



Crohn's Disease and Ulcerative Colitis:
A Guide For
Children and Teenagers



CROHN'S
&
COLITIS
FOUNDATION
OF AMERICA

The Crohn's & Colitis Foundation of America is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis. CCFA sponsors basic and clinical research of the highest quality. The foundation also offers a wide range of educational programs for patients and healthcare professionals, and provides supportive services to help people cope with these chronic intestinal diseases. CCFA programs are supported solely by contributions from the public.

We hope that this brochure will help you to better understand these illnesses, and to become an active member of your healthcare team.

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WHAT ARE CROHN'S DISEASE AND ULCERATIVE COLITIS?

Crohn's disease and ulcerative colitis are diseases of the gastrointestinal (GI) tract (also known as the “digestive tract” or “digestive system”). To help you understand disease of the GI tract, we will first discuss how it works. The GI tract is a long tunnel that begins with the mouth and pharynx (your throat). The tract continues as a series of hollow tubes, including the esophagus, the stomach, the small intestine, and the colon (also known as the large intestine). It ends at the anus. The purpose of the GI tract is to extract calories and nutrients from food, and to absorb the protein, sugar, and fats into your body. This provides you with energy to be active and to grow. When you eat, food travels down the esophagus and then is stored in the stomach. Food is slowly emptied from the stomach into the small and then large intestines. In the small intestine, food is broken down and absorbed by your body. The colon removes extra water and stores the leftover waste until it comes out of your bottom (anus) as a stool or bowel movement. The bowel is made up of your large and small intestines.

Crohn's disease is an illness in which the wall of the intestine becomes sore, inflamed, and swollen. In Crohn's disease, any part of the GI tract, from the mouth to the anus, may have inflammation. The inflamed part of the GI tract will not work as well. Symptoms of Crohn's disease will vary, depending on which part of the GI tract is inflamed. For example, if your small intestine is inflamed (where calories are absorbed), then you may have weight loss, diarrhea, and crampy belly pain. In general, common symptoms of Crohn's disease would include abdominal pain, diarrhea, fever, weight loss, and (sometimes) bloody stools. Also, children with Crohn's disease that has not been treated may have poor growth or may not enter puberty as early as their friends or classmates.

Ulcerative colitis is an illness in which inflammation is limited to the colon. Only the large intestine is red and swollen. Common symptoms of ulcerative colitis would again include stomach pain and diarrhea, often bloody diarrhea. Weight loss and poor growth occur less often than in Crohn's disease.

Because Crohn's disease and ulcerative colitis are both disorders that cause inflammation of the intestines and have similar symptoms, the two diseases are grouped together under the name "inflammatory bowel disease," or IBD.

WHAT CAUSES IBD?

We do not know what causes IBD, but there are many doctors and scientists that are actively working to find both the cause and the cure. It is believed that the immune system, which normally protects you against disease, may be overworking in the intestine. The immune cells in the intestine are very important and normally protect the intestine (and the rest of your body) from bacteria that can make you sick. There are a wide variety of chemicals that signal immune cells to increase or decrease inflammation. These chemicals usually provide a very careful balance of protection. In persons with IBD, this balance is lost. The immune system is "overactive" in the intestine, and causes inflammation.

We know that IBD is not contagious. No one gave IBD to you, and you cannot give it to anyone else. IBD is not caused by stress or by any kind of food. Nothing that you or your parents ever did caused you to have IBD, so you should not feel bad or guilty about it. You have reason to be very hopeful. Our knowledge and understanding about IBD grows each year and will lead to better treatments and, we hope, a cure.

DOES IBD AFFECT ONLY THE GI TRACT?

Although this does not happen very often, symptoms or inflammation may also occur outside the GI tract in persons with IBD.

These problems may include arthritis (joint swelling), mouth ulcers (sores inside the mouth), skin rashes, or inflammation in the eye (uveitis). These symptoms usually only occur when the bowel is actively inflamed, and they usually disappear when the bowel inflammation is treated. It is important to be checked by an eye doctor every year to be certain that your eyes stay healthy.

