



**CROHN'S
& COLITIS**
FOUNDATION

Managing Flares and IBD Symptoms



What's Inside

What is a flare?	2
Factors that may affect flares and how to avoid them	3
Missed medications and incorrect dosing.....	3
Non-steroidal anti-inflammatory drugs (NSAIDs)	3
Antibiotics	4
Smoking	4
Stress.....	4
Food	5
Treating flares	6
What will your doctor do to treat your flare?	6
Managing flares	7
Managing symptom discomfort	9
Questions for your doctor	10
IBD flares in children	12
Coping with flares	13
Talking with others	15
Complications	16
Knowledge and support are power!	16

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Having an inflammatory bowel disease (IBD) often means living with 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 Crohn's disease and ulcerative colitis, also known as IBD. Even with medical treatment, a person with IBD is likely to experience periods of time when symptoms become active.

This brochure will help you manage your life with a disease that can at times be painful, uncomfortable, inconvenient, or embarrassing.

For more information on IBD symptoms, medications, diet, surgery, or disease management, please visit the Crohn's & Colitis Foundation's website at www.crohnscolitisfoundation.org.

What is a flare?

A flare is the reappearance of disease symptoms. The most common symptoms of Crohn's disease and ulcerative colitis are:

- Frequent and/or urgent bowel movements
- Diarrhea
- Bloody stool
- Abdominal pain
- Nausea and vomiting
- Weight loss

People may also report symptoms such as fatigue, lack of appetite, joint aches, body aches, rashes, and eye problems, including pain, redness, or loss of vision. The symptoms of IBD vary from person to person, and may change over time. Your specific symptoms will depend on whether you have Crohn's disease or ulcerative colitis and, in many cases, on the location of the disease within your gastrointestinal (GI) tract.

Crohn's disease and ulcerative colitis are characterized by times of active disease (when symptoms are present) and times of remission (when little or no symptoms are present). Medical treatment is aimed at bringing the conditions into a state of remission and keeping it that way for as long as possible.



Colonoscopy pictures courtesy of Raluca Vrabie, MD

Factors that may affect flares and how to avoid them

There are several factors that may impact a flare and/or make symptoms worse, including:

- Missing IBD medications or taking the incorrect dose
- Non-steroidal anti-inflammatory drugs (NSAIDs)
- Antibiotics
- Smoking
- Stress
- Food

Missed medications and incorrect dosing

Many people with IBD take medications on a regular basis, even when the disease is in remission. Flares can occur when medications are not taken as prescribed (for example, skipping doses, weaning off medications). If you are taking your medications as prescribed and still experiencing flares, speak with your doctor. Your doctor may suggest changing the dose, frequency or type of medication. If you have missed doses of your medications or have stopped your medications and are now experiencing symptoms, talk with your doctor before restarting or increasing your medications on your own.

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs, which include aspirin, naproxen (Aleve®), and ibuprofen (Motrin®, Advil®, Nuprin®), may lead to inflammation of the bowel and make symptoms worse. Therefore, for mild pain or to

reduce a fever, it is generally recommended that people with IBD take acetaminophen (Tylenol®) rather than an NSAID.

Antibiotics

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 (for example, antibiotic-associated diarrhea) or may lead to excessive growth of specific bacteria that can cause inflammation. If you are taking an antibiotic and experience a flare of your IBD symptoms, it is important to inform your doctor.

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 disease activity, more surgery, and a greater need for medications to control their disease. Crohn's disease patients who have quit smoking report having fewer flare-ups and a reduced need for medications to control their disease.

Surprisingly, the risk of developing ulcerative colitis is decreased in current smokers compared with people who have never smoked. The numerous potential harmful health effects of smoking (e.g., cancer, heart disease) largely outweigh any benefits of smoking for people with ulcerative colitis.

Stress

It is important to understand that physical and emotional stress do not cause IBD. However, stressful situations or strong emotions may impact IBD symptoms. For those people with IBD who know that stress can be problematic, it may be helpful to be prepared for this reaction and to learn some stress-management techniques. See page 9 for stress reduction techniques.

Food

Although diet does not cause or cure IBD, paying attention to your diet may help you reduce symptoms, replace lost nutrients, and promote healing. However, no one type of food or beverage aggravates symptoms for all people with Crohn's disease or ulcerative colitis. Therefore, each person with IBD will need to determine which foods impact symptoms and which do not. Keeping a food journal may help you track how your diet relates to your symptoms.

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 general, when experiencing a flare, 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 fruits, vegetables and whole grains, can be problematic. Rather than eliminating these necessary foods from your diet, it may be helpful to eat only thoroughly-cooked fruits and vegetables. You may also want to avoid foods that are likely to cause gas, such as beans, cabbage, broccoli, caffeine, and carbonated drinks. Eating smaller, more frequent meals may be helpful.

