



CROHN'S & COLITIS
FOUNDATION OF AMERICA

Living with Crohn's Disease



What's Inside?

| | |
|---|-------------------|
| Understanding your diagnosis | 1 |
| What is Crohn's disease (CD)? | 2 |
| Will it ever go away? | 3 |
| A brief introduction to the gastrointestinal (GI) tract | 4 |
| Who gets Crohn's disease? | 5 |
| What causes Crohn's disease? | 7 |
| What are the signs and symptoms? | 8 |
| Beyond the intestine | 9 |
| Types of Crohn's disease | 9 |
| Patterns of disease | 10 |
| Making the diagnosis | 11 |
| Questions to ask your doctor | 12 |
| Treatment | 14 |
| Managing your symptoms | 19 |
| Other considerations | 20 |
| Surgery | 20 |
| Diet and nutrition | 21 |
| Complementary and alternative therapies | 24 |
| Stress and emotion | 25 |
| General health maintenance | 26 |
| Living your life | 26 |
| Hope for the future | 29 |
| Knowledge and support are power! | 30 |
| Glossary of terms | 33 |
| About CCFA | Inside back cover |

Understanding your diagnosis

Your doctor has just told you that you have Crohn's disease. Now what?

Quite possibly, you have never even *heard* of this disease before. In fact, most people are unfamiliar with Crohn's disease, and now you are coping with your diagnosis.

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 the key points about Crohn's disease and what you may expect 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.

What is Crohn's disease?

The disease is named after Dr. Burrill B. Crohn, who published a landmark paper with colleagues Oppenheimer and 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 and fatigue, 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 *remission*.

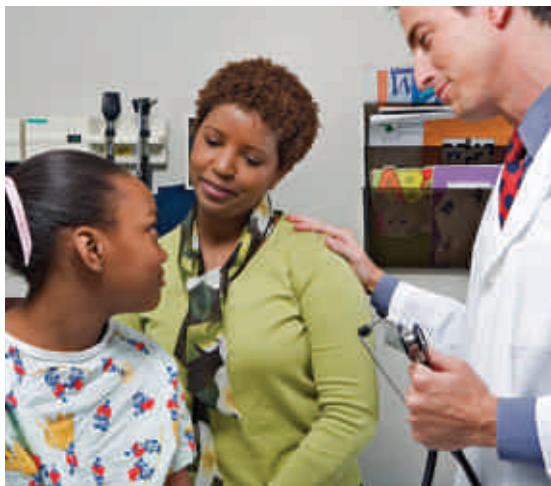
When reading about inflammatory bowel diseases, you need to know that Crohn's disease is not the same thing as *ulcerative colitis*, another type of IBD. The symptoms of these two illnesses are quite similar, but the areas affected in your body are different. Crohn's disease may affect any part of the 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. 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 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 situations. They can be controlled with treatment, but not cured. This means that the disease is a long-term condition. In fact, many medical illnesses such as diabetes, high blood pressure, and heart disease are successfully treated but not cured. Occasionally, people may develop severe complications that can be serious—such as colorectal cancer—but this occurs in a very small number of people afflicted with IBD. Studies show that people with IBD usually have the same life expectancy as people without IBD. It is important to remember that most people who have 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, even though it occupies a lot of "real estate" in our bodies.

Here's a quick overview: The GI tract (see figure 1) actually starts at the mouth. It follows a twisting and turning course and ends, many yards later, at the rectum. In between are a number of organs that all play a part in processing and transporting food through the body.

The first is the *esophagus*, a narrow tube that connects the mouth to the stomach. Food

