



CROHN'S & COLITIS
FOUNDATION OF AMERICA

Managing Flares

and Other IBD Symptoms



Information Resource Center

888.MY.GUT.PAIN

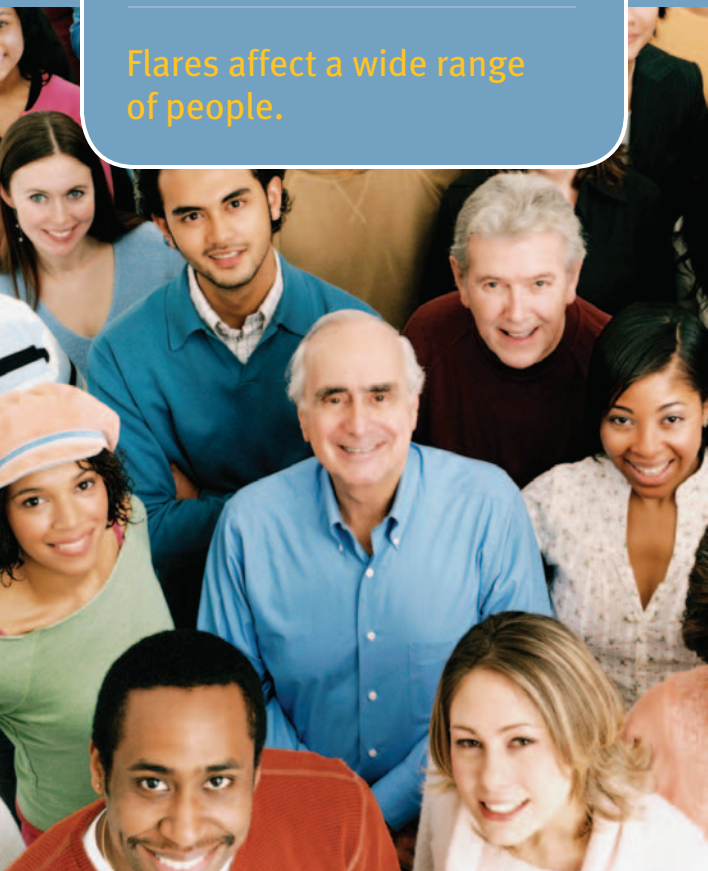
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www.ccfa.org

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Flares affect a wide range of people.



Having a chronic illness often means living with these nagging concerns lurking just under the surface of everyday thoughts:

- Will my condition flare up?
- What can I do when it does?
- How will I cope?

These concerns are very common for people with ulcerative colitis and Crohn's disease. Even with medical treatment, a person with one of these inflammatory bowel diseases (IBD) is likely to experience periods of time when symptoms become active (a *flare*).

If you're reading this brochure, you or a loved one probably has either ulcerative colitis or Crohn's disease. You likely already have general knowledge about the disease. You know the symptoms and treatment options and understand the importance of maintaining a healthy diet, reducing stress, and taking your medication as prescribed. The Crohn's & Colitis Foundation of America (CCFA) has several brochures to help you understand what is known about IBD.

For the vast majority of patients, IBD is a lifelong illness. While you can and should go about your normal daily life, you will need to make certain adjustments to cope with a disease that can flare up at times. This brochure will help you to manage your life with a disease that can at times be painful, uncomfortable, inconvenient, or embarrassing.

flares

What is a flare?

A *flare* is the reappearance of the characteristic symptoms of Crohn's disease or ulcerative colitis. This generally means diarrhea, rectal bleeding, urgent bowel movements, constipation, abdominal cramps and pain, fever, fatigue, or weight loss. Your specific symptoms will depend on whether you have ulcerative colitis or Crohn's disease and, in many cases, on the location of the disease in the gastrointestinal tract.

People with Crohn's disease and ulcerative colitis go through periods when the disease is quiet and few or no symptoms are present, alternating with times when it is active and causing symptoms. Medical treatment for IBD is aimed at bringing the conditions into a state of *remission* (no active disease or symptoms) and keeping it that way for as long as possible.

Medications control the inflammation, which relieves diarrhea and pain. Medications must be continued to maintain the remission. There is always the possibility, though, that the disease may flare up at times.

what can
cause a
flare?



What can cause a flare?

Crohn's disease and ulcerative colitis may flare up for no apparent reason. However, some possible triggers for recurrence of symptoms have been identified.

These include:

- Stress
- Lapses in taking medications/incorrect dosing of medications
- Recent use of certain medications, such as nonsteroidal anti-inflammatory drugs (NSAIDs) or antibiotics
- Eating certain foods
- Smoking

Stress or strong emotions

It is important to understand that physical and emotional stress does not cause IBD. However, stressful situations or strong emotions may lead to flare-ups of symptoms for some people with IBD. This doesn't mean that everyone who has stress will experience a flare, or even that people who are prone to having stress-related flares will always have this reaction to stress. Even some people without IBD may see a link between stress and their digestive tracts. But for those people

with IBD who know that stress can be problematic, it is helpful to be prepared for this reaction and to learn some stress-management techniques.

Stress is impossible to avoid in life. Changing jobs, getting married, moving, a death in the family, raising children, or caring for elderly parents can all cause stress, as can having a chronic illness like IBD. Even minor annoyances of life can be stressful. You can't completely eliminate stress-producing events, but it may be possible to change your reaction to them in ways that don't wreak havoc on your digestive tract. (See page 35 for some stress reduction techniques.)

