



**CROHN'S  
& COLITIS**  
FOUNDATION

# Living with Crohn's Disease



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# Understanding your diagnosis

Your doctor has just told you that you have **Crohn's disease**. Now what? You probably have lots of questions. Some of the most commonly asked questions are:

- What is Crohn's disease?
- Is there a cure for Crohn's disease, and what is the outlook (prognosis)?
- 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 Crohn's disease change my life, both now and in the future?

The purpose of this brochure is to provide helpful answers to these questions, and to walk you through some key points about Crohn's disease and what you may experience now and in the future. You won't become an expert overnight, but you'll learn more as time goes on. The more informed you are, the better you can manage your disease and become an active member of your own healthcare team.

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# What is Crohn's disease?

The disease is named after Dr. Burrill B. Crohn, who published a landmark paper with colleagues Drs. Gordon Oppenheimer and Leon Ginzburg in 1932 that described what is known today as Crohn's disease.

Crohn's disease (CD) belongs to a group of conditions known as **inflammatory bowel diseases (IBD)**. Crohn's disease is a chronic inflammatory condition of the gastrointestinal tract. Symptoms include **diarrhea** (sometimes bloody), as well as crampy abdominal pain, nausea, fever, loss of appetite, weight loss, fatigue (tired, exhausted feeling), and, at times, **rectal** bleeding. When you have Crohn's disease, you will not have the same symptoms all of the time. In fact, sometimes you may have no symptoms at all. When you have no symptoms, this is called clinical **remission**.

When reading about inflammatory bowel diseases, you need to know that Crohn's disease is not the same thing as **ulcerative colitis**, 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, from the mouth to the **anus**, but ulcerative colitis is limited to the colon—also called the large intestine.

CD most commonly affects the end of the small bowel (the ileum) and the beginning of the colon. 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. This does not occur in ulcerative colitis. 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 Crohn's disease. 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. However, one thing is certain: Crohn's disease is a **chronic** condition.

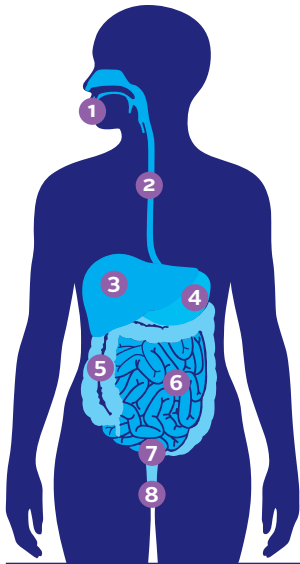
Chronic conditions are ongoing and long term. Studies show that people with Crohn's disease usually have the same life expectancy as people without Crohn's disease. It is important to remember that most people who have Crohn's disease lead full, happy, and productive lives.

## 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*) 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 GASTROINTESTINAL (GI) TRACT

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

Figure 1

The principal function of the colon is to absorb excess water and salts from 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**.

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 Crohn's disease.

## Who gets Crohn's disease?

- On average, people are more frequently diagnosed with Crohn's disease between the ages of 20 and 30, although the disease can occur at any age and an increased incidence of pediatric Crohn's disease has been reported globally.<sup>1-4</sup>
- Males and females appear to be approximately equal.<sup>1</sup>

- While Crohn's disease can affect those from any ethnic background, it is more common among Caucasians. However, prevalence and incidence rates among Hispanics and Asians have recently increased.<sup>5,6</sup>
- Both Crohn's disease and ulcerative colitis 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.<sup>6,7</sup>

## The genetic connection

Researchers have discovered that Crohn's disease 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.<sup>8</sup> 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 Crohn's disease.<sup>9,10</sup>



# What causes Crohn's disease?

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

Nothing that you did made you get Crohn's disease. You didn't catch it from anyone. It wasn't something that you ate or drank that brought the symptoms on. Leading a stressful lifestyle didn't cause it. 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 Crohn's disease.

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 Crohn's disease. 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 (diet, viruses, stress, smoking, etc.) 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 tract and causing the symptoms of Crohn's disease.