CAN IBD EVER BE CURED?

Finding a cure for ulcerative colitis and Crohn's disease is an important goal for us all. Although at present there is no cure, there are medicines and nutritional help that can restore good health and make you feel better. In some persons with severe ulcerative colitis, the disease can be "cured" by removing the colon. Most persons who have had a colectomy (surgical removal of the colon) for ulcerative colitis are able to lead a normal life and remain well. Again, please be encouraged that many physicians and scientists throughout the world are doing research to find a cure for IBD. Working together, we will find the answer, but until then, it is important to follow the instructions of your doctor.

WHAT MEDICINES WILL I HAVE TO TAKE?

Most people take medicine that contains 5-ASA, a relative of aspirin that may decrease bowel inflammation. Some examples of 5-ASA drugs include sulfasalazine (brand name Azulfidine®), Asacol®, Canasa®, Colazal®, Dipentum®, Pentasa®, and Rowasa®. These medicines are usually pills or capsules, but some of them can be turned into liquids if you are unable to swallow pills. Sometimes, the medicines are put into your bottom as solid pellets called suppositories. They also can be mixed in water before going into your bottom; this is called an enema. Persons with IBD often take prednisone, which is a steroid. Prednisone decreases inflammation. This is not the same "anabolic" steroid that body-builders

take. For some patients, antibiotics may be prescribed, especially metronidazole or ciprofloxacin; these antibiotics may be helpful both to fight infection and to decrease inflammation.

6-mercaptopurine is a drug that is used commonly to treat children and adolescents with IBD. It controls inflammation, decreases the use of steroids, and optimizes growth.

Rarely, when the medicines taken by mouth or in your bottom are not strong enough, you have to go into the hospital so that the medicine can be given through a small tube in your vein, called an IV. Remicade,[®] a new drug to treat Crohn's disease, is given by IV as well. This treatment blocks one of the chemicals that causes inflammation.

DO THE MEDICINES DO ANYTHING ELSE TO ME BESIDES MAKING MY INTESTINES HEAL?

Medicines sometimes do things we do not like. These are called side effects. Medicine for IBD can also give you an upset stomach, make your skin break out in rashes, and give you headaches. Prednisone may make you eat more, make your face swollen, slow your growth, and make you feel moody and restless, especially when it is given in high doses for long periods. As the dosage of prednisone is reduced, however, these side effects will go away. You should tell your parents or doctor if you experience side effects. You may need to take blood tests to find out if your medicine is working effectively and safely.

WILL I NEED TO EAT A SPECIAL DIET?

The main goal will be to eat a healthy, well-balanced diet. Special attention will be given to encourage a diet high in calories for optimal growth. Your diet must also provide enough calcium, a nutrient required for strong bones. You may actually be prescribed ice cream for calories and calcium!

If enough calories are not being eaten, you

may be asked to drink nutritional supplements such as PediaSure[®], Ensure[®], or Boost[®], to get those calories in. On rare occasions, in order to improve nutrition and help you grow, a thin soft tube can be passed through your nose into your stomach, and liquid food infused through the tube. This feeding tube is called a nasogastric or NG tube. These special feedings can be done while you are asleep at night. Very rarely, if you are in the hospital, very special food may be given to you into your veins through an IV. This is called TPN. Few children need these special kinds of liquid diets. Most are encouraged to eat well by mouth, in the usual way. Eating well will help your body fight disease and help you be healthier.

WILL I HAVE TO TAKE MORE TESTS?

Testing can be an important way for your doctor to evaluate your overall health as well as the health of your GI tract. Blood tests will be required on occasion to follow your blood count. These tests ensure that you have enough white blood cells to fight infection, and that you are not anemic. Other blood tests may screen the health of your liver, which is responsible for processing the medicines that you take.