Missed medications and incorrect dosing

People with IBD must take medications on a regular basis, even during times when the disease is in remission. This can be difficult to maintain over the long term, especially in the absence of active symptoms. While it is not uncommon to miss some medication doses, lapses in taking medications can lead to flares. If symptoms flare up after a period of not taking your prescribed medications, it is very important to be open with your physician about this, and discuss your medication choices and options.

Flares can also occur when medications are not taken exactly as prescribed. For example, skipping doses, doubling up on doses, or weaning off of medications such as steroids with or without your doctor's approval may contribute to a flare. If you believe your medication regimen needs to change, always speak with your doctor or other health care provider first.

Your health care provider will be monitoring your medication use to make sure you are receiving the best treatment to relieve symptoms. Therefore, it is extremely important to communicate to your health care provider any medication-related information. This includes disclosing all medications, including supplements, that you may be

taking, possible side effects, flares resulting from lapses in taking medications, as well as worsening of symptoms even when medications are taken as directed.

Nonsteroidal Anti-inflammatory and Antibiotic Drugs

Some commonly used medications may lead to flares. For example, nonsteroidal anti-inflammatory drugs (NSAIDs), which include aspirin, naproxen (Aleve®), and ibuprofen (Motrin®, Advil®, Nuprin®), are possible triggers for flares. For mild pain or to reduce a fever, take acetaminophen (Tylenol®) rather than an NSAID.

Antibiotics are good for treating bacterial infections, but they also alter the bacteria that normally live in the intestine. Changes in the balance of intestinal bacteria may cause diarrhea (antibiotic-associated diarrhea) or may lead to excessive growth of specific bacteria that can cause inflammation. For example, the bacteria *Clostridium difficile*, also called “*C. diff*,” is the cause of an inflammatory condition of the colon called pseudomembranous colitis.

If you are taking an antibiotic and experience a flare of your IBD symptoms, it is important to inform your health care provider. You should also inform your provider if you have recently taken antibiotics, even if for non-gastrointestinal infections.

Before considering any medications, either prescription or over-the-counter, talk to your health care provider. Also, be sure your other doctors and other health care providers consult your gastroenterologist before prescribing medications. In addition to possibly increasing the chance for flares, some medications may cause problems when taken along with your IBD medications.

Foods

IBD is not caused by eating any particular food. However, diet certainly can impact your symptoms. Once the disease has developed, you’ll

need to pay close attention to your diet and overall nutrition. Abdominal pain and fever can cause loss of appetite and weight loss. Diarrhea and rectal bleeding can rob the body of fluids, nutrients, and electrolytes. A well-balanced diet is necessary to prevent nutritional deficiency. In addition, some foods or beverages may irritate the digestive tract and cause symptoms.

No one type of food or beverage aggravates symptoms for all people with Crohn's disease or ulcerative colitis. Not everyone will experience diet-related flares, and not all flares are linked to diet. Therefore, each person with IBD will need to determine which foods tend to provoke symptoms and flare-ups. Keeping a food diary may help you to track how your diet relates to your symptoms. For a copy of a food journal, log on to the CCFA Community Web site, www.ccfacommunity.org, or call our Information Resource Center at **888.MY.GUT.PAIN** (888 694-8872).

In general, it is best to avoid greasy and fried foods, which can cause gas and diarrhea. Some people find that foods high in fiber, such as fresh fruits and vegetables and whole grains, can be problematic, especially when the intestines are inflamed. Rather than eliminating these necessary foods from your diet, it may be helpful to eat only thoroughly-cooked fruits and vegetables, and avoid eating them raw. You may also want to steer clear of foods that are likely to cause gas, such as beans, cabbage, broccoli, caffeine, and carbonated drinks. You'll need to keep track of these and other problematic foods. Eating smaller, more frequent meals may also be helpful in preventing flares caused by food.

Alcohol intake, whether moderate or in excess, can be associated with an IBD flare. Alcohol abstinence may not be required, but moderation is advised.

If a particular food causes problems, talk to your health care provider or dietitian before permanently eliminating it from your diet. You may

need to add a vitamin or mineral supplement to replace necessary nutrients. A registered dietitian can help you to plan a diet that works for you. If you do not have a trusted resource (such as a physician) for a dietitian recommendation, the Information Resource Center at info@ccfa.org can assist you with resources to help you locate a dietitian in your area.

Smoking

Smoking cigarettes not only raises the risk for developing Crohn's disease, it also can trigger flares. People with Crohn's disease who smoke tend to have more recurrences of their disease, more frequent need for surgery, and a greater need for immune-system-suppressing medications. Crohn's disease patients who have quit smoking report having fewer flare-ups and reduced need for medications to control the disease.

Ulcerative colitis tends to occur more in non-smokers and ex-smokers. In people with ulcerative colitis, smoking cessation can cause a flare of the disease because of this relationship. It is unclear why smoking may be protective. Smoking carries many health risks, including lung cancer and heart disease. Any protective effect against flares of ulcerative colitis is outweighed by other health risks.