## What are the signs and symptoms?

As the intestinal lining becomes inflamed and ulcerated (small and large sores), the small bowel loses its ability to absorb nutrients. The

large intestine cannot absorb water efficiently. Both of these factors lead to a progressive loosening of the stool—in other words, diarrhea. The damaged intestinal lining may begin producing excess mucus in the stool. Moreover, **ulceration** in the lining can also cause bleeding, leading to bloody stool. Eventually, that blood loss may lead to a low red blood cell count, called anemia.

Most people with Crohn's disease experience urgent bowel movements as well as crampy abdominal pain. These symptoms vary from person to person and may change over time. Together, these may result in loss of appetite and subsequent weight loss. These symptoms, along with anemia, can also lead to fatigue. Children with Crohn's disease may fail to develop or grow properly.

Symptoms may range from mild to severe. Because Crohn's disease is a chronic disease, patients will go through periods in which the disease *flares up* (is active) and causes symptoms. In between flares, people may experience no symptoms at all. These disease-free periods (known as "remission") can span months or even years, although symptoms typically do return at some point.

Inflammation may also cause fistulas to develop. A **fistula** is an abnormal connection that leads from one loop of intestine to another, or that connects the intestine to the bladder, vagina, or skin. Fistulas occur most commonly around the anal area. If this complication arises, you may notice drainage of mucus, pus, or stool from this opening.

Other complications that may result from chronic inflammation include **strictures** (narrowing of the intestine from scar tissue) or abscesses. An **abscess** is a collection of fluid outside of the intestine that contains bacteria, intestinal fluid, and pus (white blood cells).

## 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 Crohn's disease. 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)
- bones (**osteoporosis**)
- kidney (stones)
- liver (primary sclerosing cholangitis and cirrhosis)—a rare development

All of these are known as **extraintestinal manifestations** of Crohn's disease because they occur outside of the digestive system. In some people, these actually may be the first signs of Crohn's disease, appearing even years before the bowel symptoms. In others, they may coincide with a flare-up of intestinal symptoms.

## Types of Crohn's disease

The symptoms and potential complications of Crohn's disease differ, depending on what part of the GI tract is affected. The following are five types of Crohn's disease:

- **Crohn's (granulomatous) colitis:** Affects the colon only.
- **Gastroduodenal Crohn's disease:** Affects the stomach and duodenum (the first part of the small intestine).
- **Ileitis:** Affects the ileum.
- **Ileocolitis:** The most common form of Crohn's disease affecting the colon and terminal ileum (the last section of small intestine).

- **Jejunioileitis:** Produces patchy areas of inflammation in the jejunum (upper half of the small intestine).

## Patterns of disease

### • Luminal Crohn's disease (Inflammatory Crohn's disease)

Luminal Crohn's disease refers to Crohn's disease causing inflammatory changes in the lining, or wall, of the intestine.

- Approximately 55 percent of patients with luminal Crohn's disease are symptom free or in remission in any given year.
- Another 15 percent have low activity of disease, while about 30 percent experience high activity.
- A patient with luminal Crohn's disease, who remains in remission for one year, has an 80 percent chance of staying in remission for an additional year, while those experiencing active disease in the past year have a 70 percent chance of recurrent symptomatic flare during the next year.

### • Fibrostenosing Crohn's disease

Fibrostenosing Crohn's disease is characterized by strictures, or narrowing of the intestine, which can lead to bowel obstructions (blockages). This disease course in Crohn's disease varies from person to person and from year to year. It generally follows a pattern of flares (when symptoms occur and the condition worsens) and remissions. This pattern is the chronic, relapsing course of Crohn's disease.

### • Penetrating Crohn's disease

Another pattern is known as penetrating Crohn's disease. This results in fistulae, which are abnormal connections between the inflamed intestine and other parts of the intestine, bladder, skin, or vagina. These fistulae can also occur around the anus and are termed perianal. The outlook for this type of Crohn's disease depends on the location and complexity of the fistulae.

Most patients with Crohn's disease have an inflammatory pattern early in their disease course. However, many progress to fibrostenosing or penetrating disease over time.