Alcohol intake, whether moderate or in excess, may also make symptoms worse. Alcohol abstinence may not be required, but moderation is advised.

If you find that particular foods affect your IBD symptoms, talk to your doctor or dietitian. A registered dietitian can help you to plan a diet that works for you. If you need resources to help you find a dietitian, contact the Foundation's IBD Help Center at info@crohnscolitisfoundation.org.

For more information about diet and nutrition, please read our Diet and Nutrition brochure available at www.crohnscolitisfoundation.org.

Treating flares

What will your doctor do to treat your flare?

Often the first step is for your doctor to do some testing to find out if your flare is due to inflammation in the intestine or something else (infection, scar tissue, medication side effect). Your doctor may recommend blood work, stool testing, colonoscopy/upper endoscopy, or a CT scan, MRI or x-ray to find out why you have developed new symptoms.

Having disease flares may be a sign that a change in medication is needed. Your doctor may recommend the following:

- **Corticosteroids**, which have anti-inflammatory properties, can be used in the short term to get you back into remission (little to no disease activity). Repeated and long-term use of steroids is not ideal disease management, and typically means that your current medication is not working and that a new therapy should be tried.



- **Check drug levels** to see if you have developed antibodies (resistance) to your medication.
- **Medication changes**, which can include increasing current medication dosage, adding another medication to your regimen, or switching your medication entirely.

For a current, up-to-date list of all FDA-approved medications for Crohn's disease and ulcerative colitis, please visit the Foundation's online IBD Medication guide:

www.ibdmedicationguide.org. Additional information is available in our *Understanding IBD Medications and Side Effects* brochure at www.crohnscolitisfoundation.org.

Managing flares

You cannot completely prevent flare-ups of Crohn's disease or ulcerative colitis. However, in addition to taking your medications regularly and eating a well balanced diet, the following tips are recommended to help you manage your disease during flares and remission:

- **See your doctor regularly.** Remember that the management of your disease is a partnership between yourself and your healthcare team. Therefore, it is important to stay in close communication with them. During times of remission, you will probably visit your doctor every six months. During times of flares, you may visit more often. You should contact your doctor any time you have questions or concerns about symptoms or treatment.
- **Follow recommended guidelines for IBD-related tests and procedures.** With proper treatment and disease monitoring, you will maximize your chances for good health, decrease the likelihood of missing signs of additional disease, and identify possible side effects of treatment. Ask your

doctor how often you should get IBD-related tests and procedures (e.g., colonoscopies, routine blood work, etc.).

- **Monitor and track your disease.** It is important to track your disease between medical appointments so that you and your doctor can see how IBD is impacting your life and determine if any changes need to be made. The Crohn's & Colitis Foundation has a Symptom Tracker that you can find on the Foundation's website to track your symptoms and jot down questions for your next provider visit.
- **Consider taking a multi-vitamin or mineral supplement.** Because Crohn's disease and ulcerative colitis can impair the body's ability to absorb vitamins, minerals, and other nutrients, it is important to get tested for vitamin and mineral deficiencies. As always, be sure to consult your doctor about which supplements are recommended (and safe) for you to take.
- **Exercise.** 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/or improve bone strength. Some research has also shown that exercise relieves depression and boosts the body's immune system. 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.
- **Quit smoking.** Smoking can make the symptoms of IBD worse and can make it more difficult to treat.
- **Reduce your stress.** Stress reduction techniques can help you to stay calm and maintain perspective. There are numerous stress-



management techniques—no one method has proven more effective than another. 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 frequently used techniques for managing stress:

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

Managing symptom discomfort

When symptoms are flaring, you may experience a variety of uncomfortable or painful symptoms. Here are some tips to help you cope with the discomfort:

- Practice good anal hygiene by showering with a hand shower or using a perianal cleansing product (Balneol®).

- To reduce anal irritation, use a moist towelette/wipe instead of bathroom tissue.
- Apply an all-purpose skin protectant (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 in warm salt water or use a sitz bath.
- To help manage diarrhea, anti-diarrheal medications, such as Imodium[®] or Pepto-Bismol[®], may be effective. However, 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 multivitamin/mineral supplement.
- To help manage the symptoms of pain, experts recommend acetaminophen (Tylenol[®]) as the safest option for IBD patients. Consult with your healthcare 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.

Questions for your doctor

Crohn's disease and ulcerative colitis are complex conditions. During a flare, you may be overwhelmed and forget to ask critical questions of your doctor. To help you get the most out of your doctor visit, the Crohn's & Colitis Foundation 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?
- When should I expect to see results?
- What are the potential side effects of the medication? What should I do if I notice them?
- What should I do if the symptoms return?
- If I cannot see my doctor right away, are there any over-the-counter medication options that can assist with my prescribed medication? If so, which ones?
- What symptoms are considered an emergency?
- How will I know if I need a different medication?

- Should I change my diet or take nutritional supplements? If so, can my doctor 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?