Complications of IBD

A flare may be an uncomfortable but expected part of having IBD. But if a flare develops at an unusual time or brings symptoms that are not typical for you, it may also be a sign that a complication has developed. A change in medication or other treatment may be necessary.

Possible complications of ulcerative colitis include severe dehydration and anemia. People with Crohn's disease may develop a stricture, fistula, fissure, or abscess. These complications are discussed in greater detail in "Flares from Ulcerative Colitis" on page 11 and "Flares from Crohn's Disease" on page 17.

ulcerative colitis

Flares from ulcerative colitis

Both ulcerative colitis and Crohn's disease cause chronic inflammation in the digestive tract, but there are differences between these two diseases that impact disease flare-ups.

Unlike Crohn's disease, which can affect any part of the gastrointestinal tract, ulcerative colitis is limited to the large intestine (colon) and the rectum. The job of the colon is to absorb water and salts from the waste material of digestion (stool). This turns a loose, liquid stool into a formed stool that passes into the rectum. From there it is expelled in a bowel movement.

For people with ulcerative colitis, chronic inflammation in the outermost layer of the lining of the colon interferes with the ability to adequately absorb water, resulting in loose stools (diarrhea). Inflammation can also cause small sores (ulcers) to form in the colon and rectum. These can bleed, resulting in bloody stools. Blood loss can eventually lead to anemia if it proceeds unchecked. The ulcers can also produce pus, which can be passed in stool. Inflammation also causes the colon to empty frequently and/or urgently.

When inflammation is suppressed with medication the colon is better able to perform its job properly. Some people have remissions that last months or years. During times of remission, you may expe-

rience no symptoms at all, or you may have occasional diarrhea, cramping, nausea, and fever.

Symptom flare-ups result when inflammation becomes active again. The most common symptoms of a flare from ulcerative colitis are diarrhea, urgent need to have a bowel movement (many times per day), and bloody stools. Blood loss may lead to anemia, and anemia can make you feel extremely tired.

As noted above, ulcerative colitis can flare up at times for no apparent reason. Or, there may be specific triggers, such as stress, foods, medications, and the others described under “What can cause a flare?” (see page five). It is also possible that the symptoms suggest your medication is no longer working or that a complication has developed. Treatment may need to be changed—a new medication, or possibly surgery, may be required.

Medication Changes for Colitis Flares

Having flares may be a sign that a change in medication is needed. Several types of medications are available to control the inflammation of ulcerative colitis and maintain a state of remission. Drug therapy can also be used to address symptoms of a flare. The classes of medications used to treat ulcerative colitis include 5-aminosalicylic (5-ASA) drugs, corticosteroids, and immunosuppressive agents. Other supportive therapies may also be recommended by your doctor. (Please call our Information Resource Center at 888.MY.GUT.PAIN for in-depth literature about medications.)

In general, the first drug therapy to be prescribed for ulcerative colitis will be one of the 5-ASA drugs, such as sulfasalazine, mesalamine, olsalazine, or balsalazide. 5-ASA drugs are available in several forms, including pills, suppositories, and enemas. Many of these drugs are indicated for achieving and maintaining disease remission. The topical forms of the 5-ASA drugs (that is, suppositories and enemas) may be

prescribed if maintenance therapy does not adequately address flare symptoms.

If inflammation becomes active and is not controlled with the 5-ASA drugs, your doctor will likely prescribe a *corticosteroid*. Corticosteroids include prednisone, methylprednisone, and hydrocortisone. While corticosteroids are very effective at controlling inflammation, they can cause unwanted side effects if taken for long periods of time. Long-term effects of corticosteroids taken in moderate to high doses include weight gain, thinning of the bones, hypertension, diabetes, and increased risk of infection. Therefore, these drugs are often given for just a short period of time to bring the disease back into remission. This can be followed by a switch to a 5-ASA drug to maintain the remission.

If 5-ASA drugs and corticosteroids fail to quiet the inflammation and prevent flares, an *immunosuppressant* drug may be prescribed. Because the underlying cause of the inflammation in ulcerative colitis relates to a faulty response by the body's immune system, this treatment strategy takes aim at inflammation by suppressing the immune system. Immunosuppressant drugs include azathioprine and 6-mercaptopurine.

For moderate to severe ulcerative colitis, *biologic therapy* may be tried. Biologic therapies are the newest class of drugs to be used in ulcerative colitis. Biologics are genetically-engineered medications made from living organisms and their products, such as proteins, genes, and antibodies. Biologics interfere with the body's inflammatory response by targeting specific molecular players in the process such as *cytokines*—specialized proteins that play a role in increasing or decreasing inflammation. Unlike corticosteroids, which tend to suppress the entire immune system, biologic agents act selectively to suppress particular enzymes and proteins that have already been proven defective, deficient, or excessive in people with IBD.

Whatever your treatment regimen, notify your doctor if you notice that symptoms are becoming worse despite consistent adherence to your medication regimen. You may need a stronger dose of the drug, a more frequent dosing schedule, or a different medication.

If all of these types of drugs have been tried and symptoms persist, surgery to remove the colon may be recommended. The surgery cures ulcerative colitis for most patients. About 25 to 40 percent of people with ulcerative colitis will eventually have surgery, either because medical treatment is no longer working or to treat a complication of the disease.