*For more information about the management of symptoms and complications related to Crohn's disease, visit the Foundation's website at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).*

## 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 Crohn's disease, 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.
- **Colonoscopy and upper endoscopy:** Used to look at the lining of your gastrointestinal tract with a scope or a tube with a camera and a light at the end. Biopsies can be obtained through these scopes. There is also a special miniaturized camera that can be swallowed by the patient and specifically used to evaluate the small bowel.
- **Bowel Imaging:** Cross-sectional imaging refers to the use of computerized tomography (CT) scanning or magnetic resonance imaging (MRI) to evaluate the intestinal tract and surrounding structures for the presence

of inflammation or complications such as strictures, fistulae, or abnormal fluid collections. The advantage of MRI is that it does not involve radiation exposure. However, it is usually more expensive than CT imaging.

In some areas, ultrasonography, using sound waves, can detect some of these changes as well. Ultrasonography for Crohn's disease is not widely used in the U.S.

*For further information about diagnosing Crohn's disease, please read our *Diagnosing and Monitoring IBD* brochure available at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).*

## 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 during your office visit. Here is a list of questions that may be helpful for your next visit:

- Could any condition other than my Crohn's 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?
- What happens if I miss taking a dose or if I stop taking my medication?



- 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? Which 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?
- What are my options if I can't afford my medications?

## Treatment

There are very effective treatments available that may control your Crohn's disease and even place it into remission. These treatments work by decreasing the abnormal inflammation in the GI system. This permits the system to heal and will then relieve 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 severity of disease in order to improve the patient's quality of life. Some of the same medications may be used to accomplish this, but they are given in different dosages and for different lengths of time.

There is no one size fits all treatment for everyone with CD. 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. However, Crohn's disease activity may flare up at times from the reappearance of inflammation. A disease flare may also be triggered from a complication such as a fistula, stricture, or abscess. Flares of Crohn's disease may indicate that a change in medication dose, frequency, or type is needed.

Physicians have been using some medications for the treatment of Crohn's disease for many years. Others are recent breakthroughs. The most commonly prescribed 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. They are thought to be effective in treating mild-to-moderate flares of Crohn's disease, and useful as a maintenance treatment in preventing relapses of the disease. Aminosalicylates work best in the colon and are not particularly effective if the disease is limited to the small intestine. These are often given **orally** in the form of delayed release tablets to target the colon, 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 used in people with moderate-to-severe Crohn's disease. Budesonide, a corticosteroid released primarily at the end of the small bowel (distal/terminal ileum), is used for the treatment of mild-to-moderate Crohn's disease. Corticosteroids are effective for short-term control of disease activity; however, they are not recommended for long-term or maintenance use because of their 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 system response, therefore decreasing inflammatory activity. Immunomodulators are generally used in people for whom aminosalicylates haven't been effective or have been only partially effective. Some immunomodulators are added to make other medications, such as biologics, work better by preventing the **antibody** formation 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 to months to begin 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 the veins). There are also biologic medications known as **biosimilars**. Biosimilars are designed to be similar, near identical 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.
- **Antibiotics:** Antibiotics may be used when infections—such as abscesses—occur in Crohn's disease. They can also be helpful with fistulas around the anal canal and vagina.

**Future Therapies:** Research 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 Crohn's disease.

*There are many therapies currently under investigation—for a current, up-to-date list of all FDA-approved medications for Crohn's disease, please visit the Foundation's online IBD*



Medication guide: [www.ibdmedicationguide.org](http://www.ibdmedicationguide.org). Additional information is available in our Understanding IBD Medications and Side Effects brochure at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).

## Managing your symptoms

The best way to control Crohn's disease 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 Crohn's disease. In between flares, most people feel quite well and are free of symptoms.

Talk to your doctor about which over-the-counter (OTC) medications you can take to help relieve those symptoms. These may include diphenoxylate-atropine (Lomotil<sup>®</sup>) or loperamide (Imodium<sup>®</sup>) taken as needed to control diarrhea. 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 healthcare provider about taking acetaminophen (Tylenol<sup>®</sup>) rather than nonsteroidal anti-inflammatory drugs (**NSAIDs**) such as aspirin, ibuprofen (Advil<sup>®</sup>, Motrin<sup>®</sup>), and naproxen (Aleve<sup>®</sup>). NSAIDs may irritate your digestive system. Many over-the-counter medications can have adverse effects on the Crohn's disease itself or interact with some of the medications prescribed to treat your

Crohn's disease. The safest way to handle over-the-counter medications is to follow the guidelines and instructions of your doctor and pharmacist.