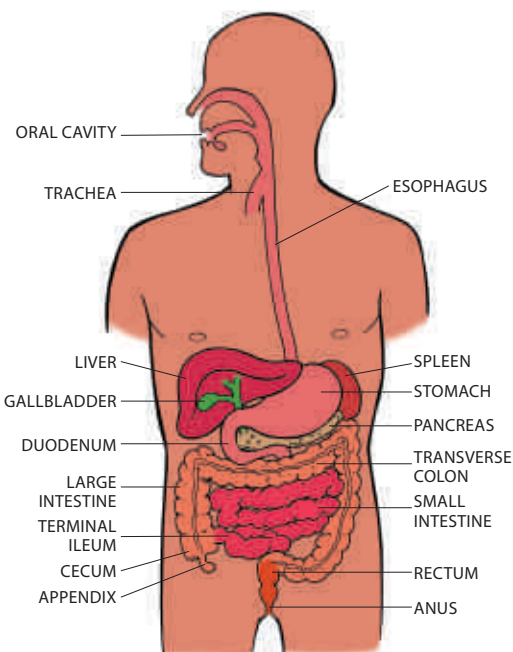


Figure 1

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 *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?

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

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

- About 30,000 new cases of Crohn's disease and ulcerative colitis are diagnosed each year.
- On average, people are more frequently diagnosed with Crohn's disease between the ages of 15 and 25, although the disease can occur at any age.
- CD can occur in people who are 70 or older and in young children as well. An estimated 10 percent of those affected are under the age of 18.
- Males and females appear to be affected equally.
- While CD can affect those from any ethnic background, Caucasians develop it more than other groups. It is especially prevalent among the Eastern European Jewish population.

- Both 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.

The genetic connection

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



What causes Crohn's disease?

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

One thing is certain: 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. The three leading factors suspected of contributing to it are:

- 1) Environmental
- 2) Genetic
- 3) An inappropriate reaction by the body's immune system

It's likely that a person inherits one or more genes that make him or her susceptible to Crohn's disease. Then, something in the environment triggers an abnormal immune response. (Scientists have not yet identified this environmental "trigger" or "triggers.") Whatever the trigger is, it prompts the person's immune system to "turn on" and launch an attack in the GI system. That's 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 Crohn's disease.

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 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 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 distress 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 a *fistula* to develop. A fistula is a tunnel 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 conditions that may occur in some patients include *strictures*, narrowing of the intestines; *fissures*, tears in the lining of the anus; and *abscesses*. An abscess is a tender mass filled with pus from an infection.

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:

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

All of these are known as *extraintestinal* manifestations of 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 affecting the colon and *ileum* (the last section of small intestine).
- **Jejunoleitis:** Produces patchy areas of inflammation in the *jejunum* (upper half of the small intestine).

Patterns of disease

- **Luminal-fibrosing Crohn's disease**

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—also known as luminal-fibrosing Crohn's disease. Fibrosing Crohn's disease is characterized by *strictures*, or narrowing of the intestine.

- **Luminal Crohn's disease**

Luminal Crohn's disease refers to Crohn's disease causing inflammatory changes in the *lumen*, or tube 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 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.

- **Fistulizing Crohn's disease**

Another pattern of Crohn's disease is known as fistulizing Crohn's disease. *Fistulas* are abnormal channels between two loops of intestine, or between the intestine and another structure (such as the vagina, bladder, or skin). The lifetime risk of people with Crohn's disease developing a fistula ranges from 20 percent to 40 percent. The prognosis or out-

look for this type of Crohn's disease depends on the location and complexity of the fistulas. However, most tend to recur following medical or surgical treatment.

For more information about the management of symptoms and complications related to Crohn's disease, visit CCFA's Web site at www.ccfa.org.

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 rule out infection or to reveal blood.
- **Blood tests:** May detect the presence of inflammation, antibodies, or anemia.
- **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 nine feet of small bowel that is not accessed easily by the endoscopes.

- **CT Scan** (computerized tomography) or **MRI** (magnetic resonance imaging) procedures may be used to look at either the thickness of the bowel wall and/or evaluate for fistulas and collections of infected fluid in the abdomen known as abscesses.
- **Computed tomographic (CT) colography** (virtual colonoscopy) is a relatively new technique for imaging polyps. The use of this technique in Crohn's disease is not supported by research and is controversial as of this writing.

For further information about diagnosing Crohn's disease, please see our fact sheet, "Diagnosing IBD," available at www.cdfa.org.

Questions to ask your doctor

It is important to establish good communications with your doctor.

Patients will need to establish a teamwork relationship with all their healthcare providers, especially their gastroenterologist, for 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 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? 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?
- 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. It also relieves the symptoms of diarrhea, rectal bleeding, and abdominal pain.