Complications of Ulcerative Colitis

Certain conditions warrant immediate medical attention. These include heavy, persistent diarrhea, rectal bleeding with clots of blood in your stool, and constant pain and a high fever. In some cases, severe diarrhea or bleeding can cause dehydration. Hospitalization may be necessary to stop the diarrhea and replenish the body with blood, fluids, and minerals. It may be helpful to speak with your doctor to determine how to look for and become aware of these conditions that may require immediate medical care.

Another possible complication of ulcerative colitis is a *perforated bowel*. Chronic inflammation of the intestine may weaken the wall to such an extent that a hole develops. This is potentially life-threatening because the contents of the intestine can spill into the abdomen and cause a serious infection called “*peritonitis*.”

The most serious complication of ulcerative colitis is *toxic megacolon*. Severe inflammation can lead to rapid dilation (widening) of the colon. The colon becomes paralyzed, preventing the body from emptying the bowel. In severe cases, the colon can rupture.

Symptoms of toxic megacolon include pain, distention (swelling) of the abdomen, fever, rapid

heart rate, constipation, and dehydration. This potentially life-threatening complication requires immediate medical treatment. If toxic megacolon is suspected based on symptoms and a physical examination, the diagnosis will be confirmed with blood tests and an abdominal X-ray.

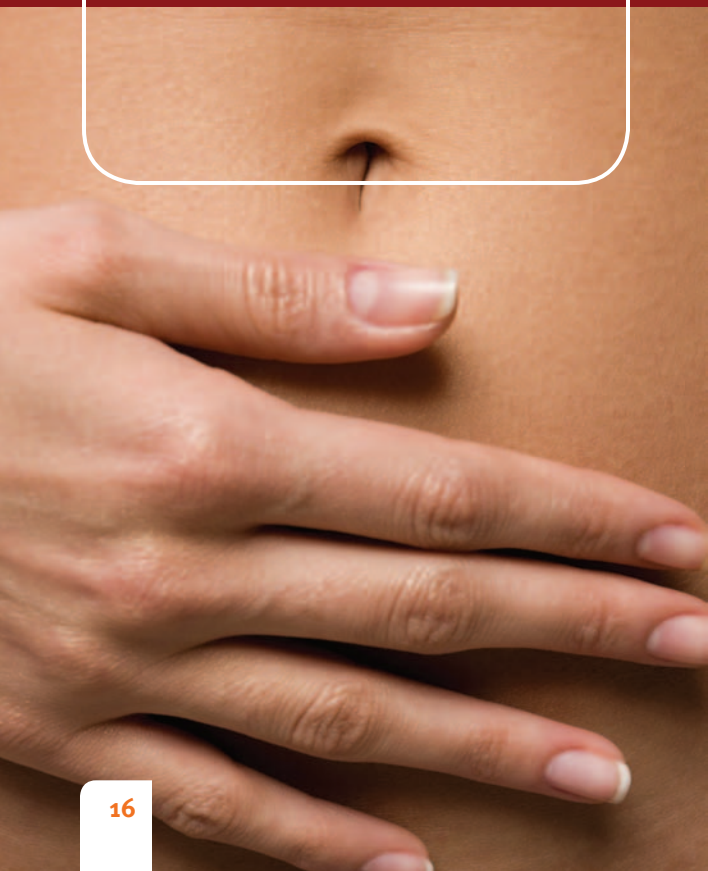
Medical intervention is aimed at controlling the inflammation and restoring fluid loss. In many cases, surgery to remove the colon (called a colectomy) will be required. Luckily, this condition is becoming more rare with improved management over the years.

In addition to the previously mentioned complications, ulcerative colitis patients are at an increased risk of colon cancer. For those with disease involving their entire colon, the risk for colon cancer starts to increase eight to ten years after disease onset. For those with disease restricted to the left colon, the risk begins to increase 15 years after disease onset. This risk applies to people with both active and inactive IBD. There does not appear to be an increased risk for those patients whose disease is confined to only the rectum.

A symptom like rectal bleeding, which is an early sign of colon cancer in the general population, is difficult to assess in people with IBD for whom this may indicate a flare-up rather than cancer. Because of the increased colon cancer risk, colonoscopies are generally recommended every one to two years beginning eight to ten years after diagnosis of IBD. How often a colonoscopy is recommended for each patient depends on the amount of colon affected and the length of time since disease onset.

Not all potential complications of ulcerative colitis are confined to the gastrointestinal tract. For reasons that are not entirely understood, some people develop symptoms that are related to the disease, but affect other parts of the body. Possible complications outside the large intestine include: arthritis (causing painful and stiff joints), osteoporosis, skin rash, anemia, and kidney stones.

crohn's disease



Flares from Crohn's disease

Like ulcerative colitis, Crohn's disease is marked by chronic inflammation. While ulcerative colitis is limited to the colon and rectum, Crohn's disease may affect any part of the gastrointestinal tract, including the small intestine, large intestine, stomach, or esophagus.

Chronic inflammation impairs the ability of the affected organs to function. It can cause the walls of digestive organs to thicken or form scar tissue, which can lead to blockages. Inflammation in the small intestine can interfere with the absorption of nutrients into the blood stream. Ulcers (sores) can form in the inside wall of the intestines or other organs. These ulcers can extend through the entire thickness of the bowel wall and form a tunnel to another part of the intestine, between the intestine and another organ, such as the bladder or vagina, or to the skin surface. These are called *fistulas*.