*For further information about managing the symptoms of Crohn's disease, please read our Managing Flares and Other IBD Symptoms brochure available at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).*

## Other considerations

### Surgery

Many individuals with Crohn's disease respond well to medical treatment and never need to undergo surgery. However, between 66 and 75 percent of people will require surgery at some point during their lives. The overall goal of surgery in Crohn's disease is to conserve bowel and return the individual to the best possible quality of life.

Surgery may become necessary when medical therapies no longer control the disease or to treat complications. For penetrating disease, surgery may be required to repair a fistula or drain an abscess. In most cases, the diseased segment of bowel is removed. This is called a **resection**. Usually, the two ends of healthy bowel are then joined together in a procedure called an **anastomosis**. While resection and anastomosis may allow many symptom-free years, this surgery is not considered a cure for Crohn's disease because the disease frequently recurs at or near the site of repair.

A **stoma** may be required when surgery is recommended for Crohn's disease. After surgeons remove the diseased bowel, they may need to re-route the intestine to the skin and attach an external pouch. If the small bowel is used, it is called an ileostomy. If the large bowel (colon)

is used, it is termed a colostomy. A stoma may be required if the amount of disease and/or inflammation is so severe that an immediate anastomosis is not safe. A colostomy is also required if the rectum is removed. In some instances, the stoma may be temporary and can be closed in several months once the severe inflammation and/or infection is controlled.

*For further information on surgery and Crohn's disease, please read our [Surgery for Crohn's Disease and Ulcerative Colitis brochure](http://www.crohnscolitisfoundation.org/brochures) available at [www.crohnscolitisfoundation.org/brochures](http://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. 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.



There is no single diet or eating plan that will work for everyone with Crohn's disease. Dietary recommendations must be tailored specifically for you—depending on what part of your intestine is affected and what symptoms you have. Crohn's disease varies from person to person and even changes within the same person over time. What worked for your friend may not work for you, and even 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 blockages in Crohn's disease patients with strictures and to avoid stimulating bowel movements in CD.
- **Low-fat diet**—Typically recommended during a flare in Crohn's disease 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.
- **Other diets**—There are many other diet plans that have been tried or suggested for management of Crohn's disease. These include gluten-free diet, low FODMAP diet, Specific Carbohydrate Diet,<sup>™</sup> and the Mediterranean diet. While an individual may benefit from such a diet, there is no strong evidence to support recommending these for broad use at this time.

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.

Although no specific foods worsen the underlying inflammation of Crohn's disease, 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.
- If you are lactose intolerant, limit the amount of dairy products in your diet. If you are not lactose intolerant, dairy products do not need to be limited.
- 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, although not always.
- Restricting your intake of certain high-fiber foods such as nuts, seeds, and raw vegetables may decrease your symptoms, especially if you have a narrowed segment of bowel.

Maintaining proper nutrition is important in the management of Crohn's disease. 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.

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 carbo-

hydrates; 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 and Nutrition brochure available at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).*

## Complementary and alternative therapies

Some people living with Crohn's disease look toward 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 about complementary and alternative therapies, view our Complementary and Alternative Medicine fact sheet at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).*

## Stress and emotional factors

Crohn's disease affects virtually every aspect of a person's life. If you have Crohn's disease, 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 or periods, there is no proof that stress causes Crohn's disease. It is much more likely that the emotional distress people sometimes feel is a reaction to the symptoms of the disease itself. Individuals should seek understanding and emotional support from their families and caregivers. 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. In addition, the Crohn's & Colitis Foundation offers local and online support groups to assist patients and their families in coping with Crohn's disease and ulcerative colitis.

*Please review the list of other resources the Foundation offers in the "Knowledge and support are power" section at the end of this brochure.*

## General health maintenance

It is important for Crohn's disease patients to continue general health maintenance. While working with your gastroenterologist, also remember to speak with your primary care provider about other important issues, including vaccinations, oral health, vision, heart, breast and prostate screening, and periodic blood testing.

For detailed information about general health-care maintenance in Crohn's disease and a helpful chart for your records, view our *General Healthcare Maintenance* fact sheet at [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).

