

FREQUENTLY ASKED QUESTIONS ABOUT INFLAMMATORY BOWEL DISEASE

Find answers below to commonly asked questions about Inflammatory Bowel Disease.

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Q: *What is Inflammatory Bowel Disease (IBD)?*

A: There are the two main types of inflammatory bowel disease (IBD), Crohn's disease and ulcerative colitis. Ulcerative colitis can cause inflammation and ulcers in the large intestine and rectum. Crohn's disease can cause inflammation in any part of the gastrointestinal track. It most commonly occurs in both the small intestine and colon. Symptoms of these long term diseases may range from mild to severe and may include, but not are not limited to, ongoing diarrhea (loose, watery, or frequent bowel movements), crampy abdominal pain, nausea, fever, and, at times, rectal bleeding. Fatigue, loss of appetite and weight loss are common.

Because the symptoms of Crohn's disease and ulcerative colitis are so similar, it is sometimes difficult to make a clear diagnosis. In approximately 10 percent of colitis cases (with inflammation in the colon only) an exact diagnosis of ulcerative colitis or Crohn's disease cannot be made. This is called indeterminate colitis.

Q: *What causes Crohn's disease and ulcerative colitis?*

A: A lot of progress has been made in IBD research, but researchers do not yet know what causes this disease. Studies show that many things work together to cause IBD including inherited traits called "genes" and something in the environment. Substances from the environment (called "antigens") may cause inflammation, or they may cause the body's defenses to "turn on" inflammation. Researchers believe that once the IBD patient's immune system is "turned on," it does not know how to properly "turn off" at the right time. As a result, inflammation damages the intestine and causes the symptoms of IBD. For example, cigarette smoking is one factor in the environment that is known to increase the risk of Crohn's disease.

Many other causes in the environment and the genes that can increase the risk of IBD are being studied.

Q: Will the diseases ever go away? Do I have to take medications for life?

A: IBD is a chronic condition, which means you will have it for the rest of your life. However you can go through periods of remission, with no symptoms at all to disease flare ups with active disease symptoms. Currently there is no known cure for IBD, although advances are being made all the time. Often people will need treatment to control symptoms and improve their quality of life. Most patients are on medication for the rest of their lives even if the disease symptoms are not active (in remission).

Q: Will I need surgery?

A: About one third of people with ulcerative colitis and up to three fourths of people with Crohn's disease will need surgery. Some people can choose surgery, but for some people surgery is necessary due to complications. Surgery may be needed if a person's life has been affected even with medical treatment or if side effects of the medications cause problems. For ulcerative colitis, a patient may need removal of the entire colon, called a "total colectomy". This is because even if a patient has severe disease in only one area of the colon, removing only that area will not cure the disease, and it will return. In Crohn's disease, the most common area of the gut affected is bottom of the small intestine where it connects to the colon (at the "ileocecal valve"). This part of the gut is the most common area requiring removal by surgery (called an "ileocecal resection").

Q: What foods can I/can't eat? What is a good diet plan?

A: Unfortunately, there is no pre-formulated diet plan that works for every IBD patient. Dietary guidelines must be developed based on your very specific needs. These will take into account whether you have Crohn's disease or ulcerative colitis, the severity and location of your disease, and complications, if any. The goal is to keep a well-balanced, healthy diet that is rich in nutrients. It may help to keep a food journal which can pinpoint which foods are troublesome for you. Many patients also find it helpful to ask their doctors to recommend a nutritionist or dietician. There are online options to help you keep track of your diet at <https://qibuddy.ibdetermined.org/>

Q: What types of alternative treatment are helpful for IBD?

A: Some individuals with IBD seek a complementary approach to the treatment of their Crohn's disease or ulcerative colitis. Unfortunately, research studies that prove or disprove the various alternative treatments' effectiveness are lacking at present. Although we have heard a number of anecdotal reports about many different alternative therapies, and we do not dispute that some individuals may have benefited from using them, most treatments have not undergone rigorous

testing required to show they are truly effective for management of IBD. The decision to go on alternative therapy should be a topic of discussion between the patient, the physician, and the nutritionist on the team. It is always important to remember to continue taking your medicine. If you choose to locate alternative options on your own, please be cautioned that there is little, if any, regulation of these alternative therapies, so you may not be aware of exactly what you may be taking.

Q: Does stress play a role in the disease and where can I find emotional support?

A: 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.

There are currently 40 CCFA chapters throughout the United States <http://www.ccfa.org/chapters/>. Some chapters may cover more than one state. Each of our chapters provides support groups, patient to patient telephone/email support, educational events and seminars in different areas. There are also online support groups and a community site where you can get support in the privacy of your own home www.ccfacommunity.org.

Q: Are there any financial assistance programs available to help me pay for my medication?

A: In some cases pharmaceutical companies offer “patient assistance programs”. These programs can give assistance to those who need financial support in paying for their medication. An option may be to contact the pharmaceutical companies to find out the requirements to be eligible. These programs may only work for patients who don't have health insurance. Here is the link for more information: <http://www.needymeds.org>. There are also organizations who provide “copay assistance”, which means programs to help pay for medications. The CCFA **Irwin M. and Suzanne R. Rosenthal IBD Resource Center** (IBD Help Center) at info@ccfa.org can assist you in finding the appropriate resources. Also, your physician and support staff may be able to help you.

Q: Who is the best specialist in my area for this disease?

A: Finding the “best” specialist is particular to the individual. It is important to remember that you may want to find a specialist who is best suited for your individual needs and circumstances. A list of CCFA physician members is a great place to start at <http://www.ccfa.org/living-with-crohns-colitis/find-a-doctor/>. The CCFA Information Resource Center info@ccfa.org can also help you find a gastroenterologist, other health care professionals and treatment centers that

are experienced in treating IBD patients. They can also provide you with important questions for you to ask to find the right specialist for your specific case.

Q: Will IBD affect my ability to become pregnant? What medications can I take during pregnancy?

A: Many women with ulcerative colitis or Crohn's disease without active disease can become pregnant as easily as other women of the same age. Women with active IBD may have more difficulty becoming pregnant. Women who have had surgery in the pelvis, particularly a colectomy with an "ileal pouch anal anastomosis (IPAA)", also called a J pouch, may have significantly lower fertility rates. In general, men with IBD do not have an increased rate of infertility.

It is very important for a pregnant woman with IBD be in disease remission if possible. This leads to the best outcomes for both mother and baby. Pregnancy outcomes for women with IBD are similar to the general population when disease is under good control. When a woman with IBD gets pregnant, she may or may not experience a disease flare. For these reasons, and because most medications used for treatment of IBD are considered safe in pregnancy, medication schedules are often not changed during pregnancy. Your physician will help you with these decisions. One medication used for treatment of IBD called methotrexate should not be used in pregnancy.

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