Common symptoms of Crohn's disease, as well as symptoms of flare-ups, include abdominal pain, diarrhea, urgent need to defecate, loss of appetite, fever, and weight loss. These will vary depending on the location of the disease. The following are five types of Crohn's disease:

- **Gastroduodenal Crohn's disease** affects the stomach and first part of the small intestine (*duodenum*). Symptoms include loss of appetite, weight loss, and nausea. Vomiting may indicate that narrowed segments of the bowel are obstructed.
- **Jejunoleitis** produces patchy areas of inflammation in the upper half of the small intestine (*jejunum*). Symptoms include abdominal pain, ranging from mild to intense, and cramps following meals, as well as diarrhea. Fistulas may also form.
- **Ileitis** affects the ileum only. Symptoms are the same as for ileocolitis (see below). Complications may include an inflammatory abscess in the right lower quadrant of the abdomen, or fistulas.
- **Ileocolitis** (the most common form of Crohn's disease) affects the lower part of the small intestine (*ileum*) and colon. Symptoms include diarrhea and cramping or pain in the right lower part or middle of the abdomen. It often is accompanied by significant weight loss.
- **Crohn's colitis** affects the colon only. Symptoms include diarrhea, rectal bleeding, and disease around the anus (abscess, fistulas, or ulcers). Skin lesions and joint pains are more common in this form of Crohn's than in others.

Medical treatment for Crohn's disease can bring about remission, which can last for months to years. But the disease will flare up at times from the resurgence of inflammation, or from one of the triggers discussed under "What can Cause a Flare?" (see page five).

A disease flare-up may also occur from a complication, such as a fissure, fistula, stricture, or abscess.

- A **fissure** is a tear in the lining of the anus, which may cause pain and bleeding, especially during bowel movements. These often occur as a result of having frequent bowel movements.
- **Fistulas** occur most commonly around the anal area. If this occurs, you may notice drainage of mucus or stool from the anus or from an area adjacent to the anus. Fistulas can become infected.
- A **stricture** is a narrowing of a section of intestine caused by scarring. This can lead to an intestinal blockage. Nausea and vomiting or constipation may be a sign of a stricture.
- An **abscess** is a collection of pus. It can lead to symptoms of severe pain in the abdomen, painful bowel movements, discharge of pus from the rectum, fever, and a lump at the edge of the anus that is swollen, red, and tender.

As with ulcerative colitis, some possible complications of Crohn's disease occur outside the digestive tract. These include:

- Arthritis
- Kidney stones
- Gallstones
- Inflammation of the eyes and mouth
- Skin rashes
- Liver disease

Medication Changes for Crohn's Flares

Flare-ups of Crohn's disease may indicate that a change in medication dose, frequency, or type is needed. Some of the medications used for Crohn's disease are the same as those used for ulcerative colitis. They are aimed at controlling inflammation and maintaining a state of remission. Drug therapy can also be used to address symptoms of a flare. (Please call our Information Resource Center at 888.MY.GUT.PAIN for in-depth literature about medications.)

There are several families of medications used for Crohn's disease. *Aminosalicylates* are aspirin-like compounds that contain 5-aminosalicylic acid (5-ASA) and include sulfasalazine, mesalamine, olsalazine, and balsalazide. These medications, which can be given either orally or rectally, alter the body's ability to start and maintain an inflammatory process. They are effective in treating mild-to-moderate episodes of IBD.



Corticosteroids, such as prednisone, methylprednisone, and hydrocortisone, are also used. *Immunosuppressant* drugs include azathioprine, 6-mercaptopurine, and methotrexate. Finally, the newest therapies are *biologics* such as anti-tumor necrosis factor agents (infliximab, adalimumab, certolizumab-pegol) and anti-adhesion molecule therapies (natalizumab).

Other drugs that may be used for Crohn's disease include antibiotics, anti-diarrheal medications, and fluid replacement therapy.

Antibiotics, such as ciprofloxacin (Cipro®, Proquin®) and metronidazole (Flagyl®), may be used to treat a fistula, or abscess. For short-term relief of diarrhea, anti-diarrheal medications, such as loperamide (Imodium®), can be helpful. Fluid replacement may be necessary if diarrhea causes dehydration. Malnutrition may be treated with nutritional supplements.

support



Flare management

Experiencing flare-ups of your disease can be upsetting and confusing.

Remember that the management of your disease is a partnership among yourself, your doctor, your loved ones, perhaps a dietitian, and other health care providers.

Your health care provider is monitoring your condition. Therefore, it is important to stay in close communication with them. You should call them any time you have questions or concerns about symptoms or treatment.

During times of remission, you will probably visit your doctor about every six months, and more often during times of flare-ups. At these visits, your doctor will make sure your medication regimen is providing the highest level of symptom relief. He or she may also order tests to reveal the source of any new or troubling symptoms. During these visits, or when you communicate with your doctor, be sure to discuss your bowel frequency, discomfort, and other symptoms to make sure they are being addressed.