The two basic goals of treatment are to achieve remission and, once that is accomplished, to *maintain* remission. If remission cannot be established, then the next goal is to decrease the 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. But the disease will flare up at times from the reappearance of inflammation or from a particular trigger. A disease flare may also be triggered from a complication such as a fissure, 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 five basic categories:

- **Aminosalicylates:** These include medications that contain 5-aminosalicylate acid (5-ASA). Examples are sulfasalazine, mesalamine, olsalazine, and balsalazide. These drugs are not specially approved by the Food and Drug Administration (FDA) for use in Crohn's. However, they can work at the level of the lining of the GI tract to decrease inflammation. They are thought to be effective in treating mild-to-moderate episodes of Crohn's disease and useful as a maintenance treatment in preventing relapses of the disease. They work best in the colon and are not particularly effective if the disease is limited to the small intestine.
- **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 for people with moderate-to-severe Crohn’s disease. They are effective for short-term control of flareups; however, they are not recommended for long-term or maintenance use because of their side effects. If you cannot come off steroids without suffering a relapse of your symptoms, your doctor may need to add some other medications to help manage your disease. With steroids it is very important not to stop abruptly.

- **Immunomodulators:** This class of medications modulates or suppresses the body’s immune system response so it cannot cause ongoing inflammation. Immunomodulators generally are used in people for 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 working.
- **Biologic therapies:** Also known as anti-TNF agents, these represent the latest class of therapy used for people suffering from moderate-to-severe Crohn’s disease. Tumor necrosis factor (TNF) is a chemical produced by our bodies to cause inflammation. Antibodies are proteins produced to attach to these chemicals and allow the body to destroy the chemical and reduce the inflammation.
- **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.

For further detailed information about treatment options, view our “Understanding IBD Medications and Side Effects” brochure at www.ccfafa.org.

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 side effects, or just minimal ones, it may still seem like a nuisance to be on a steady regimen of medication. Seek support from your healthcare provider. Remember, though, that taking maintenance medication can significantly reduce the risk of flares in Crohn's disease. In between flares, most people feel quite well and free of symptoms.



Medications for Crohn's Disease

| Class of Drugs | Generic Name (Trade Name) | Indications |
|--------------------------|---|---|
| Aminosalicylates (5-ASA) | <ul style="list-style-type: none"> • sulfasalazine (Azulfadine®) • mesalamine (Apriso™, Asacol®, Asacol HD® Lialda®, Pentasa®, Rowasa®) • olsalazine (Dipentum®) • balsalazide (Colazal®) | Although... tions... mod... usefu... |
| Corticosteroids | <ul style="list-style-type: none"> • budesonide (Entocort®EC) • prednisone (Deltasone®) • prednisolone (Pediapred Oral Liquid®, Medrol®) | For m... Bude... stero... disea... contr... |
| Immunomodulators | <ul style="list-style-type: none"> • azathioprine (Imuran®, Azasan®) • 6-Mercaptopurine (6-MP) (Purinethol®) • cyclosporine (Neoral®, Gengraf®, Sandimmune®) • methotrexate | Indic... spon... and c... pend... to th... |
| Biologic therapies | <ul style="list-style-type: none"> • infliximab (Remicade®) • adalimumab (Humira®) • certolizumab pegol (Cimzia®) • natalizumab (Tysabri®) | For p... disea... and f... |
| Antibiotics | <ul style="list-style-type: none"> • metronidazole (Flagyl®) • ciprofloxacin (Cipro®, Proquin®) | For in... absco... |

| Indications (Use) | Route of Delivery |
|--|--|
| <p>Although not FDA-approved, these medications are thought to be effective for mild-to-moderate episodes of Crohn's disease and are useful in preventing relapses of disease.</p> | <p>Oral or rectal</p> |
| <p>Useful for mild-to-moderate Crohn's disease. Vedolizumab is a newer type of non-systemic immunomodulator. It is also effective for mild-to-moderate Crohn's disease. Also effective for short-term control of flares.</p> | <p>Oral, rectal, or intravenous (by vein)</p> |
| <p>Indicated 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.</p> | <p>Oral</p> <p>Methotrexate is rarely used subcutaneously (injection given just under the skin).</p> |
| <p>Useful for people with moderate-to-severe Crohn's disease. Effective for maintaining remission and for tapering people off steroids.</p> | <p>Intravenous infusion or subcutaneous injection</p> |
| <p>Useful for infections of Crohn's disease, such as abscesses.</p> | <p>Oral or injection</p> |

