relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain.

However, 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.

It is important to note that even if a patient is in remission, ulcerative colitis may flare up at times from the reappearance of inflammation. Flares may indicate that a change in medication dose, frequency, or type is needed.

### **Medications**

Some medications for the treatment of ulcerative colitis have been available for many years. Others are recent breakthroughs. Medications are given in different dosages and formulations and for different lengths of time.

Some medications are taken as pills that are swallowed, while others are administered intravenously (through a vein) or injected under the skin. Topical therapies (applied to body surfaces) are given rectally, as suppositories, enemas, creams, foams, and ointments. Taking your ulcerative colitis medication(s) as prescribed reduces the risk of a flare-up.

The most commonly prescribed medications fall into the following categories:

- Aminosalicylates: These include medications that contain 5-aminosalicylic acid (5-ASA). These medications work by inhibiting certain pathways that produce substances that cause inflammation. They can work in the lining of the GI tract to decrease inflammation. Aminosalicylates work best in the colon and are often given orally in the form of delayed-release tablets, or rectally as enemas or suppositories.
- 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. Corticosteroids are effective for short-term control of disease activity; however, they are not recommended for long-term or maintenance use because of their potential side effects. If you cannot come off steroids without a relapse of symptoms, your doctor may need to add some other medications to help manage your disease. Because of their effect on the adrenal glands, steroids cannot be stopped abruptly.
- Immunomodulators: This class of medications controls or suppresses the body's immune response, therefore decreasing inflammatory activity. Immunomodulators generally are used in people for whom aminosalicylates and corticosteroids haven't been effective or have only been partially effective. Some immunomodulators are added to treatment regimens to make other medications, such as biologics, work better by preventing the formation of antibodies to biologic medications. They may be useful in reducing or eliminating the need for corticosteroids. They may also be effective in maintaining remission in people who haven't responded to other medications and may take several weeks or months to begin to working.



• Biologic therapies: These are protein-based therapies made from living organisms, either human or animal. These medications are antibodies that stop certain proteins in the body from causing inflammation. They are currently offered in an injectable form, or through intravenous infusion (through veins). There are also biologic medications knowns as biosimilars.

Biosimilars are designed to be similar, nearidentical copies of another, already approved biologic therapy, known as an originator drug or reference product. They have the same safety and effectiveness and are taken in the same way as the originator drugs.

- Janus kinase inhibitors (JAK Inhibitors):
  These medications, currently available as tablets, are broken down in the gastrointestinal tract after ingestion and are directly absorbed into the bloodstream via the intestinal wall. Due to the small size of these chemically active substances, they can be transported to nearly any site in the body through the bloodstream, including the immune system. Unlike some of the other tablet-based agents, these agents work more quickly and can induce and maintain remission. They are currently approved to treat ulcerative colitis.
- Future Therapies: Recent advances have contributed to breakthroughs in the development of newer medical options for the treatment of IBD. Further developments may lead to expanding how currently approved medications are used in other diseases, including ulcerative colitis.

There are many therapies currently under investigation. For a current, up-to-date list of all FDA-approved medications for ulcerative colitis, please visit the Foundation's online Medication guide at <a href="https://www.ibdmedicationguide.org">www.ibdmedicationguide.org</a>. Additional information is available in our Understanding IBD Medications and Side Effects brochure at <a href="https://www.crohnscolitisfoundation.org/brochures">www.crohnscolitisfoundation.org/brochures</a>.

### **Managing your symptoms**

The best way to control ulcerative colitis is by taking medications as prescribed by your doctor or other healthcare professional. 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.

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

Talk to your doctor about which over-thecounter (OTC) medications you can take. OTC products that may help include loperamide (Imodium®) to control diarrhea, anti-gas products, and digestive aids. Most anti-gas products and digestive aids may also be safe to use, but you should ask your doctor about these first. 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. Many OTC medications may have some adverse effects on the ulcerative colitis itself or interact with some of the medications prescribed to treat your ulcerative colitis. The

safest way to handle OTC medications is to follow the guidelines and instructions of your doctor and pharmacist.

For further information on managing symptoms, please read our Managing Flares and Other IBD Symptoms brochure available at www.crohnscolitisfoundation.org/brochures.

### Other considerations

### Surgery

Many individuals with ulcerative colitis respond well to medical treatment and may never need to undergo surgery. However, after 30 years of disease, up to a third of people with ulcerative colitis 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.