If symptoms are mild or routine—such as occurring after eating a food you know will cause a reaction—you may not need to speak to your doctor urgently. You may be able to manage the effects of the disease through changes in diet, use of stress-management techniques, or with help from friends, relatives, or a support group. Always contact your doctor if you think a change in medication may be needed. Do not attempt to alter medication doses or frequency of dosing on your own, as this may lead to a worsening of symptoms.

special populations



Special populations

Pregnancy and Flares

Women who wish to become pregnant may be concerned about how their disease will impact pregnancy, as well as how pregnancy will affect their condition. Having IBD does not necessarily affect the ability to have children. With the careful supervision of both a gastroenterologist and obstetrician, most women with IBD can have a healthy pregnancy and healthy baby. But there are some important considerations, particularly in relation to flares of Crohn's or colitis.

Typically, the best time to become pregnant is during a period of disease remission. Conceiving during a flare-up is not advised. About 70 percent of women with either Crohn's disease or ulcerative colitis who become pregnant while the disease is in remission will remain in remission during pregnancy. Most studies show that women who stay in remission throughout their pregnancy have no increased risk for pregnancy-related complications, miscarriage, or having a child with abnormalities.

If conception occurs during a flare-up, the disease is more likely to remain active throughout the pregnancy. For 50 to 70 percent of women with ulcerative colitis who become pregnant during a flare-up, the disease becomes chronically active or becomes worse during pregnancy. Among women with Crohn's disease, one-third of those who become pregnant during active disease will achieve remission, one-third will have chronically active disease, and one-third will have worsening of the disease.

In addition, if conception occurs during an active disease phase, the risk is greater for problems such as miscarriage, premature delivery, or having a baby with low birth weight. The risk appears to be somewhat greater for women with Crohn's disease than ulcerative colitis.

To maintain a state of remission and prevent flares during pregnancy, it is important to continue taking prescribed medications. Many IBD medications have been shown to cause minimal risk to the pregnancy. For some IBD medications, not enough information is available about risk during pregnancy, and at least two drugs (methotrexate and thalidomide) should not be taken while pregnant. It is also important to note that sulfasalazine in men decreases sperm count and therefore may cause infertility. A man taking this medication should talk with his doctor about switching to another 5-ASA therapy if planning for a child.

If you are pregnant or planning to become pregnant, it is extremely important to review all medications with your physician.

Children and Flares

Understanding and coping with IBD flares is difficult for many adults, but it can be especially problematic for children and adolescents. Parents face a challenging task when helping their children come to terms with their illness and adapt to a situation that sets them apart from their peers.

The peak age of IBD onset is adolescence and young adulthood. Adolescence is a time when we seek to become more independent and self-sufficient. This often leads to rebelliousness. A chronic illness like Crohn's disease or ulcerative colitis imposes a need for a certain amount of dependency on family and health care providers, and teenagers may have a tendency to resist. They may be in denial about the disease and may not take medications consistently.

Children and adolescents may suffer from depression or anxiety as a result of their disease. Emotional support from a counselor or psychologist may help to ease the burden. A support group may be particularly helpful, especially if teenagers can interact with other teens who have IBD. This may help to alleviate some of the peer-related stresses of having the disease.

Practically speaking, children and adolescents need help from parents and health care professionals to understand how to manage flare-ups of their condition. It is also important to advise teachers and the school nurse about the disease, to ensure the child has adequate bathroom access, and that authorities are prepared to deal with issues that arise.

The same IBD medications that are used to maintain remission and manage flares in adults are used in children. But some of these medications have special considerations when taken by children, mostly related to potential side effects. For example, prednisone can cause physically and emotionally disturbing side effects in children, including acne, puffy faces, weight gain, and growth impairment. These can usually be minimized by discussing with the doctor a reduction in the dose of the medication.

Special consideration must be given to younger children who are unable to swallow tablets or capsules. Although a commercially available form of liquid sulfasalazine is no longer available, many pharmacies will formulate one if requested. Additionally, capsules may be opened and the contents placed in yogurt, peanut butter, or other appropriate food.

Discuss all medications prescribed for your child, including possible side effects, with your child's physician and other health care providers.

ask your
doctor



Questions for your doctor

Crohn's disease and ulcerative colitis are complex conditions. At the time of a flare, you may be overwhelmed and forget to ask critical questions of your doctor. To help you to get the most of this interaction, CCFA has compiled a list of questions you might want to ask at the time of a flare:

- Could any condition other than my disease be causing my symptoms?
- What tests do I need to take to get to the root of my symptoms?
- How often should I get these tests done? Should it be during the time of a flare-up or on a routine basis?
- What parts of my digestive system are affected?
- How will we know if my medication needs to be adjusted?



- What is an estimated period of time that I should see some results, or be cautioned that it may not be the right medication for my case?
- 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 see you 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 symptoms or degree of symptoms would show that I should schedule an appointment with you sooner?
- What should I do if I experience pain, bleeding, or other issues?

diet & lifestyle



Take care to prevent flares

You can't completely prevent flare-ups of ulcerative colitis or Crohn's disease. But you may be able to reduce the number or severity of flares and lengthen the time spent in remission by adopting some healthy habits.

- **Take all IBD medications regularly**, as directed by your doctor.
- **Eat a well-balanced diet.** There is no universal diet for all people with IBD, because each person will have unique needs. Nevertheless, proper nutrition is an essential part of staying healthy and minimizing the effects of the diseases.