Imaging studies are various ways to evaluate “pictures” of the GI tract without physically entering the body. Images can be taken with x-rays (GI series, CT scan), sound waves (ultrasound), or with magnets (MRI). The different imaging studies give different types of information. An upper GI series is often used to examine the esophagus, stomach, and small intestine. The patient will drink a chalky liquid that outlines the intestines on an x-ray image. A CT or CAT scan uses a computer to generate pictures of the entire abdominal cavity based upon X-ray images. Less often, ultrasound or MRI are used to examine the GI tract as well.

Alternatively, doctors can directly examine the

GI tract via endoscopy. An endoscope is a bendable tube with a bright light and a tiny camera that projects an image or picture onto a computer screen. For example, if the tip of the endoscope is in the esophagus, then a clear picture of the esophagus will be seen. The doctor can examine the inside lining of your GI tract, viewing sites of inflammation directly. The endoscope may go down your throat or into your bottom. Although an endoscopy causes very little pain, it is usually not done while you are awake. Instead, you get medicine through an IV or a breathing mask to make you sleepy, make the procedure pain free, and allow you to not be frightened. For the endoscopy through your mouth, you must have an empty stomach, which means skipping a meal. For the colonoscopy (an endoscopy through your bottom), stools in your colon need to be cleaned out. This means drinking a lot of clear liquids and taking laxatives to “flush out” your intestines the night before the test. Imaging tests and endoscopies are not done regularly once the diagnosis of IBD has been clearly established. However, if the medicines you are taking are not keeping you well, at some point it may be necessary to re-evaluate your GI tract. The tests are not fun, but they may be the only way your doctor can tell which part of your intestine is inflamed, and which medicine is most likely to make it better.

WILL I HAVE TO HAVE AN OPERATION?

There are many medicines used to treat IBD, and new and exciting medicines are being developed. If medical therapy fails to restore good health, then surgery is an option to help make you get better. As stated, surgery can provide a cure for ulcerative colitis, by removing the entire colon. Unfortunately, surgery is not a cure for Crohn’s disease. Because Crohn’s can involve any part of the GI tract, the disease may recur (come back) in a different part of the intestine after the

operation. Therefore, surgery for Crohn's disease is avoided, if possible. If surgery is performed, it is limited to removing only severely inflamed or scarred intestine.

Be optimistic! With newer and better medicines, surgery will be needed less often. And also, when necessary, an operation can be healing.

WHAT CAN I DO TO MAKE MYSELF FEEL BETTER?

First, it is important to recognize that having IBD is not fun, and it is not fair. Then, it is more important to recognize that you can help yourself get better! You will need to pay attention to your symptoms (belly pain, diarrhea, bloody stool) and report them to your parents, your nurse, and doctor. You are all a team! Do your best to take all your medicine, to eat well, and to believe you will get well. You are taking control of IBD and your own body. You are helping yourself to get well.

You will have to think about sharing information about IBD- your diagnosis, your feelings. Your school nurse and teachers will be able to understand and help if they know more about IBD. You and your parents may help educate your teacher. For example, it may be helpful to get permission to leave the classroom to use the bathroom without asking every time. It may also help to tell friends about your feelings, so your friends can understand what you are going through, and be supportive. CCFA has free brochures written especially for teachers, which you also can give to your principal, guidance counselor and school nurse. Just call us at 1-800-932-2423 to order. (You'll find a complete list of our brochures on the inside back cover.)

CAN I GO TO SCHOOL AND TAKE PART IN SPORTS?

You should do anything you feel like doing. You can play in sports if you feel well enough and if your doctor and parents permit it. On days when you do not feel well, you should not feel guilty about staying home until you feel better. Your teachers, nurse, doctor and parents will be supportive and help you. Remember, do your part to stay healthy, take your medicine, rest, and eat well. Your goal will be to have no limitations because of IBD: Go to school, go to college, play soccer, tennis, baseball—you decide!



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