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 ileostomy, an opening on the abdomen through which waste is emptied into a pouch attached to the abdomen. The second is an internal pouch, called an ileal pouch-anal anastomosis

(IPAA), or j-pouch, which is created by attaching the small intestine to the rectal cuff, eliminating the need for an external pouch.

For further information on surgery and ulcerative colitis, please read our Surgery for Crohn's Disease and Ulcerative Colitis brochure at www.crohnscolitisfoundation.org/brochures.

### **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 of complications often means more effective treatment. Complications can include profuse intestinal bleeding (including clots of blood in the stool), and toxic megacolon (a rare development where the colon becomes dangerously dilated and surgical removal is required).

Infection is also a concern. There is a rise of Clostridium difficile (C.diff) 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.

Occasionally, people with ulcerative colitis may develop colorectal cancer, but this occurs in a very small number of people afflicted with IBD.

For further information on complications, please read our Managing Flares and Other IBD Symptoms brochure available at www.crohnscolitisfoundation.org/brochures.

#### **Diet and nutrition**

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—ulcerative colitis varies from person to person and even changes within the same person over time.

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.
- Other diets —There are many other diet plans that have been tried or suggested for management of IBD. These include gluten-free diet, low FODMAP diet, Specific Carbohydrate Diet<sup>™</sup>, and the Mediterranean diet. While an individual may benefit from



such diets, there is no strong evidence to support recommending these for broad use at this time.

Although no specific foods worsen the underlying inflammation of ulcerative colitis, certain ones may tend to aggravate the symptoms. 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. Here are some additional 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.
- If you are lactose intolerant, limit the amount of dairy products in your diet.
- 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.
- Restricting your intake of certain high-fiber foods, such as nuts, seeds, and raw vegetables may decrease your symptoms.

Maintaining proper nutrition is important in the management of ulcerative colitis. Abdominal pain and fever can cause loss of appetite and weight loss. Diarrhea 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.

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

correct these deficiencies through vitamin and nutritional supplements.

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 (if tolerated) are sources of carbohydrates; and 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 at www.crohnscolitisfoundation.org/brochures.

## 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.

For more information about complementary and alternative therapies, view our Complementary and Alternative Medicine fact sheet at www.crohnscolitisfoundation.org/brochures.

### **General health maintenance**

It is important for ulcerative colitis patients 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, vision, heart, breast and prostrate screening, and periodic blood testing.

For detailed information about general healthcare maintenance in ulcerative colitis, view our General Healthcare Maintenance fact sheet at www.crohnscolitisfoundation.org/brochures.

## Stress, emotional factors, and support

If you have ulcerative colitis, you're bound to have questions about the relationship between stress and emotional factors and this disease.

Although flares are sometimes associated with stressful events, there is no evidence 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.

As depression can be associated with chronic illness, a doctor may recommend 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.



### **Support**

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 coworkers. Discuss it with them in order to help them understand what support you need.

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. Smart phone apps are available to help with locating restrooms.
- Carry extra underclothing, toilet paper, or moist wipes when traveling, as needed.
- Before venturing further away or for longer periods of time, speak with your doctor. Travel plans should include a long-term supply of your medication, its generic or non-brand 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 Crohn's & Colitis Foundation chapter offers support groups.

- Join the Foundation's free online community at www.crohnscolitiscommunity.org to get the support you need through discussion forums, personal stories, online support groups, and much more.
- Develop a support network of family and friends to help you manage your disease.
- Follow your doctor's instructions about taking medication (even when you are feeling well).
- Bring a family member or friend to your doctor's appointment for support.
- Maintain a positive outlook. That's the basic and best—prescription!

There's no doubt that living with this disease 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

With many new treatments for IBD in clinical trials, experts predict that a wave of new therapies is on the way. It is becoming increasingly clear that a person's immune response to intestinal bacteria plays an important role in IBD. A great deal of research is currently directed at understanding the composition, behavior, and precise role of the microbiome in the symptoms of IBD. Hopefully, this new knowledge will uncover new treatments to control or prevent the disease.

Crohn's & Colitis Foundation-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 the

Foundation's continuing research efforts, much more will be learned, and eventually cures will be found.