Everyone with IBD will benefit from a diet that provides the recommended number of calories and contains essential vitamins, minerals, and other nutrients. At the same time, you should avoid foods that trigger symptoms. Because dietary issues differ from person to person, you may want to get individualized help and instruction from a registered dietitian.

- Because ulcerative colitis and Crohn's disease can impair the body's ability to absorb vitamins, minerals, and other nutrients, **consider taking a multi-vitamin or mineral supplement.** As always, be sure you consult your doctor about which are recommended (and safe) for you to take.
- **A regular exercise routine** can improve overall health, and may be particularly beneficial for people with IBD. Engaging in regular physical activity can reduce stress and maintain and improve bone strength. Some research has also shown that it relieves depression and boosts the body's immune system response.

If having IBD limits the amount and intensity of exercise you can undertake, keep in mind that even low-intensity activities, like taking a 30-minute walk three times a week, can produce results. Talk to your doctor to determine an exercise program that works for you. If your symptoms make mobility difficult, find ways to be active at home.

- **If you smoke, quit.** Smoking is harmful for many reasons, and it can worsen symptoms of IBD. Quitting smoking has been suspected of triggering the onset of ulcerative colitis or a flare in certain cases. However, with the multiple choices in medications, continued smoking is not usually recommended. The benefits of quitting smoking likely outweigh any potential colitis-related risks.

- Stress is a common trigger for symptom flare-ups. Of course, avoiding all stress is impossible. In fact, focusing too heavily on stress can cause an anxiety response which has a tendency to aggravate symptoms, and cause even more stress.

Stress reduction techniques can help you to stay calm, maintain perspective, and break this anxiety cycle. There are numerous stress-management techniques, and no one method has been proven to be more effective than another for everyone. Each person needs to find their own healthy balance. Try an approach that appeals to you; if that doesn't work, don't despair. Try another. Here are some techniques for managing stress:

- Biofeedback
- Relaxation and breathing exercises
- Practicing yoga or tai chi
- Hypnotherapy
- Cognitive behavioral therapy
- Meditation
- Books, recordings, guided imagery, etc.

what you
can do



Managing symptom discomfort

- To reduce anal irritation, use a moist towelette or wipe instead of bathroom tissue.
- Practice good anal hygiene by showering with a hand shower or using a perianal cleansing product (Balneol®).
- Apply an all-purpose skin protectorant (Vitamin A&D® ointment, Desitin®) at night to relieve irritation of the skin around the anus.
- For anal soreness or painful bowel movements due to an anal fissure or fistula, bathe your buttocks in warm salt water.
- To help manage diarrhea, anti-diarrheal medications, such as Imodium® or large amounts of Pepto-Bismol®, may be effective. Never take any of these drugs without consulting your health care provider.
- For joint-related discomfort, doctors may recommend resting the affected joint as well as the occasional use of moist heat. Range-of-motion exercises, as demonstrated by a physical therapist, may also be helpful.
- To reduce the irritation of small mouth ulcers (also known as canker sores), medicinal mouth washes may be helpful, along with a balanced diet and a multi-vitamin/mineral supplement.
- To help manage the symptoms of pain, experts state acetaminophen (Tylenol®) may be the safest option for IBD patients. Consult with your health care provider about the appropriate pain management options.
- Remember to take care of yourself. Get plenty of sleep, eat well, and take time to recharge and reduce stress when you need it.

plan
ahead



Coping with flares

There is no escaping the reality that having Crohn's disease or ulcerative colitis requires coping strategies. Having a chronic disease that affects bowel function can impact many areas of your life beyond the practical symptomatic issues.

Difficulties may arise in your personal relationships, work, ability to travel, or sense of independence. It is not uncommon to develop strong emotions about the disease. You may be angry, fearful, or uncertain. You may wonder how your body can betray you by making you lose control over such a basic function as bowel movement. You may feel embarrassment, or become apprehensive about leaving home.

While it is possible to go about your normal daily life with IBD, especially during times of remission, the disease is ever present. You'll need to find ways to handle the symptoms when the disease flares up. You'll also need to deal with your feelings about it. And you will need to be attentive to your body's needs—even during remission.

It is important not to let the fear of embarrassment (like having diarrhea at inconvenient times) overtake your life. You may be inclined to stay home rather than risk an “accident” in public. But there are some practical steps you can take to ease your mind.

- **Put together an emergency kit.** This might include spare underwear and an extra pair of pants, a packet of baby wipes, toilet tissue, panty liners, and deodorizer. Even if you never need to use these supplies, just knowing they are there in case of an emergency may free your mind and allow you to engage more fully in life.
- **Obtain a “Can’t Wait” card from CCFA.** If you find yourself in a situation where there is no public rest room, you can use this card, available with CCFA membership, to gain access to any available bathroom, such as the staff toilet in a store. To become a CCFA member, call 800.932.2423.
- When you leave home, **plan your itinerary in advance** and learn where the rest rooms are located in restaurants, shopping areas, and on public transportation. Knowing where the bathrooms are can ease anxiety and reduce stress. The Information Resource Center at CCFA has resources to help locate public bathrooms throughout the U.S., as well as countries abroad.
- Be sure **a trusted friend or co-worker is aware of your issues** and can be called upon for help in case of a difficult or embarrassing situation.
- Symptoms of Crohn’s disease may be more active at certain times of the day. For example, you may find that you need to stay close to a bathroom after getting up in the morning, or in the evening after eating. **Knowing when your symptoms are likely to occur** can help you to organize your daily routines to accommodate your bathroom needs.