## Support

Learning you have Crohn's disease may be difficult and stressful. As time goes on, this will not always occupy the top spot in your mind. In the meantime, try not to hide your condition from the people in your life. Discuss it with them and help them understand what kind of support you need.

You'll learn that there are numerous strategies that can make living with Crohn's disease 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.
- When venturing farther 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 is 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, mentoring programs, and informational meetings. It helps to share what you know with others too.
- Join the Foundation's free online community at [www.crohnscolitiscommunity.org](http://www.crohnscolitiscommunity.org) to get the support you need through discussion forums, personal stories, an online support group, and much more.
- Develop a support network of family and friends to help you cope with 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 Crohn's disease are able to lead rich and productive lives.

## Hope for the future

Investigators all over the world are devoted to research for patients with Crohn's disease, which is promising news when it comes to the development of new treatments for this disease. Experts predict that a wave of new therapies for Crohn's disease 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 gut 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 locate clinical trials for Crohn's disease therapies in your area, visit the Foundation's Clinical Trials Community at [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org) or call 888-MY-GUT-PAIN (888-694-8872).

## Knowledge and support are power!

Find the answers you need to help control your Crohn's disease 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](http://www.crohnscolitisfoundation.org) to find your local chapter.

- **“Power of 2”**

The Foundation's “Power of 2” 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 [powerof2@crohnscolitisfoundation.org](mailto:powerof2@crohnscolitisfoundation.org).

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

The IBD Help Center is a free service designed to provide patients and caregivers 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@crohnscolitisfoundation.org](mailto: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](http://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 to help manage them. The site offers tools and resources, perspectives from IBD patients and experts, and a chance to connect with others. Learn more by visiting [www.ibdetermined.org](http://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 [www.crohnscolitisfoundation.org/camps](http://www.crohnscolitisfoundation.org/camps) 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 nationwide events to increase awareness and raise funds for mission-critical programs. Here's a selection of events. Contact your local chapter or visit [www.crohnscolitisfoundation.org](http://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 [www.spin4.org](http://www.spin4.org).



- **Take Steps** is the Crohn's & Colitis Foundation'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 [www.cctakesteps.org](http://www.cctakesteps.org) 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 are 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 disease and ulcerative 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](http://www.ccteamchallenge.org).



## Glossary of terms

**Abscess:** A collection of pus from an infection.

**Aminosalicylates:** Medications that include compounds containing 5-aminosalicylic acid (5-ASA).

**Anastomosis:** The surgical connection of normally separate parts or spaces.

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

**Antibiotics:** Drugs 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:** 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 healthcare systems, practices, and products that are not generally considered part of conventional medicine.

**Chronic:** Long lasting or long term.

**Colon:** The large intestine.

**Corticosteroids:** Medications that affect the body's ability to begin and maintain an inflammatory process.

**Crohn's disease:** A chronic inflammatory bowel disease that primarily involves the small and large intestine, but can affect other parts of the digestive tract 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 manifestations:** Complications that occur outside of the gastrointestinal tract.

**Fistula:** An abnormal connection occurring between two loops of intestine or between the intestine and another nearby structure (such as the bladder, vagina, or skin).

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

**Gastroenterologist:** A doctor who specializes in problems of the gastrointestinal tract.

**Gastrointestinal (GI) system or tract:** Referring collectively to the esophagus, stomach, rectum, anus, and small and large intestines.

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

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

**Immunomodulators:** Medications that basically override the body's immune system so that it cannot cause ongoing inflammation.

**Inflammation:** A response to tissue injury that causes redness, swelling, and pain.

**Inflammatory bowel diseases (IBD):** A term referring to a group of disorders, including Crohn's disease (inflammation anywhere in the gastrointestinal tract) and ulcerative colitis (inflammation limited to 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.

**Microbiome:** The human microbiome is a community of micro-organisms, like bacteria, viruses, fungi and archea, that live on the human body, especially inside the gastrointestinal tract. Scientists hypothesize that when the microbiome composition is disturbed, as may be the case in IBD, serious health problems can arise as a result.

**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.

**Resection:** Surgical removal of a diseased portion of intestine.

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

**Stoma:** A surgical opening into the body from the outside.

**Stricture:** A narrowing of a section of intestine caused by scarring.

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

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







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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.