Talk to your doctor about which over-the-counter (OTC) medications you can take to help relieve those symptoms. These may include Lomotil® or loperamide (Imodium®) 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®) rather than non-steroidal anti-inflammatory drugs (NSAIDs) such as aspirin, ibuprofen (Advil®, Motrin®), and naproxen (Aleve®). 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 brochure, "Managing Flares and Other IBD Symptoms."

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.

Surgery may become necessary when medical therapies no longer control the disease well. It also may be performed to repair a fistula or fissure. Another reason for surgery is the presence of an intestinal obstruction from a *stricture* (narrowed segment of bowel), or another complication such as an abdominal abscess. In most cases, the diseased segment of bowel and any associated abscess are 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* also may be required when surgery is performed for Crohn's disease. After surgeons remove the segment of bowel, they re-route the small bowel to the skin so that waste products may be emptied into an external pouch attached to the abdomen. This procedure may be needed if the rectum is diseased and requires removal. Without a rectum present, an anastomosis cannot be performed. In this situation, the stoma is permanent. A stoma may also be formed if the amount of infection or inflammation is severe and immediate anastomosis is not safe. Under these circumstances, the stoma is usually temporary and may be closed in several months once the severe inflammation or infection is controlled.

The overall goal of surgery in Crohn's disease is to conserve bowel and return the individual to the best possible quality of life. However, unlike surgery for ulcerative colitis, surgery for Crohn's disease does not offer a cure.

For more information on surgery in Crohn's disease, see CCFA's website at www.ccfa.org.

Diet and Nutrition

You may wonder if eating any particular foods caused or contributed to your CD. 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 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 patients with strictures and to avoid stimulating bowel movements in CD.
- **Low-fat diet** – Typically recommended during a flare in Crohn's when fat absorption may become an issue.
- **Lactose-free diet** – For those who have an intolerance to dairy products.
- **High-calorie diet** – For those who experience weight loss or growth delay.

Some patients with IBD may become deficient in certain vitamins and minerals (including vitamin B-12, folic acid, vitamin C, iron, calcium, zinc, and magnesium) or have trouble ingesting enough food to meet their caloric needs. Your healthcare provider 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 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. Good nutrition is essential in any chronic disease, but especially for Crohn's. Abdominal pain and fever can cause loss of appetite and weight loss. Diarrhea and

rectal bleeding can rob the body of fluids, minerals, and electrolytes. These are nutrients in the body that must remain in proper balance for the body to function properly.

That doesn't mean that you must eat certain foods or avoid others. Most doctors recommend a well-balanced diet to prevent nutritional deficiency. A healthy diet should contain a variety of foods from all food groups. Meat, fish, poultry, and dairy products (if tolerated) are sources of protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrates; margarine and oils are sources of fat. A dietary supplement, like a multivitamin, can help fill the gaps. For more information, you may want to talk with a dietitian and read our "*Diet and Nutrition*" brochure, available at www.ccfa.org.

Complementary and alternative therapies

Some people living with 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.ccfa.org.

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, CCFA offers local support groups to assist patients and their families in coping with Crohn’s disease and ulcerative colitis.

Please review the list of other resources CCFA offers in the “Knowledge and Support are Power” section at the end of this brochure.

General health maintenance

It is important to continue general health maintenance. While working with your gastroenterologist, also remember to speak with your primary care 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.ccfa.org.

Living your life

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 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.
- 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 CCFA chapter offers support groups as well as informational meetings. It helps to share what you know with others too.
- Join CCFA’s free online community at www.ccfacommunity.org to get the support you need through participation in discussion boards, personal stories, and much more.

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

While Crohn's 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 Crohn's disease are able to lead rich and productive lives.