- **Fatigue** can be another symptom of a flare. It may be manageable or it may be debilitating. Those who suffer from severe fatigue will need to find ways to **manage their energy**. For example, know your limitations and take naps when needed. If you must attend a function, set aside time before or after the event to rest. Your doctor may recommend specific vitamins to help with energy. Each person who experiences IBD-related fatigue will need to develop their own strategies for managing their energy to accomplish daily tasks.
- **Create a support network** of people who can be called upon to help out during difficult times. These people should understand the occasionally serious nature of your disease and be ready to take you to the hospital or doctor if necessary. They may also be called upon to take care of tasks you are temporarily unable to handle, such as child care, grocery shopping, and others.
- **Speak with your employer** about the Family Medical Leave Act (FMLA) in the event you need to take unpaid medical leave from work.
- **Ensure educational equity** by securing reasonable accommodation as needed for elementary, secondary, and post-secondary school students.

Although it may be difficult and even embarrassing to talk about a health condition that causes diarrhea, consider discussing your illness with your friends and possibly your work colleagues or boss. How open you want to be and how much you want to explain is a personal decision. But some sort of disclosure may make life easier, especially during times when your disease flares up. If you must cancel social engagements, your friends are less likely to feel insulted if they understand what's happening. If they know why you keep running to the bathroom, you don't have to feel embarrassed.

Crohn's disease and ulcerative colitis can take a toll, both physically and emotionally, and you will need to attend to both. The emotional needs surrounding a chronic illness differ from person to person. Most people find it helpful to have support from people they are close to. Support from people who share the same disease, or possibly from a mental health professional, may also be of help.

Support groups can be especially helpful. Probably 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 can also be a great source of information. Local chapters of CCFA offer support groups as well as informational meetings. To locate your local chapter, go online to www.ccfa.org/chapters or call the Information Resource Center at CCFA.

CCFA also has a free online community where you can share your story with others and participate in discussion boards. You can join the community at www.ccfacommunity.org.

Kids and teens can find specialized online information and support at www.UCandCrohns.org.

Your doctor or dietitian may also point you in the direction of support groups or local resources. If the burden of the disease overwhelms you emotionally, consider consulting with a social worker or psychologist. Depression is not uncommon among people with any chronic illness, including IBD. A mental health professional can help you to gain perspective and feel like you can regain control over your life.

Flare tracker

Improving Quality of Life:

CCFA has established a range of educational brochures, fact sheets, and helpful tools, such as the enclosed Flare Tracker, and other programs designed to increase awareness about these digestive diseases. We know living with Crohn's or colitis can be difficult, but the right resources and support can make day-to-day living more tolerable. That's why CCFA has developed a comprehensive, free online community (www.ccfacommunity.org) to provide the support individuals need in managing their condition.

We recognize the importance of distributing unbiased, accurate, and authoritative information in order to provide education of the finest quality. One avenue used to accomplish this is the Information Resource Center (IRC). Through a toll-free number (1-888-MY-GUT-PAIN), e-mail, or live chat on our Web site (www.ccfa.org), professionals are trained to answer questions and direct people to resources important to their quality of life.

Flare Symptoms Tracker

This log has been created to help you keep track of your symptoms and the level of severity on a daily basis. Fill out the chart below and bring the completed charts to your next doctor's visit. You may want to make extra copies for future use. It is also recommended to have this tracker available for emergency hospital visits. Provided is a sample flare tracker and a blank flare tracker for your records. Please note we have provided general guidelines in the sample, it will be utilized differently according to the individual.

Date	Symptom(s)/General Well-being	Description	Level of Intensity*	Report to Doc or Nurse? (Action for Each Flare)
01/01/09	Stomach Pain 1=None at all; 10=Extreme	Cramping on the left side.	5	Left a message with the nurse.
	Diarrhea 1=None at all; 10=Extreme	Loose, watery, mucous involved; occurs after each meal.	7	Visited the doctor; he/she increased my medication dosage.
	Bowel Movements (number of bowel movements)	Two bowel movements with blood or six bowel movements without blood.	8	
	Fatigue Level 1=None at all; 10=Extreme	Extremely tired all day.	9	
	Stress Level 1=None at all; 10=Extreme	Stressed about upcoming exam.	9	
	Other Symptom(s)			
	Other Symptom(s)			
	Other Symptom(s)			
	Other Symptom(s)			

*Please refer to the scales provided in the Symptom(s)/General Well-Being column.

Flare Symptoms Tracker

[illegible]

Notes:

[illegible]

You Can Help

Founded in 1967, the Crohn's & Colitis Foundation of America (CCFA) is a non-profit, volunteer-driven organization dedicated to finding a cure for Crohn's disease and ulcerative colitis. Today, the organization has grown to 40 local chapters, with more than \$136 million raised and invested in research for a cure and improved treatments. This funding has enabled many ground breaking treatments, improved the quality of care for individuals with these conditions, and brought hope to countless lives. But there's still plenty of work left to do.

To learn how you can help,
please contact us at:

800.932.2423 or
info@ccfa.org



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

4/09