With the 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 in your area, visit the Foundation's Clinical Trials Community at www.crohnscolitisfoundation. org/clinical-trials-community or call 888-MY-GUT-PAIN (888-694-8872).

# Knowledge and support are power!

Find the answers you need to help control your ulcerative colitis by joining the Crohn's & Colitis Foundation.

• Local Education and Support Programs
To find programs, support groups, and events in your area, visit www.crohnscolitisfoundation.org to find your local chapter.

#### Power of Two

The Foundation's Power of Two program allows patients seeking guidance on a specific issue to speak with another peer within the IBD community who can share their experience and provide support. To find out more, contact powerof2@crohnscolitisfoundation.org.

 Irwin M. and Suzanne R. Rosenthal 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. EST, or by emailing info@crohnscolitisfoundation.org.

## Crohn's & Colitis Foundation Online Community

The Foundation hosts a free website where patients can get the support they need in managing their condition. They'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.crohnscolitiscommunity.org.

#### I'll Be Determined

I'll Be Determined is here to help patients and caregivers learn more about Crohn's disease and ulcerative colitis and the choices available for managing them. The site offer tools and resources, the perspectives of IBD patients and experts, and a chance to connect with others. www.ibdetermined.org.



### Camp Oasis

The Crohn's & Colitis Foundation's Camp Oasis is a co-ed residential summer camp program. Its mission is to enrich the lives of children with IBD by providing a safe and supportive camp community. For more information, visit <a href="https://www.crohnscolitisfoundation.org/camps">www.crohnscolitisfoundation.org/camps</a> or call the IBD Help Center.

### Membership

By joining the Crohn's & Colitis Foundation, you'll get:

• Under the Microscope, our newsletter with research updates.

- News, educational programs, and supportive services from your local 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.

The Crohn's & Colitis Foundation sponsors specific major events to increase awareness and raise funds to find a cure for Crohn's disease and ulcerative colitis. Contact your local chapter or visit www.crohnscolitisfoundation. org to find an event nearest you.



### • spin4 crohn's & colitis cures

Use your #power2cure in an exciting new way to connect with the IBD community—participate in a high-energy spin4 crohn's & colitis cures event near you! With inspirational instructors and fun playlists to keep you motivated, these indoor cycling relays are truly a #partyonabike. Teams of up to four people each ride for a 30-minute session, and every teammate receives plenty of swag! The events generate awareness of Crohn's disease and ulcerative colitis and raise funds to support groundbreaking IBD research and patient services. Learn more at <a href="https://www.spin4.org">www.spin4.org</a>.



• **Take Steps** is the Crohn's & Colitis Foundations'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. Visit <a href="https://www.cctakesteps.org">www.cctakesteps.org</a> for more information.



### Team Challenge

Team Challenge is the Foundation's endurance training and fundraising program. With options including running, walking, triathlon, cycling, and hiking, there are unlimited ways to challenge yourself while raising vital funds to cure these diseases. Each of our training programs is created by expert coaches to suit all experience levels, and you'll be joined by a supportive community of teammates who share the common goal of ending Crohn's and colitis. For more information on our destination events, or to participate in your own event through our Race In Orange program, 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.

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

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

**Biologic therapies:** Antibodies that bind with specific proteins 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 health-care systems, practices, and products that are not generally considered part of conventional medicine.

Chronic: Long-lasting or long-term.

**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 and/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.

**Inflamed:** 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 illnesses—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 and rectum. 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.

**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.

**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.

**Ulceration:** The process of ulcer formation.

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

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# About the Crohn's & Colitis Foundation

Established in 1967, the Crohn's & Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases.

Since our founding, the Foundation has remained at the forefront of research in Crohn's disease and ulcerative colitis. Today, we fund cutting-edge studies at major medical institutions, nurture investigators at the early stages of their careers, and finance underdeveloped areas of research.

In addition, the Crohn's & Colitis Foundation provides a comprehensive series of education programs, printed and online resources, support services, and advocacy programs to members of the IBD community, including patients and caregivers.

### We can help! Contact us at:

888-MY-GUT-PAIN (888-694-8872) info@crohnscolitisfoundation.org www.crohnscolitisfoundation.org

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The Crohn's & Colitis Foundation is a nonprofit organization that relies on the generosity of private contributions to advance its mission to cure Crohn's disease and ulcerative colitis and to improve the quality of life of children and adults affected by these diseases.