IBD flares in children

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.

Children and adolescents may suffer from depression or anxiety as a result of their disease. Emotional support from a counselor, psychologist, or support group may help.

It is also important to advise teachers and the school nurse about the disease, to ensure your child has adequate bathroom access, and that his/her teachers and school administrators are prepared to deal with issues that arise.



Many of the same IBD medications used in adults are used in children. But some of these medications have special considerations when taken by children, mostly related to potential side effects. Discuss all medications prescribed for your child, including possible side effects, with your child's physician and other healthcare providers.

Kids and teens can find information and support by visiting www.justlikemeIBD.org and www.crohnscolitisfoundation.org/campus-connection/.

Coping with flares

Having Crohn's disease or ulcerative colitis impact much more than just your physical health - it can also have a profound impact on your mental health and emotional wellbeing. Finding strategies to help you cope with daily life with your disease is essential.

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, uncertain, or anxious. You may wonder how your body can betray you by making you lose control over such a basic function as a bowel movement. You may feel embarrassment, or become apprehensive about leaving home.

It is important not to let your fears and worries overtake your life. There are some practical steps you can take to ease your mind:

- **Put together an emergency kit.** This might include spare underwear, 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 may free your mind and allow you to engage more fully in life.

- **Obtain an “I Can’t Wait” card from the Crohn’s & Colitis Foundation.** This card, available with Foundation membership, may provide help when asking to use public restrooms. To become a 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. A bathroom location app on your phone can help you find bathrooms in the area.
- 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 IBD 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 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.
- **Create a support network** of people who can be called upon to help out during difficult times. These people should understand the 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 childcare, grocery shopping, and others.

- **Speak with your employer** about the Family Medical Leave Act in the event you need to take unpaid medical leave from work or need accommodations in the workplace.
- **Ensure educational equity** for your child by securing reasonable accommodation as needed for elementary, secondary, and post-secondary school students. Talk to the school's guidance counselor and make him/her aware of your child's needs. For information on school accommodation (504) plans visit www.crohnscolitisfoundation.org.

Talking with others

We know that it can be difficult and even embarrassing to talk about having IBD, but sharing what you're going through is important to help you create a support network. You may want to consider discussing your illness with your friends and family, and, possibly, your work colleagues or boss. How open you want to be and how much you want to explain is up to you and what you are comfortable with. Some sort of disclosure may make life easier, especially during times when your disease flares up.





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 others.

If you are feeling overwhelmed emotionally by your IBD, there are mental health professionals, such as psychologists or social workers, who can help. Feeling worried, sad, or isolated is not uncommon in people living with a chronic illness like IBD. A mental health professional may help you process your emotions, gain new perspectives, and ease the social and emotional burdens of IBD.

Complications

Certain conditions require immediate medical attention. These include:

- inability to hold down liquids from nausea, vomiting, or pain
- rectal bleeding with clots of blood in your stool
- constant pain
- high fever (above 100.3° F)

Speak with your doctor about these conditions so that you know what to look for and can respond accordingly.

Knowledge and support are power!

Find the answers you need to help control your IBD by joining the Crohn's & Colitis Foundation:

- **Local Education and Support Programs**

The Foundation has chapters across the country covering all 50 states. Visit our website at www.crohnscolitisfoundation.org to find local programs, support groups, and events.

- **Power of Two**

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

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

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

- **Crohn's & Colitis Foundation Online Community**

The Foundation hosts a free website where patients can get the support they need in managing their condition. They'll participate in discussion boards, share or read personal stories, and much more.

The Crohn's & Colitis Community is waiting for people just like you. Join today at www.crohnscolitiscommunity.org.

- **I'll Be Determined**

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



- **Camp Oasis**

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

- **Membership**

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

- » News, educational programs, and supportive services from your local chapter
- » An "I can't wait" card (may provide help when asking to use a public restroom)
- » A chance to contribute to research to find a cure for these challenging diseases

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



- **spin4 crohn's & colitis cures**

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



- **Take Steps** is the Crohn's & Colitis Foundation's national walk program. Take Steps enables patients and families to raise money for crucial research and to build awareness about Crohn's disease and ulcerative colitis. Visit www.cctakesteps.org for more information.



- **Team Challenge**

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

About the Crohn's & Colitis Foundation

Established in 1967, the Crohn's & Colitis Foundation is the leading non-profit organization focused on both research and patient support for inflammatory bowel diseases (IBD). The Foundation's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life for the estimated 3 million Americans living with IBD.

For over 50 years, we have been inspiring and engaging patients and caregivers in the country's largest IBD community, and helping to dramatically accelerate the pace of research by breaking down traditional barriers to patients, data, funding, and collaborations. We also provide extensive educational resources for patients and their families, medical professionals, and the public.

We can help! Contact us at:

888-MY-GUT-PAIN

(888-694-8872)

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