Remember, too, that taking maintenance medication can significantly decrease flare-ups of Crohn's disease. In between disease flares, most people are free of symptoms and feel well.



Hope for the future

Investigators all over the world are devoted to research for patients with Crohn's disease.

That's good news when it comes to the development of new treatments for this disease. It is a very exciting time in the development of new therapies. With many experimental treatments for IBD in clinical trials, experts predict that a wave of new therapies for Crohn's disease is on the way.

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

Genetic studies also are expected to yield important insights that will drive the search for new therapies. The hope is that new therapies may be capable of reversing the damage caused by intestinal inflammation, and even prevent the disease process from starting in the first place.

It is becoming increasingly clear that a person's immune response to normal intestinal bacteria plays an important role in CD and UC. A great deal of research is currently directed at understanding the composition, behavior, and precise role of intestinal bacteria in the symptoms of IBD. Hopefully this new knowledge will uncover new treatments to control or prevent the disease.

CCFA-sponsored research has led to huge strides in the fields of immunology, the study of the body's immune defense system; microbiology, the study of microscopic organisms with the

power to cause disease; and genetics. Through CCFA's continuing research efforts, much more will be learned and eventually a cure will be found.

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

Knowledge and support are power!

Find the answers you need to help control your Crohn's disease by joining CCFA.

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

■ **Support groups**

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

■ **Local chapters**

Local programs are provided through 12 regional divisions that serve all 50 states and the District of Columbia. To find programs, support groups, and events in your area, visit our Web site at www.cdfa.org/chapters, or call CCFA's Information Resource Center at 888.MY.GUT.PAIN (888-694-8872).

■ **"Power of Two"**

You can find support and comfort through talking to someone by phone or e-mail who knows the challenges of living with ulcerative

colitis. You can also provide a helping hand to those in need of help. Our “Power of Two” connection program will match you up based on your needs or your request to help others by answering questions, or just being there to listen.

■ **Information Resource Center (IRC)**

Information Specialists at CCFA’s Information Resource Center offer help through answer chat, phone, and e-mail. The IRC is here to help you understand IBD from diagnosis to treatment and living with IBD. Call us at 888.MY.GUT.PAIN (888-694-8872) Monday through Friday, 9 a.m. to 5 p.m. Eastern Time, or email us at info@ccfa.org.

■ **CCFA Online Community**

CCFA hosts a free Web site where you can get the support you need in managing your condition. Participate in discussion boards, share personal stories, and much more. The Crohn’s & Colitis Community is waiting for people just like you. Join today at www.ccfacommunity.org.



■ Kids and Teens Web Site

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

■ Camp Oasis

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

■ Membership

By joining CCFA, you'll receive:

- *Take Charge*, our national magazine.
- *Under the Microscope*, our newsletter with research updates.
- News, educational programs, and supportive services from your local CCFA chapter.
- Discounts on select programs and merchandise.
- An "I can't wait" card (provides help with restroom access).

Members are also able to contribute to research to find a cure for these challenging diseases. Join today!

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

- **Take Steps for Crohn's & Colitis** is CCFA's national walk and celebration. 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 for more information.

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

Glossary of terms

Abscess: A collection of pus from infection.

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

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, 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 health-care 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.

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 manifestations: Complications that occur outside of the intestine.

Fissure: A crack in the skin, usually in the area of the anus in Crohn's disease.

Fistula: An abnormal channel 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: 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 causes redness, swelling, and pain.

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

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

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

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

Oral: By mouth.

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

Rectal: Having to do with the rectum.

Rectum: Lowest portion of the colon.

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

Resection: Surgical removal of a diseased portion of intestine. Reattachment of the two ends of healthy bowel is called *anastomosis*.

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.

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

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

Ulceration: The process of ulcer formation.

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



About CCFA

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

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

Contact CCFA to get the latest information about disease management, research findings, to learn more about our advocacy efforts, or to join us and become a member. When you become a member, you help support vital research that will one day lead to a cure.

We can help! Contact us at:

888.MY.GUT.PAIN

(888.694.8872)

info@ccfa.org

www.ccfa.org

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

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